THE LIVED EXPERIENCE OF PARENTING CHILDREN WITH TOURETTE’S SYNDROME: A PHENOMENOLOGICAL STUDY

DISSERTATION

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By

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ABSTRACT

Parents of children diagnosed with Tourette’s Syndrome (TS) cope with a myriad of problems associated with this condition, as these children often experience significant behavioral, social-emotional, and academic problems in multiple ecologies. These problems are often exacerbated by commonly occurring comorbid conditions, which may include, among others, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive-Compulsive Disorder (OCD), anxiety disorders, mood disorders, learning disorders, and various behavioral problems, such as Conduct Disorder (CD), sleep disorders, and sexually inappropriate behavior. “Tourette’s Syndrome Plus (TS+),” a term coined by Dr. Leslie Packer, a noted author in the field of TS, refers to cases in which TS is accompanied by comorbid disorders. The purpose of this study was to examine the lived experience of parenting a child with TS+. A descriptive phenomenological approach was used to guide the research. Primary parents of children diagnosed with TS+, who were students in a public school system, were recruited through state chapters of the national Tourette Syndrome Association, via purposive sampling. Data were collected through semi-structured interviews. Transcriptions were derived from the audio tapes of the interviews. Data analysis revealed parents of children with severe TS+ experience suffering as a result of their child’s behaviors and special needs, as follows: 1) Parents feel irritated, deeply troubled, or frightened for their child when witnessing their child’s
TS+ symptoms and are troubled by the negative impact these behaviors have on family functioning and relationships. 2) These parents mourn the absence in their child of normal social relationships and social/emotional development, and feel deep anguish when their child is a victim of bullying, teasing, or ostracism. 3) Parents are fearful at times that their child is being poorly educated, misunderstood, or mistreated at school. 4) Parental suffering, related to the affects of parenting a child with severe TS+, adversely affects the parents’ own mental health.
DEDICATION

I gratefully dedicate this work to my mother and father, Maxine Adell Sasnett and Joseph Randolph Sasnett, Jr., for their examples of devoted service to others and effective, loving parenting. I also am grateful to my kind, thoughtful children, Joey, Nicole Hudson, and Ben, for their faith in my ability to reach my goals, and to my dear wife of 30 years, Dr. Kathleen Sasnett, for her loving support, and her generous contributions to this project.
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CHAPTER 1
INTRODUCTION

Parenting in today’s world is difficult enough, yet when a child has a chronic disorder or disability, the parental role can become even more complex. One particular childhood disorder that would pose difficulty for parents is Tourette’s Syndrome (TS). According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition: Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000), TS is a neuropsychiatric disorder that is characterized by the presence of both motor and vocal tics that are present for longer than one year (See Appendix B). By definition, the symptoms of this disorder first appear in childhood (American Psychiatric Association, 1994). TS, the most severe form of tic disorder, was once thought to be rare; however, recent reports suggest that TS affects up to 3.8% of school-aged children in regular education classrooms, and 7.0% of students in special education classrooms (Kurlan et al., 2001). The parents of a child afflicted with TS may have to cope with a myriad of problems associated with the condition, as children with TS are at a heightened risk of experiencing significant behavioral, social-emotional, and academic problems (Stefl & Rubin, 1985), particularly when this disorder is accompanied by commonly occurring comorbid conditions [e.g., Attention Deficit Hyperactivity Disorder (ADHD), Obsessive-
Compulsive Disorder (ODC), Conduct Disorder (CD), learning disorders, etc.]

Tourette’s Syndrome Plus (TS+) is a term that was coined by Dr. Leslie Packer, a noted author in the field of TS. This term refers to cases in which TS is accompanied by comorbid disorders. Edell and Motta (2001) reported that the “intensely disturbing characteristics” of this condition create “great distress for both patients and their families.” The current study attempts to investigate how such distress is experienced by both child and parent by conducting interviews with those parents.

*Personal Interest in Tourette’s Syndrome*

I only recently became interested in TS+ as a topic of research due to my personal encounter with this disorder. In 1996, at the age of 48, I was diagnosed with TS, despite symptoms being present in my youth. As a teen, I recall screaming vocalizations while attempting to do homework in my bedroom. While most children with TS display motor tics such as eye-blinking, head nods, twitching of facial muscles, etc., my physical tics took the form of grimacing, and motor movements that might have appeared like nervous gestures (e.g., repeatedly sweeping my hair from my face). As a result, my tics were overlooked. My two brothers reported that during the teen years, my parents asked them on multiple occasions, “What is wrong with Roger?” As with most others with TS, I have also been plagued with comorbid neuropsychiatric conditions that, for me, have been more debilitating than my tics. Specifically, I have been diagnosed, at one time or another, with ADHD, Generalized Anxiety Disorder (GAD), OCD, Social Anxiety Disorder (SAD), and Dysthymic Disorder (DD).
I have also been affected by TS+ as a parent and as an educator. My two sons were diagnosed with a tic disorder (one with TS), and with other commonly co-occurring disorders that, according to my sons, have caused them greater problems than their tics. As in my case, my sons’ tic symptoms developed later in their childhood than is typically seen. Furthermore, their tics were somewhat mild. Thus, unlike most parents of children with TS, I was spared the difficulty of raising young children who presented with severe tic conditions. More recently, I have had a multitude of experiences in my role as a school psychologist related to the diagnosis, treatment, and educational interventions for students with TS+.

**Rationale for Investigating the Parental Experience**

A thorough search of literature revealed that a multitude of investigations have explored the school experience of children with this disorder, and relatively few studies have viewed the home environment of children with TS+. There appears to be a gap in knowledge pertaining to the experiences of parents who raise children with TS+. Understanding the parenting experience of parents who have a child with TS+ is important because of the crucial role these individuals must play in assisting their child through the school-age years. For children with TS+ especially, parents are the crux of the child’s personal development and educational progress. Given the high intensity of these disorders, the importance of the child’s adolescent years in the course and development of TS+, as well as the potential for negative outcomes for adult functioning due to the possible adverse affects of TS+ in childhood, the presence of TS+ can have long-term ramifications on the child’s life. The parent, then, is the key adult who must
advocate for their child, who may need to educate their child’s teachers and other school personnel, and who must help their child mitigate the affects of TS+ in all aspects of the child’s life.

Parents have an especially important role to play as advocates for their child in the educational arena. Studies show that teachers lack a sufficient degree of knowledge of TS that would enable these professionals to reliably identify the symptoms of TS, or to design appropriate accommodations for students with this condition (Sasnett, 2003; Emmerich, 2006). Furthermore, it is unlikely that educators in the near future will be trained in college or on the job to have knowledge of TS. The low frequency of TS will likely never justify schools devoting funds to train all of their staff in TS, and teacher education programs are not likely to emphasize TS in their curriculum (due to the current trend to trim curricula to the “essentials”). For these reasons, it is important that the advocacy role of parents who raise children with TS be understood.

Another reason to study the parenting experience of those who are raising a child with TS+ is to shed light on the coping skills used by these parents as a model for other parents in similar circumstances. Currently, a model does not exist that outlines a systematic way to talk about these parental experiences. While the national Tourette Syndrome Association (TSA) has material to help parents and educators, most of this information is not based on data gathered from systematic studies, but more on personal opinion and experience. Providing an informational model founded on evidence-based studies would likely benefit other parents who have children with TS, or any disorder that has similar characteristics to this condition. Parents who have a child who was newly
diagnosed will also stand to gain from learning of other parents’ experience. School professionals who work with a child with TS+ could also access this model of understanding. In many respects, such a model that captures the essential experience of parents of children with TS+ could create a ripple effect, providing a source of information and inspiration to parents, school professionals, and all those invested in the lives of children with TS+.

Statement of Purpose
This study aims to investigate parental perspectives regarding their child’s experiences with TS and their own experiences caring for a child with this disorder. More specifically, this study aims to discover themes that describe the experience of parenting children with TS+, focusing on the ecologies of home, community, school, and self. In order to get at the meaning and experiences of parents of children with TS+, a qualitative approach will be used, and in particular, descriptive phenomenology. This approach is employed so as to describe the meaning of the lived experiences of individuals with regard to a particular phenomenon. The phenomenon of interest in this study is the experience of parenting a child with TS+. 
CHAPTER 2
LITERATURE REVIEW

Tourette’s Syndrome

Tic disorders.

Tic disorders are classified into three diagnostic categories according to the DSM-IV-TR (American Psychiatric Association, 2000), namely, Transient Tic Disorder (TTD), Chronic Tic Disorder (CTD), and TS (see Appendix B for the diagnostic criteria of the three forms of tic disorders). There is no formal diagnostic test for these disorders. Instead, a diagnosis is made on the basis of a patient’s history and clinical presentation of symptoms. Parents could play an important role in the diagnostic process by taking note of tics as they occur in their child’s ecologies (i.e., home, school, and with peers). Records of tic type (motor and/or vocal), anatomical location(s), frequency, and of other observable features, that were kept by parents would be of invaluable assistance to a physician attempting to assess the presence of a tic disorder.

Prevalence rates.

The prevalence rates of tic disorders are hard to determine as estimates can vary due to the source of a study’s sample, the diagnostic criteria used, the knowledge level of the observer(s), and the methods of data collection (Scahill, Tanner, & Dure, 1999).
Using a semi-structured interview, Caine et al. (1988) found a prevalence rate of 2.28 children per 10,000. Based on an in-person interview, Costello, et al. (1996) determined the rate to be 10 per 10,000. In 2001, Hornsey, Banerjee, Zeitlin, and Robertson attempted to identify the clinical characteristics of TS in 13- to 14-year-old schoolchildren who attended six mainstream schools in West Essex, U.K by basing prevalence rates on diagnosable cases of TS, rather than on symptomatic information gathered from clinical records, questionnaires, or interviews. These researchers argued that TS had been previously underestimated, as they found a TS rate of .76%, and speculated that a more “realistic” estimate is closer to 1.85% as this study’s participants were older than the mean age for the peak of tic symptoms.

Changes in criteria for TS in different editions of the DSM might have contributed to variation in the reported rates of TS. A “significant impairment” criterion was added to the DSM-IV, published in 1994. This clause added the criterion that read “…the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.” In the DSM-IV-TR edition, published in 2000, this significant impairment criterion was withdrawn. Basing their study on the DSM-IV-TR criteria for TS, Mason et al. (1998) found 2.9% of a sample of ninth grade pupils was found to have TS, whereas 18% of the subjects were identified as displaying tics. As previously noted, Kurlan et al. (2001) sampled special education and regular education students in a school district in Rochester, NY, finding 7.0% in special education classes, and 3.8% in regular education classes, met criteria for TS. Thus, the prevalence rates for TS are substantially higher than previously reported, especially when
students are directly observed by trained diagnosticians, study participants are of an age when tics are most likely to occur, and the criterion for impairment is excluded. The good news for parents is that many cases of TS are mild, and in these cases, tic symptoms do not cause significant impairment.

Transient Tic Disorder (TTD) is considerably more common than TS. Shapiro, Shapiro, Young, and Feinberg (1988) found an estimated occurrence rate of TTD in 5 to 24% of school children. More recently, Chronic Tic Disorder (CTD) is estimated to be found in 5 to 10% of juveniles (Singer, 1994; Comings, Himes, & Comings, 1990). Regarding the relationship between CTD and TS, Spencer, Biederman, Harding, Wilens, and Faraone (1995) compared CTD and TS in a clinical study and found they are part of the same “disease entity,” due to a shared pattern of clinical correlates.

In a 2005 study, Saccomani, Fabiana, Manuela, and Giambattista also found evidence for a genetic link between different tic disorders. As well, these researchers showed that similarities and differences in comorbidity exist between TS and CTD. Both TS and CTD were alike in the degree of comorbid ADHD and mood disorders, while when compared to CTD, TS was associated with significantly higher rates of OCD and anxiety disorders. Research is lacking pertaining to the rates of comorbidity for TTD. A preponderance of literature pertaining to tic disorders focuses exclusively on TS, as the most severe form of tic disorder.

Regarding the epidemiology of TS, this condition appears to occur independent of race, culture, or geographic region of the world (Freeman et al., 2000; Staley, Wand, & Shady, 1997). The symptoms of TS are universally the same. A well documented
demographic difference, however, is that males are affected by tic disorders more frequently than females (approximately three to four times more often, according to some studies) (Kadesjo & Gillberg, 2000; Robertson & Stern, 1998; Singer & Walkup, 1991). Despite some variance in the reports of the rate of male to female incidence of tic disorders, Scahill, Tanner, and Dure (2001) concluded through a comparison of the literature on this topic that TS and CTD have more often been found in males than females.

*The nature of tics.*

Tics may be described as rapid, involuntary, repetitive, and stereotyped muscle movements (motor tics) or phonic productions (vocal tics) (Leckman, Peterson, King, Scahill, & Cohen, 2001) (see Appendix A). Motor tics can be categorized as simple or complex, according to the length of time and the number of muscle groups involved in the tic behavior. As examples of simple motor tics, a child might be observed to blink their eyes, twitch their nose, shrug their shoulders, or other such involuntary movements that repeatedly appear without apparent purpose. Complex motor tics are of longer duration than simple tics and involve greater motor activity, such as whole body twisting, jumping, arm flapping, or facial contortions. Complex motions may also occur in combinations and tend to vary in number, frequency, anatomical location, complexity, and severity. Typically, simple and complex physical tics are displayed concurrently. Tics may occur in a slow and sustained manner (*dystonic*) or they may appear rapid with a quick onset (*clonic*) (Jankovic, 1997). According to Leckman et al. (2001), relatively few individuals with tic disorders display involuntary lewd gestures with the tongue or
hands, referred to as copropraxia. In general, motor tics first present in simple forms, and in some cases become more complex.

Vocal tics can also be classified as simple or complex. Simple vocal tics are meaningless sounds and are brief in duration. For example, a parent might observe their child repeatedly clearing his or her throat without due cause, sniffing, hissing, or making other meaningless sounds. Depending on the individual, complex vocal tics can vary in volume (from whispers to screams), pitch, and duration. Some individuals who display complex vocal tics might repeat phrases or words heard from others (echolalia), or repeat their own sounds/words (palilalia). Coprolalia, the involuntary interjection of cursing or profanities, is frequently associated with TS. One can only imagine the angst felt by parents of a child who displays coprolalia. Surely, these children must face frequent ridicule and scorn. Fortunately, coprolalia only affects a minority of individuals with TS.

In separate studies, coprolalia was found to occur in 8% of cases of TS patients in a pediatric clinic, and in 39% of TS patients in university medical centers (Singer, 1997). As with motor tics, vocal tics typically are simple in nature upon onset of the tic condition, and may become increasingly more complex over time (Findley, 2002). This trend might explain the higher incidence rates of coprolalia found among older patients in the university medical center setting.

A phenomenon experienced by approximately 70 – 90% of those with tic disorders is that of “premonitory urges” that precede vocal and motor tics (especially dystonic tics) (Leckman, Walker, & Cohen, 1993; Cohen & Leckman, 1992). Premonitory urges are described by some as being similar to the sensation of a pressure,
urge, ache, or itch to tic (Bullen & Hemsley, 1983). The average age when these urges were first experienced was 10 (three years following the average age of onset of tics). After experiencing a tic, 84% of the subjects in this study experienced at least a partial sense of relief and 84% have been found to be able to suppress their tics for a time and thus, consider their tics to be at least somewhat volitional. However, tics that are suppressed for a period of time tend to be more forceful when finally released.

Understandably, parents unfamiliar with TS might be confused by their child’s apparent ability to control when they tic. For some children with tic disorders, who are conscious of the effects their tics have on others, there can be an internal struggle between wanting to relieve the discomfort of premonitory urges by ticcing, and not wanting to deal with bystanders’ negative reactions when they finally do tic.

*The course of Tourette’s Syndrome.*

Investigating the course of tic disorders, Leckman et al. (1998) found an age-related pattern to the natural history of TS tics in children that showed a mean onset of tics at age 5.6 years, a worsening of tics to peak at a mean age of 10.0, and a gradual decline through the adolescent years. Tics may first appear, however, in infants as young as one year of age, and in adolescents up to 18 years of age. For children in whom tics persist, symptoms tend to emerge during the initial years in a predictable pattern. Specifically, tics first appear as simple motor tics (often eye blinking, or, in fewer cases, facial grimacing or body movements), tend to disappear for a few weeks and then reemerge. Simple motor tics, in some, may progress to complex tic forms. Vocal tics generally emerge several years or more after the onset of motor tics, between the ages of
8 and 15 years (fewer than 5% of those with tic disorders display only vocal tics) (Leckman et al., 2001). Here, again, the typical progression is from simple to complex forms of vocal tics. Tics tend to wax and wane over time, changing in intensity and frequency, and in the case of motor tics, shifting from one body part to another. For most children with TS, the symptoms of this condition go into remission after age 15 [(73 and 72%, respectively, according Erenberg, Cruse, and Rothner (1987) and Singer (1994)].

Arguably, physicians and educators who work with children with TS could serve these clients more effectively if parents provided these professionals with specific information about their child’s unique experience with this condition. For example, parents could aide their child’s physician in the treatment of their child by monitoring the types of tics their child exhibits, the ebb and flow of these tics, and other behaviors that might signal the presence of other frequently occurring comorbid disorders. Teachers of these children may be helped by parents by being made aware of the involuntary nature of tics, of the fact that tics will wax and wane over time, and of the situations that can trigger tics in individual children (e.g., talk of tics, stress, loud noises, etc.). Based on a thorough review of the literature over the last 30 years, no research has been conducted that has assessed the knowledge of TS that parents of children with TS have of this condition, or how effective these parents are in communicating information to these professionals.

*The etiology of Tourette’s Syndrome.*

The etiology of TS is unknown, although the results of current research implicate various environmental risk factors (e.g., perinatal developmental problems, exposure to
drugs, and trauma to the brain), neurobiological substrates, and genetic factors (Leckman & Cohen, 1999). Pertaining to environmental factors, some children exposed to strep throat infection have developed OCD/TS-like symptoms that appeared immediately after exposure. Possible links between TS and brain abnormalities may exist as ample evidence has shown lesions and biochemical dysfunction in the frontal-subcortical and basal ganglia-thalamo-cortical regions and interconnecting circuitry of the brain. Specifically, imbalances in synaptic neurotransmitters have been implicated, involving the dopaminergic, serotonergic, and noradrenergic systems (Singer, 1998; Singer & Walkup, 1991). As well, neuroimaging studies have found reduced volume of the basal ganglia, and a lack of normal left-right basal ganglia asymmetry in those with TS (Peterson et al., 1993) (Singer et al., 1993). Genetically mediated, TS is likely the result of multiple genes in confluence with numerous environmental factors. Pauls (2001) reported a 53% concordance rate for monozygotic twins and a much lower rate of 8% for dizygotic twins with TS. Despite the research into the etiology of TS, the actual genetic, neurobiological, and environmental causes of this disorder remain elusive (Robertson & Stern, 1998).

Given the genetic and familial factors contributing to the etiology of TS, parents might be concerned about the likelihood of the TS gene being passed to a family member. Pauls, Alsobrook II, Gelernter, and Leckman (1999) surveyed literature on TS and genetics and found that reports agree that the “…risk for Tourette’s syndrome among family members of an individual with Tourette’s syndrome is about 10 – 11%, and the risk for chronic tics is approximately 15%.” The risk for OCD (without TS) was 11 –
12%. As well, these investigators found evidence that “…there is a significant risk (approximately 35%) for a first degree relative of an individual with Tourette’s syndrome to have Tourette’s syndrome, chronic tics, or obsessive-compulsive disorder.”

These genetic factors of TS, that lead to males being affected at much higher rates than females (somewhat unique to this condition), may lead to differences in the parental experience between mothers and fathers of children with TS. One might presume that the spouse who does not contribute the TS gene would have a different parenting experience than a parent with TS. Arguably, the parent with TS (assuming only one parent carries the TS gene) might experience feelings of guilt if symptoms of TS (or another expression of the gene, such as CTD, OCD, etc.) are exhibited by their children. Since these parents share some of the difficulties in life associated with this disorder, these individuals may be more empathetic to their children who share this disorder. One might also speculate that the parent who is not a carrier (more likely the mother than the father), and, thus, who has not personally experienced TS, might have difficulty fully understanding the involuntary nature of tics, the feeling of embarrassment that ticcing in public might bring, or the symptoms of conditions that frequently accompany TS. And yet it is mothers more often than fathers who carry the responsibility of contacting school personnel if school problems arise and of accompanying their child to community activities (National Council for Educational Statistics, 1997). Thus, the parenting partner who more often has the least intimate knowledge of TS may have to carry the bulk of parenting responsibilities and may need to be the chief spokesperson when educating others about TS.
Comorbid disorders.

In some cases, raising a child who struggles with TS may be the least of the parent(s)’ concerns, as individuals with TS are at risk for having comorbid disorders. Rates of co-occurrence, according to Leckman and Cohen (1999), are as follows: OCD (11 to 80%), ADHD (50 to 90%), and Learning Disorders (LD) (approximately 23%). Support for high rates of psychiatric comorbidity was found in another study among a clinically referred sample of 190 youths (Coffey, et al., 1999). The investigators found evidence of numerous emotional-behavioral disturbances among those with mild to moderate and severe cases of TS, including anxiety disorders (53 and 70%), mood disorders (56 and 64%), and disruptive behavior disorders (85 and 93%), respectively. Overall, among subjects deemed to have mild to moderate TS, 94.8% were reported to have comorbid disorders, whereas this figure rose to 100% among youths with severe cases of TS. According to Carter et al. (2000), the symptoms of conditions associated with TS may be more problematic for afflicted children than the tics. Furthermore, numerous studies have found clear evidence that the behavioral symptoms associated with TS and its comorbid conditions, or the combination of these disorders, may impair school performance, lead to problems with peer relations, and affect family functioning.

Parenting Experience

While the prevalence rates of TS may be low, TS can be a high intensity problem for children with this condition, and for their parents who may be overwhelmed by their child’s special needs. These children may require intensive emotional support and guidance from their parents, as children with TS are sometimes rejected and ridiculed by
peers, neighbors, teachers, and even bystanders because of the unusual nature of tic behavior. Life in a home with a child with TS can be difficult, as tic behaviors and emotional disturbances in the child may be hard for other family members to tolerate. As previously noted, the school ecology may present barriers to learning and social growth for the child with severe TS, as these individuals are prone to academic failure and poor relationships with peers. Such school related problems may add strain on parents of children with TS, as these caretakers may need to take the lead in educating their child’s teachers and classmates about this condition, and to aggressively advocate for their child in the educational arena in order to gain special education services. Hence, parents of children with TS may face difficult challenges in meeting the unique social and educational needs of their children.

As previously stated, children with severe TS are at increased risk for academic failure and social mistreatment. Research that investigates the experience of parents who raise children with TS might yield positive outcomes for these children and their families. Studies in this domain could provide valuable information as to the dynamics of family functioning of families with children who have TS or similar disorders. As well, insights could be gained from knowing the parents’ perspective as to the experiences of children with TS in their multiple ecologies (i.e., home, school, community, and self). Parents of children with TS may benefit from this information as they learn from other parents who have experienced similar challenges. As previously discussed, parents may have a crucial role to play in helping their child gain needed services and accommodations in the child’s school environment and program. Learning from the successes of parents who have
become advocates for their child may lend strength to other parents in similar circumstances. Also in regard to school, educators might learn from the parents’ viewpoint as to the school experience of children with TS. Based on this knowledge, school personnel could make appropriate adjustments and accommodations in their instructional methods, programs, and personal management of students with TS.

Based on a review of literature pertaining to TS, there is a dearth of research that has addressed the experience of parents who raise children with TS or on the effects on family members. Numerous studies, however, have investigated the nature of TS, including this condition’s etiology, epidemiology, and neurophysiology. Furthermore, relatively few researchers appear to have studied the problems associated with school for children with TS. Therefore, the purpose of this study is to explore and examine parental perspectives regarding their child’s experiences having TS and their own experiences caring for a child with this disorder.

*Parenting and Tourette’s Syndrome.*

Parenting a child with TS presents severe challenges due to problems related to their child’s condition. Possible sources of strife may include recognizing and emotionally processing the loss of normalcy in their child, having to cope with the behaviors associated with their child’s TS condition, and having to manage their child’s problems at home, in the community, and at school. The resultant parental strife can affect family functioning and the parents’ own psychological health (Hubka, Fulton, Shady, Champion, & Wand, 1988; Wamboldt, Weintraub, Krafchick, & Wamboldt, 1996; Schoeder & Remer, 2007).
The initial diagnosis of TS may evoke a range of emotional reactions in the parents of children with TS. Kubler-Ross (1969) posited that people who experience a significant loss (e.g., death) experience a progression of feelings, beginning with shock, then anger, bargaining (seeking a way-out), depression, testing (seeking realistic solutions), and finally to acceptance (finding a way forward). When learning of their child’s disorder(s), parents may mourn the loss of their child’s normalcy and experience such grieving stages.

Family functioning seems to be negatively impacted when a child with TS lives in the home, putting additional pressure on parents. In one study, a majority of Canadian families, who had one or more family members with TS, considered the effects of TS to cause interference in their daily family activities “to some extent,” or, “a great deal,” (Hubka et al., 1988, p.260). Verbal tics may be especially troublesome to live with, depending on severity and complexity. Hubka et al. describe an anecdotal account of a child returning home from school. The child’s mother knows the child is nearing home because she can hear the child’s verbal tics through closed windows and doors. Screaming tics are often included in lists of verbal tic behavior. Children who emit screaming tics in public would surely be targets for mistreatment from bystanders, especially in places reserved for quiet voices, or silence (e.g., libraries, church, movie theaters, test sessions in classrooms, etc.). Parents would likely feel even more distress if their child utters coprolalia type tics, whether at home or in public. Consider the case of a child cursing at church or in the home, whose parents hold strict religious views around profanity. Remarking on her personal experience as a parent of a child with severe tics,
Shimberg (2003) wrote: “I know what it’s like to have strangers glare at my child, or worse, step back in fear. I’ve held a sobbing pre-teen who has been judged and found guilty of one of the worst offenses of adolescence: being different.”

Another possible source of distress for parents would be the presence of self-injurious behaviors in their child, which affect 25 – 50% of children with TS (Hood, Baptista-Neto, Beaseley, Lobis, & Pravdova, 2004). Examples of self-injurious behaviors include biting, scratching, cutting, engraving, or hitting (particularly in the eye and throat). In one case, a 16-year old girl, previously diagnosed with TS and OCD, was admitted to a local hospital after repeatedly and severely biting her tongue during the five days prior to her admission. According to hospital records, the patient bit her tongue approximately every 15 minutes, causing significant bleeding and cries of pain. When asked why she bit herself she exclaimed, “I can’t help it.” (Hood et al. p.1298).

Parents may also have to cope with the effects of one or more disorders that are likely to be present along with TS in their child. As previously noted, roughly 90% of children with TS can also be expected to develop one or more comorbid or associated disorders (e.g., ADHD, OCD, CD, mood disorders, anxiety disorders, etc.). According to recent investigations, functional impairment in families is most often associated with the symptoms of comorbid disorders (particularly ADHD and Oppositional Defiant Disorder ODD), in conjunction with TS, rather than solely with the tic behaviors related to TS (Woods, Himle, & Osmon, 2005; Greene et al., 2002; Carter et al., 2000). For example, ODD co-occurs in approximately 57% of individuals with TS. The symptoms of ODD include frequent temper outbursts, refusal to comply with adult rules and requests, and
excessive arguing with authority figures. Greene et al. (2002) found that ODD was a significant predictor of family conflict. The presence of any one of the comorbid disorders that frequently accompany TS may present significant challenges for parents, not to mention the combined effects of behaviors associated with a constellation of neuropsychiatric conditions.

Parents’ ability to handle the challenges associated with raising a child with TS, and their capacity to act as effective advocates for their children, may be compromised by their own psychological ill health. Research suggests that parents of children with chronic developmental disorders are themselves at risk for higher levels of psychopathology (e.g., mood disorders, anxiety disorders, etc.). Furthermore, parents who are genetic carriers of TS are more likely themselves to display symptoms of TS and its associated disorders (Robertson, 2003; Pauls, Alsobrook II, Gelernter, & Leckman, 1999).

A study conducted by Cooper, Robertson, and Livingston (2003) further illustrates the likelihood of psychopathology in parents who raise children with TS. These investigators compared parents of children with two forms of chronic, severe illness, namely, TS and asthma. Asthma, like TS, has been shown to cause significant parental burden (Horner, 1997). Another similarity between asthma and TS is that asthma is associated with higher incidence of other disorders in first-degree relatives of asthma sufferers. In the case of asthma, these disorders include affective disorders, Post-Traumatic Stress Disorder, increased substance abuse, and Antisocial Personality Disorder (Wamboldt et al., 1996). These researchers found that parents of children with TS were “…more likely to have psychological illness than parents of children with
asthma. They also experienced greater burden, specifically in the domains of relationship, well-being, and activities (p.1374).” Cooper et al. also found that parents of children with asthma were prone to high rates of “psychological morbidity.” Since parents that had children with TS had significantly higher rates of psychological illness than their counterparts, the differential may be attributable to the unique aspects of TS. Interestingly, the parents of children with asthma in the study by Cooper and colleagues attributed parental stress to physical aspects of their child’s condition, while those with children with TS named their child’s behaviors and actions as the source of parental stress. A noteworthy limitation reported by the authors of this study was that parents with children with TS generally show higher levels of comorbid psychopathology due to the influence of genetics.

As previously discussed, parents who are genetic carriers of TS are subject to variable expression of the gene(s) in themselves (Robertson, 2003). In other words, a percentage of these parents may display TS, and/or other disorders tied to basal ganglia dysfunction (i.e., ADHD, OCD, anxiety disorders, mood disorders, etc.). Considering the affect that ADHD in a parent might have on caregiver skills, Murray and Johnston (2006) investigated differences in parenting effectiveness between mothers with ADHD, and mothers without this disorder. These researchers found that mothers with ADHD scored lower on several measures of monitoring their child’s activities, on problem solving, and on consistency in parenting. Murray and Johnston reported that previous research has shown a link between low levels of monitoring and increased behavioral problems in children. The implications of these findings for children with TS, who themselves may...
have significant behavior problems, are obvious. Furthermore, Ramchandani and Stein (2003) report research findings, suggesting that when parents are affected by psychiatric disorders, “…several aspects of children’s development can be affected, including their physical, cognitive, social, emotional, and behavioural development” (p. 242). Edell-Fisher and Motta (1990) found that parents of children with TS have lower, general self-concepts than parents of children without this disorder. Presumably, this finding is due to parental feelings of inadequacy in coping with their child’s disorder related problems and behaviors. One implication of the results of these studies is that family members should also be considered in the treatment of children with TS.

Social and economic stressors may also affect parents of children with TS, increasing caregiver stress level, and negatively impacting parents’ self-concept and emotional health. For example, many parents might not be able to afford to provide after-school childcare for their children and must work during after school hours. Barnett and Gareis (2006) determined that this situation resulted in stress for working parents, particularly for parents of girls. Reason would suggest that the degree of stress would be amplified for parents of children with TS, given the increased risk these children face of peer rejection and teasing. Adolescents with TS are known to engage in higher rates of risky behavior than their peers (due to inhibition that is characteristic of TS and comorbid ADHD, CD, etc.). Arguably, children that are unsupervised after school would be less likely to successfully complete homework assignments, compounding these students’ school problems, and, in turn, creating additional concern for their parents.
Studies show that parenting a child with a disability contributes to caregiver stress and strain, which, in turn, may lead to psychological and mental ill health in parents. For example, Brehaut et al. (2004) reported that parents of children with cerebral palsy were more likely than parents of children without disabilities to have a number of physical and mental health problems. With regard to parents of children with TS, Schoeder and Remer (2007) demonstrated that several factors were responsible for caregiver strain, namely, perceived support, the age of the caregiver, and the severity of the child’s TS symptoms. Based on the results of their study, 43% of the variance in a path analysis was attributed to these three variables. While caregiver age was found to be a predictor of strain, other personal caregiver characteristics, such as gender and ethnicity, were not. Also according to these researchers, a child with TS and comorbid ADHD or ODD appeared to more strongly predict caregiver strain (accounting for 29% of the variance), and caregivers who raised a child with TS without comorbidity reported less caregiver strain. An especially important finding was that caregiver strain was strongly related to the caregiver’s perception of the amount of social support, implying that increasing social support for parents of children with TS might play an important part in decreasing their stress. Given that parents of children with disabilities are more likely than parents of children without disabilities to have a number of physical and mental health problems, it is important to look at factors such as social support that could reduce parental stress.

*Parents, Tourette’s Syndrome, and schools.*

Given the multitude of reports of school difficulties frequently encountered by children with TS (Burd, Kauffman, & Kerbeshian, 1992; Abwender et al., 1996), parents
of children with this disorder may have deep concerns regarding their child’s experience at school. As previously established, students with TS are at greater risk of peer rejection and teasing, and academic difficulties. Students with TS may also contend with a range of tic related phenomenon (i.e., tic suppression, premonitory urges, and tics), affects of comorbid psychopathology (e.g., ADHD, OCD, mood disorders, anxiety disorders, etc.), and self-injurious behavior, any of which may hinder academic performance and make life at school difficult. Since parents release their children to the care of school personnel, parents who witness problematic behaviors in their children would likely feel some degree of distress. In many respects, children with severe TS may need special care and handling at school, and considering the heavy workload of classroom teachers, parents may feel concern that their child is without needed support while in the school environment.

Unfortunately, most school personnel appear to be ignorant as to how to assess TS and how to provide appropriate interventions for students with this disorder. Obtaining knowledge of the presenting signs of TS, and developing an understanding of appropriate classroom modifications are key to teachers and school psychologists providing or acquiring academic, parental, and medical help for affected children (Bronheim, 2000; Hagin, 1995). Most teacher education programs are unlikely to train pre-service teachers to instruct children with neuropsychiatric conditions. Previous research has assessed teacher knowledge about high incidence disorders, such as ADHD, and found that despite the plethora of information about this disorder, teachers lack basic knowledge about these disorders (Weyandt, 2001). Providing further evidence for this information gap, Miranda,
Presentacion, and Soriano (2002) reported that elementary teachers most often attributed their difficulty in effectively meeting the classroom needs of students with ADHD to a lack of knowledge about this disorder. Arguably, if teacher knowledge about high incidence disorders (i.e., ADHD) is negligible, then their knowledge about low incidence disorders (i.e., TS) is likely to be minimal as well.

When the school is not able to effectively work with a child with TS, the blame for the child’s learning and/or behavioral difficulties may be put on the child’s TS condition. Research related to teacher self-efficacy suggests that when some teachers are faced with a difficult child, teachers tend to display signs of having an external locus of control (Guskey & Passaro, 1994). Teachers in this position may feel that they can not affect learning in this child because the student’s performance is affected by her/his home environment, or in the case of a child with TS, his/her illness. Given the unique presentation of tics and the myriad of possible school related problems, the perplexing nature of neuropsychiatric disorders, and a lack of teacher knowledge of TS, it is not surprising that instructors might focus on within-child characteristics to explain academic difficulties. Teachers might view such biological, genetic disorders as immutable, and feel helpless to influence the child’s educational progress.

Given that schools may not have the knowledge to adequately respond to a student with severe TS, parents may need to actively advocate for their child in the school arena by informing school personnel about this disorder and spearheading a drive to gain special education services. According to counsel provided by TSA, parent knowledge is the main factor for obtaining help at school (Shimberg, 2003). A TSA publication for
parents suggests that parents “… may have to run interference for their child and clear the way within the school setting. (p. 6)” Once a diagnosis of TS is made by a physician, parents are advised to inform all school personnel that make contact with their child of their child’s tic condition (Shimberg). Teachers may be unaware that a child has TS because, as previously stated, tics may be overlooked by educators or mistaken for purposeful behavior. Teachers may also have the common misconception that coprolalia must be present for a diagnosis of TS (Zinner, 2004). In such cases, school personnel may need to be convinced that a child has TS, possibly leading to parental frustration and anger that further complicate their “grieving” process after learning of the child’s diagnosis.

When children with TS leave the school environment at the end of a school day, these individuals may display heightened symptoms of tics and emotional disturbance (Zinner, 2004). Some children with tic disorders withhold tics during the school day out of fear of being chastised or ridiculed, or as an attempt to avoid annoying their classmates or teacher(s). Once the child leaves the school environment, a rebound effect may occur due to the extended suppression of tics, resulting in more frequent and intense tics. Other emotional factors may contribute to a child with TS needing to “let off steam” after school. For example, they might experience frustration with having to maintain attention to their studies during the school day, or anger due to the effects of teasing or ridicule by classmates. Zinner (2004) reports that social discomfort and shame may be the most troublesome aspects of TS, especially for older students. After school, these feelings of anger, frustration, and irritability may be directed towards parents or siblings, wherein
parents may become scapegoats for problems at school. Parents, who are the advocate for these children, may become a target of hostility. Hence, parents at home after school may struggle to cope with their child’s reactions to school-related problems. TSA publishes a pamphlet entitled “Coping” that explains that such outbursts are common in children with TS, particularly in response to stress or fatigue. This publication outlines parental strategies to manage emotional outbursts in their child.

Another possible source of conflict for parents with school personnel might be discrepancies in how parents and teachers view the behaviors of children with TS. Christie and Jassi (2002) compared parent and teacher perceptions of children with TS and found that parents of male students reported behavior problems as more severe, and to occur more frequently, than did classroom teachers. Parents also rated their children with TS to have higher rates of internalizing problems (i.e., withdrawn, somatic complaints, and anxiety) than did teachers. Parents are probably more attuned to the stress related to having TS, and how this condition can affect depressive symptoms, anxious symptoms, social issues, etc. One explanation for teachers’ lack of awareness of internalizing problems in students might be due to teachers being less able to attend to individual students (Wodrich, 1998), while parents, understandably, have a more intimate knowledge of their child’s behaviors (Miller, 1995). As well, teachers tend to view students through an academic lens, while parents have a more holistic view of their children. School staff members need to be aware that serving children with TS in school goes beyond accommodating for tic behaviors. These professionals also need to recognize and manage the ripple effects that stem from the social and emotional problems
that have a direct impact on academic performance. Teachers and parents were in greatest agreement regarding the degree of attentional problems in students (Christie & Jassi). These findings suggest that while teachers may be equally aware of inattentiveness in students, parents of children with TS are more aware of the causes of inattentiveness, such as anxiety, depression, obsessive thoughts, or inner tension related to tic control.

As previously noted, a common recommendation for parents of children with severe tic disorders is to educate teachers, and perhaps the child’s classmates, about TS. Understandably, not all parents with children with TS have the time, resources, or personal comfort level to confront school officials and deal with school related matters. Meeting with a committee of educators, or even with a child’s teacher, could be an intimidating event for some parents, especially if the parent also is afflicted with TS and/or the comorbid disorders associated with TS (Messer et al., 1998). Other possible barriers to parents participating as advocates for their child at school might include socio-cultural, racial/ethnic, language differences between parents and school personnel, lack of transportation or child care, or a shortage of knowledge of the education system. Given the importance of parents acting as advocates at school for their children with TS, some children may lack necessary support at school due to their parents’ inability to serve in this capacity. Research is lacking that accesses the ability of parents to provide needed support for their children with TS.

TSA suggests that parents also act as advocates for their children in the special education/referral process, if necessary. Unfortunately, this process is complex. Many children with TS do not qualify for special education services based only on the results of
testing because they may not meet the standard for eligibility based on a significant discrepancy between academic performance and IQ. It is recommended by TSA that parents make evaluation committee members aware that regardless of whether a child with TS is deemed to have a learning disability, the student with significant impairment(s) qualifies for special education services under the category “Other Health Impaired,” in that TS is a medical (neuropsychiatric) condition that interferes with learning. The Individual with Disabilities Education Act calls for consideration of other factors as well as test information, including background information obtained from the child’s physicians, parents, and school staff. As well, specific tests must be conducted that pertain to all areas of the particular disability. For example, a functional behavioral assessment should be conducted when a student’s behavior is negatively affecting academics, or the academic behavior of others. Schools are often unaware of the range of tests that should be conducted to adequately assess neurological function that may be affected by TS, OCD, and ADHD. In fact, TSA recommends that parents have an independent neuropsychologist conduct a comprehensive evaluation of children suspected of being affected by TS, rather than entrusting testing duties to school personnel (Conners, 2003). For many parents, this service is expensive, and thus prohibitive. Furthermore, there are no laws that require public school systems to pay for evaluations conducted by private test agencies. Understandably, spearheading such an intensive process of determining eligibility for special education services may be beyond the ability, or comfort level, for many parents of children with TS.
Thus, parents of children with TS and related disorders may be emotionally distraught due to having to contend with issues emanating from their child’s TS disorder and school-related problems. Because of caregiver burden, and/or genetic inheritance, parents themselves may exhibit symptoms of psychopathology that can worsen family functioning. Consequently, these parents may experience an array of negative emotions related to their child’s TS related condition(s), including fear, frustration, anger, confusion, shame, or guilt.

Examining the experience of parents of children with TS may yield important information for school psychologists regarding an affected child’s experience at school, as viewed from the parent’s perspective. Depending on the degree of communication between home and school, teachers may in some cases be unaware of how children experience school. Parents, from their own vantage point, may be privy to anecdotal information about school problems that is shared by their child, or by their child’s behavioral reactions to the school experience that are exhibited at home. In other words, parents may become aware of their child’s TS related academic, social, or behavioral school difficulties that are due to their child’s TS condition that may be hidden to school personnel. In-depth, personal interviews with parents of children with TS may reveal that information. Such information may lead to improved school responses to meeting the unique needs of students with TS.

School psychologists are the obvious choice among other school personnel to take the lead in assisting students with TS. It is plausible that school psychologists have a higher knowledge level about TS than most teachers, since school psychologists are more
likely to have received formal training and have experience in diagnosing and designing
classroom interventions for children with neurological, emotional, and/or behavioral
disorders (Fowler & Henderson, 1995). For example, D’Amato, Hammons, Terminie,
and Dean (1992) indicated that as of 1992, neuropsychological coursework was a
mandatory part of doctoral programs in school psychology in 59% of accredited schools
and 53% of non-accredited schools, representing a growing trend of neuropsychological
training. Beyond the training level, school psychologists have professional standards that
regulate their roles of diagnosing and designing interventions for mental and
physiological disorders that affect learning (NASP, 1997). According to the National
Association of School Psychologist: Standards for the Provision of School Psychologist
Services (NASP, 1997), these professionals are to conduct psychological and
psychoeducational assessments in the areas of personality, emotional status, social skills
and adjustment, adaptive behavior, achievement, and sensory and perceptual motor
functioning. Another standard for school psychologists, set by the National Association
of School Psychologists, is to design direct-service programs to enhance cognitive,
affective, and social programs. Thus, it is clear that a professional duty of school
psychologists is to recognize the symptoms of TS and to help provide appropriate social
and educational accommodations for children with this disorder.
A qualitative research design was selected to meet the purpose of the present study. Creswell (1998) defines qualitative research as “…an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem.” The present study lends itself to a qualitative research approach for four primary reasons. First, a qualitative study is most often used to explore the meanings that people make of their experiences, and to study individuals in their natural environment (i.e., field focused) (Patton, 2002). Secondly, qualitative research can be used to discover substantive areas about which there exists a paucity of information, and about which one wishes to gain novel understanding (Stern, 1980). A third justification for the use of a qualitative research design is to gain a deep understanding of the phenomenon being explored through a detailed view, as opposed to a wide, topical view that would result from using a quantitative research approach. Lastly, a qualitative approach is employed in order to best address goals of the study. Creswell suggests that researchers use a qualitative approach when the research question(s) asks “what” or “how” (as befits the present study) instead of addressing cause and effect issues, answered best through quantitative research methods.
Given the focus of this study, and the difficulty of obtaining participants, a qualitative research design was chosen. While a quantitative design (e.g., survey research) could be used to investigate the phenomenon of interest, quantitative methods would not sufficiently explore this phenomenon to the degree of depth or complexity that may be achieved through a phenomenological approach. Additionally, a quantitative design would necessitate a sample size that would be difficult to attain, given the relatively low prevalence rate of TS and the difficulty of finding participants who match the inclusion criteria. Thus, due to the nature of the phenomenon being studied, as well as the qualities of the population under investigation, a descriptive phenomenological approach was employed.

The term phenomenology may have multiple definitions, ranging from a reference to a philosophy, to a social science orientation (Patton, 2002). According to Creswell (1998), phenomenological research is based on the philosophical orientation of the German mathematician, Edmund Husserl. To Husserl, phenomenology refers to the study of what people describe as their experience gained through their senses (Patton). The purpose of phenomenology research is to describe the meaning of the lived experiences of individuals with regard to a particular phenomenon, and the primary goal of phenomenological researchers is to search for and capture the essence of that phenomenon. In the present study, I attempted to understand the lived experience of parenting a child with TS+.

A widely used form of phenomenological research, based on Husserl’s philosophic paradigm, is descriptive phenomenology. This approach, selected for use in
the present study, relies on describing universal essences, or eidetic structures, that reveal truths, as experienced by participants. Other key features of descriptive phenomenology are as follows: an emphasis on human consciousness as a way attaining knowledge of the world; maintaining scientific rigor when analyzing data; constant reflection on the researcher’s own knowledge, biases, and experiences, and holding these in abeyance while attempting to understand others’ lived experiences (Wojnar & Swanson, 2007.

Participants

Consistent with the aims of a phenomenological study, purposeful sampling was applied to obtain participants. The specific type of purposive sampling employed (Nieswiadomy, 1998) involved the researcher using “…personal judgment to select subjects that are representative of the population (p. 367).” More specifically, the present study used the strategy of criterion sampling (Miles & Huberman, 1994), recommended when participants need to meet certain criterion for inclusion. This strategy is useful when attempting to control quality assurance (Creswell, 1998). Such sampling measures are needed due to the narrow population of potential participants. The potential pool of recruits was limited because participants had to be sought among the population parents of children who were school-aged, and who had been diagnosed with TS. A further limitation to recruiting participants was that parent interviewees of those children had to share personal thoughts and feelings regarding their parental experience raising their child, and regarding their child’s experience at home, community, and school, as pertains to the child’s TS+ conditions.
Inclusion criteria for this study included being a primary parent of a child formally diagnosed with TS. The term “parent” refers to one who raises and nurtures a child, who may be a single (unmarried) male or female, a biological father or mother, a step-parent, an adoptive parent, a grandparent, or those in a same-sex relationship. When two or more parents were known to be involved in the child’s life, the primary parent was invited to participate. Primary parent is defined as the parent who has taken responsibility for greater than 50% of the day-to-day parenting duties (e.g., getting the child to school, taking care of the child’s health care needs, etc.). Participants were included without regard to race or ethnicity, sexual orientation, marital status, or gender. The parent, as well as the child, may have been diagnosed with TS and/or one or more psychological or physical disorders. Another criterion for inclusion was that the children being represented by their parent in the study must have been attending a public school and be in grades K through 12. Furthermore, the additional diagnosis of one or more comorbid disorders was not considered reason to exclude children from the study, except in the case of severe hearing or visual impairments, or psychotic disorders (e.g., schizophrenia). Since the phenomenon under investigation is parenting experiences of parents who raise children with TS, an important criterion for inclusion was that the participant reported having had intense parenting experiences around issues pertaining to their child’s TS+ conditions. This study excluded individuals who did not speak English.

Regarding sample size, Streubert (1991) reported that four to seven participants is the average sample size of phenomenological studies. Creswell (1998) called for recruiting up to ten participants for a phenomenological study. According to Patton
(2002), it is difficult to set a firm number on the subject size in qualitative research, and sample size ought to depend on the purpose of the study and the resources available to the researcher. In all, six participants were interviewed in this study (See Tables 1 and 2), recruited through state chapters of TSA.

Established in 1972, TSA is a nonprofit, voluntary organization that was created by a group of parents of children with TS. The mission of TSA is to assist in finding the cause of, the cure for, and to control the effects of TS. This organization disseminates information on TS and provides referrals for families of children with this disorder (Tourette Syndrome Association, Inc., 2006). Presumably, the parents who are members of this organization, as opposed to parents of children with TS who are not members, are more likely to have greater access to information about TS to be more aware of available treatments for their child, and be more knowledgeable about coping strategies for themselves and their child due to the training and materials made available by TSA. By documenting the coping skills used by parents influenced by the teachings of TSA, other parents might learn from their example.

Brief descriptions of each the six children, represented by the parent participants in this study, are as follows:

The child of subject one (S-1) was 15 years of age at the time of the interview. This boy is white, lives with three siblings, and participates in a gifted education program in a public high school. He was diagnosed with TS at 10 years of age. His mother described his TS symptoms as including coprolalia, obscene gestures, and random vocalizations (shrieking). He has also been diagnosed with OCD and GAD.
The child of subject two (S-2) is a multiracial, six-year-old female who is currently in a special education classroom. According to her father, she resides with himself and his wife, and two other children. The child was diagnosed with TS at five and one-half years of age by her pediatrician. Her father rated her TS condition as “moderate.” Reportedly, this child exhibits symptoms of multiple disorders, including TS (e.g., “barks,” physical tics, and sexually inappropriate behaviors), OCD, and ADHD – Combined Type.

Subject three (S-3) reported that she adopted her son when he was approximately 8 years of age. He was diagnosed with TS by both a pediatrician and psychiatrist at age nine, despite exhibiting symptoms of TS at a younger age. This Hispanic boy lives with his mother, maternal grandmother, and another adopted child. At the time of the interview, the boy was 17 years of age. Presently, his symptoms include excessive throat clearing/sniffing, some head/neck movements, and muscle tensing. The child has also been diagnosed with ADHD (inattentive type), OCD, and GAD. According to his mother, the symptoms of his SAD cause him the most difficulty.

The child of subject four (S-4) was 14 years old at the time of the parent interview. His mother, who lives with her significant other, described her boy as white. He was diagnosed with TS at 8 years of age by a psychiatrist. His symptoms of TS (rated as “severe”) include self-injurious behaviors (hitting himself in the head), sniffs, throat clearing, abdominal twists, and toe stretching. He has also been diagnosed with ADHD (combined type), OCD, mood disorders (Depression and Bipolar Disorder), GAD, LD, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS).
Subject five (S-5) revealed that her white, 13 year old daughter was diagnosed with TS at age 12. The diagnosis was made by a neurologist. According to her mother, this child’s primary symptoms of TS are verbal outbursts, which are coprolalic at times. She has also been diagnosed with OCD and GAD, both rated by her mother as “mild.” This child lives with her mother and father, and two older siblings.

Lastly, subject six (S-6) stated that she lives alone with her 13 year old grandchild, an Hispanic male, who was diagnosed with TS at six years of age. She stated that his symptoms of TS include moving his neck, eyes, and arms, and “talking to himself” a lot. She added that he has also been diagnosed with ADHD, OCD, Depression, and Separation Anxiety.
<table>
<thead>
<tr>
<th>Parent Participants</th>
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Gender of participants (i.e., interviewees)

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Age at Time of Interview

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Ethnic Background

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<tr>
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Relationship to Child with TS+

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<tr>
<td>Biological father</td>
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<tr>
<td>Maternal grandmother</td>
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<tr>
<td>Adoptive parent</td>
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Educational Level of Participants

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Employment Status

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Number of Children in Household

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<td>3</td>
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Table 1: Demographics of the Study Participants (N=6)
Table 2: Demographics of Children with TS+, Represented by Participants (N = 6)

Data Collection

The participants were solicited via a flyer, announcing the goals and terms of the research project. Written consent was obtained, allowing for the interviews to be tape recorded, and for the data to be published in the form of the current dissertation. Data were collected through semi-structured, audio-taped personal interviews, conducted by
the researcher. The initial interview sessions lasted approximately one and one-half hours. The second interview session was conducted by phone, lasting approximately 20 minutes.

*Interview settings.*

Since phenomenological research depends on participants revealing personal thoughts and feelings, maximizing participant comfort while providing them a sense of privacy and security were important considerations when selecting interview sites. As such, interviewees were offered the option of meeting at a public site of their choosing (e.g., library, school, or café), or meeting at the participant’s home. In one case, a public coffee house was utilized as the interview site. In another interview, I interviewed the participant in an empty office space at the participant’s place of employment. The other four interviews were conducted in the homes of the participants. In general, the only individuals present in the same room during the interviews were the participants and myself, with the exception of the session held at the coffee café.

*Interview format.*

Regarding the interview format, four global tour questions, supported by 17 optional prompts, addressed four areas of parental experiences in raising a child with TS. The questions were as follows: 1) How do parents experience the symptoms of their child’s TS+ condition(s)? 2) How do parents experience their child’s TS+ in the home setting? 3) How do parents experience their child’s relationship with peers and people in the community? and 4) How do parents experience their child’s school issues related to
their TS+ condition? Thus, four of the child’s ecologies (i.e., self, home, community, school) were explored through the experiences of the parents.

Two possible risks were associated with this study: breach of confidentiality and psychological stress. Breach of confidentiality: If, during the course of this study a parent participant revealed that he/she had harmed someone else, confidentiality would have been considered to have been breached and the appropriate authorities would have been informed. The likelihood of breach of confidentiality occurring was deemed minimal. At the outset of each personal interview, the researcher/interviewer informed the interviewee of the conditions under which confidentiality may be broken, according to the ethical codes of the American Psychiatric Association.

Psychological stress: The interview questions in this study were meant to explore the academic and social/emotional effects of TS+ on the interviewee's child, on the participant, and on the participant’s family members. Each interviewee was asked to relate information as to her/his everyday life as a primary parent of a child with TS. In addressing these issues, there was a minimal chance that the interviewees may experience some degree of temporary psychological stress. The chance of stress being experienced by the interviewees was mitigated, however, by the freedom the subjects had to disclose as much or as little information as they chose. In my observation, most interviewees experienced a sense of relief in sharing their thoughts and feelings with the interviewer and viewed the interview as a cathartic event. No long-term consequences were anticipated as a result of any psychological stress incurred from this study's interview experience. Although the interviewees might have described their child, their self, or
another family member as experiencing the symptoms of a known disorder, the researcher did not offer diagnostic information to the interviewees. Should the interviewees have reported feeling stress, participants would have been informed of community resources where psychiatric help could be accessed.

Regarding the safeguarding of data, all participants received an identification number that appeared on all private information (demographic information, tapes, interview transcriptions, etc.). Identifying information was recorded on a master sheet and stored separately from the data in a locked file cabinet that is accessible only by the co-investigator (Roger Sasnett) and the principal investigator to this study (Dr. Antoinette Miranda). The data will be destroyed within one year following the conclusion of this study.

Method of data collection.

Prior to engaging in the task of analyzing data, according to Giorgi and Giorgi (2003), the researcher is to modulate her or his attitude towards that which is being studied. More specifically, the phenomenological tradition requires one to engage in what Husserl referred to as reduction, which is attained through the implementation of two practices: bracketing and phenomenological reduction.

Since the investigator may have preconceived ideas about the topic being studied, due to personal experience, it is important to gain insight into one’s personal orientation. Such preconceived ideas may serve to bias one’s description of another’s viewpoint. Husserl admonished the phenomenologist to avoid tainting data with one’s own biases, attitudes, or beliefs by engaging in a practice he called “bracketing.” Bracketing stems
from Husserl’s concept of “epoché,” meaning to stay away or abstain (Groenewald, 2004). This practice, according to Miller and Crabtree (1992, p. 24), is concerned with the researcher setting aside her/his preconceptions about the phenomenon under investigation. In short, the researcher “…must ‘bracket’ her/his own preconceptions and enter into the individual’s lifeworld and use the self as an experiencing interpreter.”

In the present study, I will achieve bracketing by keeping a personal journal. The journaling, at the outset, will serve as a means to establish my own experiences, thoughts, and feelings about parenting children with TS. I expect to accomplish this first phase through my answering the questions in the interview protocol that will be used in this study. The second phase of journal writing will involve my noting my biases and prejudices as they arise through the data analysis process, and how my awareness of my own attitudes, beliefs, and prejudices with regard to the phenomenon of interest informs my data analysis work in the present, and might alter my approach in the future.

A second practice is to achieve phenomenological reduction by accepting the interviewee’s experience as it is given, i.e., as the object presents itself to the individual. As with bracketing, the researcher is called upon to hold their preconceptions about the object in abeyance, and to maintain an open consciousness so as to accept and understand what presents itself to the consciousness of the interviewee, without regard to the object’s realness. Such a state of mind allows for the presence (and subsequent examination) of psychological phenomena, such as emotions and values (Kleiman, 2004). Having attained a level of consciousness that facilitates reduction, the researcher is then in a proper frame of mind to begin analyzing the data.
Data Treatment

Using a method prescribed by Colaizzi (1978), the data was analyzed in seven steps. Colaizzi emphasizes that these steps are not hard and fast and may overlap. Thus, the following seven steps may be modified somewhat, depending on the researcher’s needs.

1. The first step in the data analysis process involves gaining a holistic view of one participant’s responses to interview questions by reading all of the transcriptions. At this point, the researcher is not to attempt to identify themes, but to understand how the parts of the individual’s responses are constituted (Giorgi & Giorgi, 2003).

2. Extract statements that are significant from each participant’s transcription. A statement is significant if it relates to the phenomenon of interest. Redundant statements may be eliminated. If statements refer to a specific situation, these ideas may be made into a more general form.

3. Create “formulated meanings” from the extracted statements. Colaizzi views this step as a creative process for the researcher, who must draw broader, more general meanings from the statements. In the process, however, the investigator must retain the connection between the original statements and the newly formulated meanings.

4. Repeat steps one through three for each interviewee. Next, cluster the formulated meanings into still more broad themes (essences). As with step three,
maintain a connection between the clustered themes and the extracted statements. Linking themes and extracted statements is an important means of theme validation. Colaizzi adds that at this point, the researcher must avoid the temptation to ignore themes that do not appear consistent with other themes, or to prematurely generate an overall theory in order to mask apparent inconsistencies in themes. In Colaizzi’s words, “…the researcher must rely upon his tolerance for ambiguity: he must proceed with the solid conviction that what is logically inexplicable may be existentially real and valid” (p. 61).

5. The themes derived from step 4 are further distilled into an “exhaustive description” of that which is the focus of the phenomenological study.

6. The exhaustive description, found in step 5 is to be further condensed into a clear statement that identifies the fundamental structure of the construct being investigated.

7. As an additional means to validate the end result achieved in step 6, Colaizzi (1978) recommends that each participant be re-interviewed (member checking). During this final session (or sessions), the interviewee is questioned as to how well the interviewee’s experience compare with the end results. In this final step, the researcher is to learn whether the results have misconstrued the experience of the interviewees, or whether elements of the participants’ initial responses have been omitted. Any new information is to be integrated with the final product.
Data Analysis

There were several procedures followed prior to engaging in the data analysis process, outlined above. Before each interview, an audio tape was labeled with a number that was assigned to each participant. Immediately following each interview, I personally transcribed the information from the tape recording through the process of word processing. So as to protect the identities of individuals that might have been named in the participants’ responses, as well as the names of the interviewees, I created a pseudonym during the data analysis process for each person, including a pseudonym for each interviewee. Verification of accuracy of the transcript was made through two repetitions of my replaying the tape in its entirety while reading the transcript. Transcripts, audio tapes, and other interview related materials were kept in a locked file cabinet in my office.

Each of the seven steps in the data analysis process, prescribed by Colaizzi (1980), were followed. Member checking, achieved in step 7, was conducted via telephone with each of the participants. The exhaustive description was read. Uniformly, participants were in agreement that the exhaustive description captured their experiences. Interviewee comments included, “Very well done,” “Strong… good,” and, “That tells my story.”

Trustworthiness

Trustworthiness is a qualitative methodological term that may be used in place of the quantitative terms of validity and reliability. Lincoln and Guba (1985) posited that trustworthiness of a study is attained if the end result accurately reflects the experience of
the study participants. Put another way, trustworthiness may be defined by the question: "How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of (p. 290)?"

According to a model proposed by Lincoln and Guba (1985), trustworthiness is comprised of four components, namely credibility, transferability, dependability, and confirmability. The following represents a description of each component and the means I used to ensure that each of these elements, used to establish trustworthiness of the data, was addressed.

Credibility refers to the degree that the themes, which are the end result of the data analysis process, accurately reflect the realities depicted by the contributing participants. This element was satisfied by using the procedures of peer review and member checking. In the peer review stage, two peers (Dr. Kathleen Sasnett, Assistant Professor at Gettysburg College, and Dr. James Moore, Assistant Professor at Howard University), examined my work in order to clarify the ideas, reveal possible researcher bias, and scrutinize my interpretations or conclusions (Schwandt, 2001). Peer review was used as a form of investigator triangulation, which was used to achieve the purpose of gaining multiple perspectives on the data to help build data credibility. Member checking (Denzin and Lincoln, 2003), as described in “Step 7” in the data analysis section, refers to having each interviewee review the researcher’s summary of their interview transcriptions in order to ensure that the participant’s statements were accurately described and fairly interpreted.
Transferability refers to the degree to which the findings may be generalized to other settings or respondents. One strategy this study employed to enhance transferability was through the use of “thick” descriptions of the data (Patton, 1990). Detailed descriptions of the findings, and the participants and their personal contexts (e.g., values, family dynamics, parenting concerns, etc.) allow others to assess the extent to which the findings are transferable to their own situation.

Dependability and credibility are closely related checks for trustworthiness that tend to overlap. Dependability refers to the extent to which the results would be replicated if the study was repeated with the same participants. Confirmability is a measure of the degree that the study’s results reflect the participants’ responses as opposed to the investigators’ biases. These two components can be strengthened by performing an audit trail (Lincoln and Guba, 1985). An audit trail refers to an independent auditor reviewing the analytic procedures of the study. The procedures to this study were analyzed by the auditor to this project, Dr. James Moore, Professor at Howard University. According to Dr. Moore, the procedures were appropriate for a study of this nature and were applied in a consistent manner. Dependability was strengthened by means of my creating detailed descriptions of my methods of data collection, data analysis, and situational variables, including factors affecting the selection of participants and the selection of interview sites. Confirmability was affirmed by careful record keeping practices, including proper maintenance of files of taped interviews, transcripts, interview notes, and data analysis worksheets. Journal entries (field notes) were another source that was used to enhance the confirmability factor of this study.
CHAPTER 4
RESULTS

Research participants were interviewed in order to gain information according to one overriding research question: What is the lived experience of parenting a child with TS+? Data analysis revealed themes (i.e., essences) that fell into four general categories: (1) diagnostic/treatment issues; (2) the home/community experiences; (3) experiences pertaining to their child’s schooling; and 4) intrapersonal affects on the parent of raising a child with TS. Verbatim text of substance (i.e., significant statements), taken from transcripts, are provided as a means to provide examples of overarching themes. Interviewees are differentiated by the symbols “S-1” (i.e., subject 1), through “S-6.”

Grand Tour Question 1: How do parents experience the symptoms of their child’s TS+ condition(s)?

Regarding diagnostic/treatment issues, participants described experiences that fell into two themes. Specifically, most parent interviewees (A) struggled to gain a diagnosis of TS for their child and felt relief once a diagnosis(es) was made; and/or (B) sought help for their child through multiple health care systems and struggled with pharmaceutical treatments.
Theme A: Parents reported having struggled to gain a diagnosis of TS, but felt a sense of relief once the diagnosis was made.

One parent, echoed by other participants, stated that her child’s physician was unable to make a diagnosis without witnessing the tics first-hand.

I mentioned something to the doctor and he said, “Unless she’s doing something, I really can’t help her. I really need to see her do it.” So I followed her around with a video camera for several weeks, and she didn’t do it (i.e., tic). So we just let it go. When she started really doing things that we felt were hurting herself, I pretty quickly diagnosed her with Tourette’s; we pretty quickly did that ourselves (S-5).

One parent shared that she questioned the validity of her child’s TS diagnosis.

It was confusing (the TS diagnosis) because from what I had read there needed to be a family history; there generally is a family history… we informed her teachers at that point (once the diagnosis was made) and she told some of her closest friends, but pretty much nobody really noticed, saying, “That’s just the way she is” (S-5).

Three interviewees reported feeling relief when their child received a formal diagnosis of TS:

I was just concerned to make sure that in his birth history, I read there was a history of epilepsy and just wanted to make sure that he didn’t have a seizure disorder or something that was going awry neurologically with him… So I think I felt more comfortable knowing what it was, and that there is help and treatment available… I think it (the TS diagnosis) is a positive thing because I know there’s help out there (S-3).

I felt actually more relieved knowing that I was finally getting somewhere, where he has had all these diagnoses and for me it was like the one I find it, “Okay, maybe we are hitting on something that we can find something that works for him (S-4).”

We actually went to a pediatric neurologist and they said, “Yes, it’s Tourette’s.” It was a relief that that’s what it was, and it wasn’t something more serious; it’s not fatal (S-5).
Unique to one interviewee, he reported having been accused by school personnel of sexual molestation, based on the sexual behavior of his child exhibited in school. The school claimed that the child’s sexual behaviors, which are not uncommon to children with a diagnosis of TS, were due to the father having sexually molested his daughter. This parent sought to have his child’s pediatrician wave the criterion of waiting one year upon the onset of tics before making a formal diagnosis of TS:

Well when that meeting (a school meeting where the accusation was made) was over, I marched myself up to the doctor, and I said, “Doctor, I need the diagnosis of Tourette’s because I am under suspicion of molestation.” And of course this is our pediatrician who examines my daughter all the time, and who examines her, and who knows that this child has never come in with a bruise, scrapes, or stories, and she’s not a kid who is withdrawn by any means. So it didn’t make any sense to him, and the Tourette’s did. I got the information (on TS), and I read over it, and everything was in there, everything…. As if it wasn’t a mystery, as if there was no suspicion, as if it was expected and normal within the context of the Tourette’s community, which allowed my wife and I to exhale (S-2).

Following their child receiving a diagnosis(es), most parents stated they sought to become knowledgeable about TS, and other related conditions appearing in their child, in order to assist their child. For example, one parent explained, “…and I read so much research years ago. I don’t know where I found Leslie Packers stuff on the Internet on rage attacks. Thank god, because I was trying to intervene and get in there (S-1).” Another interviewee reported, “I read a lot about Tourette’s syndrome through the Internet when the doctor mentioned it to me (S-3).”

**Theme B: Parents sought help for their child through multiple health care systems and experienced mixed results with pharmaceutical treatments.**

In response to their children’s TS condition, and related disorders, several parents reached out to multiple health care systems for support. Three of the five interviewees
reported having their children’s TS+ needs administered to by multiple health care providers, including pediatricians, neurologists, and mental health counselors. In one case, a child had received care in a partial hospitalization setting “eight to ten” different times. Another parent stated, “We had already seen a second pediatric neurologist. We had also her seeing a counselor (S-5).”

A common complaint among the interviewees was the difficulty their child had with pharmaceutical treatments that often produced mixed results. Finding the right balance of medications was often made more difficult due to a drug’s exacerbating comorbid conditions. Some parents reported that the side effects of some drugs were more odious than the symptoms they were meant to treat:

*(One particular medication)* was the first thing that gave the side effect of sleep. That kicked up his sleep. He went on Paxil for the anxiety… It would wake him up nauseous. We’d give it to him before bed and he’d wake up sick. So he went off that and he had these brain shocks… A little Prozac, which I can see with adolescents, took away all his anxiety and all his fear of all consequences (S-1).

From that point, well the Risperdal has really been helpful, because what would happen is, it would slowly get to the point where it wasn’t working anymore and we had to increase it and increase it. He was eating so much he would throw up and then he would eat some more and he was gaining an amazing amount of weight is like back-and-forth, back-and-forth. We’re still going through that. Then once he was on the medications we were trying many, many different medications. I can’t tell you how many single and cocktail medications he was on, nothing has really worked. It *(Ritalin)* even increased his hyperness, and he would talk, talk, talk, talk, talk, even more. And none of the normal medications that they use for ADHD, nothing works for him. He tends to get…, ever since he was young, he tends to become violent. He gets aggressive… And the medications that they placed him on at that time were Lithium and Risperdal. I was amazed because when I went to to see him, and I brought him home, it was like it wasn’t even my son anymore. He was very calm. He was very attentive. It was the first time I really could look into his eyes. And what I call look into his eyes and see his soul. Before, he was just like not here… They started with Haldol recently, and that seemed to work better well for his tics. The Risperdal helped more for his mood. The constant being real agitated and frustrated and anxiety type mood. It
seemed to level him out, but we’re at a space right now where it’s not working, and the doctor has needed to increase it again (S-4).

So we thought some of that was anxiety and we started her on Prozac to help calm her down. Right now she is on Prozac for the anxiety. Her counselor thinks she’s on Prozac because she has Obsessive Compulsive Disorder, but her psychiatrist doesn’t think so. … I have never been able to correlate whether this medication worked, because the tics have changed so much. …we stayed on Risperdal for almost a year, I guess, and adjusted the dosages and really didn’t see, although I don’t know how much better she was because she was on it, what would have happened if we took her off. So right now, it’s Prozac, Topamax, and Orap (S-5).

In one case, a parent suspected that a stimulant medication, prescribed as a treatment for the child’s ADHD, induced her child’s tics:

They (child’s physicians) believed that the tic was already there and that the medication brought it out. I don’t necessarily believe that it probably caused if he hadn’t been given a stimulant wouldn’t have brought it out (S-4).

Two parents reported that their children’s involvement in activities accounted for partial alleviation of TS+ symptoms:

He swims three hours a day, which helps, I think. I used to think that I didn’t want to stress him out or over-schedule him. The more stuff he has to do, the healthier he is (S-1).

I started him volunteering at the (names animal rescue facility). He doesn’t even ride the animals. He gets to pet them and feed them after he’s done working, but he can be down there for four or five hours and there’s nothing (no tics). It’s the only thing I have found that seems to help (S-4).

Theme C: Interviewees reported being deeply troubled by symptoms of TS+ that were odd, offensive, or physically harmful.

Some parents reported being victims of their child’s tics that were directed towards others:

Sometimes he would use what I call “weaponized tics.” Like he would do it in your face, and your ear, with your name, and attach the coprolalia stuff. He always has to go to their face. Somebody has to hear it and somebody has to see it. He would burp in people’s faces and in their ears. We had to do something. But
you don’t have to be literally in their face or in their ear. There was a lot of fighting. The punching ones, or the poking ones, right here (parent gestures to her ribs) Bruises, you want to just punch him back. It’s just a natural reaction (S-1).

…he’ll punch tables and walls and things like that (S-4).

Some types of vocal tics, especially those of a coprolalic nature, were seen by interviewees as being disturbing and difficult to manage:

The mild motor tics were one thing, but these words, these vocal things are just something entirely different (S-5).

There are a multitude of words. We say that she zones out, she becomes a different person and she will repeat entire paragraphs from movies that she has seen and she sometimes repeats things over and over again (S-5).

That was fourth-grade in fifth grade was like a shrieking. I called it like stabbing a peacock. He pulled a ligament in his throat and all that kind of stuff (S-1).

The coprolalia started during the summer Olympics. I guess it was in ‘04. All of a sudden one night he just started to start this big onset of yelling like that. All of his tics would change, would start just like that. He looked so surprised by the look on his mouth. (parent mimics tic) “Fucking Thomas…” We all knew what it was. Ever since that, it went on for three years now (S-1).

This verbal is bad. We started out with the motor tics and I have watched some documentaries and things and I thought really, this is a pretty mild case. We can live with this. This is not bad. Once these words started coming out and extremely inappropriate words that we never say in our household, it has just been a totally different situation. It’s been extremely difficult…. …and instead of just saying “fuh..”, it came out “fuck.” And she would say that word a thousand times a day just constantly it moved from that particular word to all kinds of words at this point. You know, “Do you want a pancake for breakfast?” “Yeah, I want a fucking pancake for breakfast,” and that’s just what comes out pretty much all the time now…. …It was, “Pass me the Fucking French fries.” And it’s really an uncomfortable…, we try to laugh at it, but it’s not a pleasant feeling (S-5).

That's all what we did in the last four weeks of school…We called and said, “What she is doing at home if she is doing that in school because it wasn't just the f-word. It was “nigger” and all kinds of words. So it's really not appropriate; she can't be in the classroom doing this. She told us she could not suppress them (S-5).
Parents also reported being disturbed by the symptoms of other co-occurring conditions, such as OCD or Sensory Integration Disorder:

Yeah, you know, he had these flashes of things when he was like 10 or 11, where he had everything all at once, yeah, he had a couple of episodes of that. I don’t know. Oh when he was just, the weird thing, around that time, everything just glommed up together, where this and a black monkey, and if he turned his head really fast, he would look, and part of his vision, garage, or driving by, or in school, and he would see it far away in the distance, and I don’t know what that was, or whether his OCD could get to the point where, it’s not really delusional, it’s a visual, which freaked me out (S-1).

He became obsessed with fire. Lighters and fire and matches and things like that. We couldn’t burn candles anymore in the house and hide, or get rid of, lighters and matches. He did find a lighter over at the park, and he refused to hand it over and he actually did put some paper on fire in his room. Fortunately he put it out himself and did not catch anything else on fire, but it became a danger to him and to the family to the point that I had to call his psychologist and ask for an intervention. And I did go to the hospital and it was hard, but the police did come, and he was taken to the hospital and we put him in a facility for a week of intense counseling (S-3).

And my best friend was in the car also my mother was driving and the boys were in the car and just out of the blue. He said, “I have testicles,” just out of the blue. And my friend was like, “oh okay. He’s 14 years old and why is he saying that?” So we had to have what I would call, what you would expect to have with a younger child, this talk about potty talk because sometimes it would occur at the table. He would just start talking, you know, in health we talked about testicles, and that’s your balls, and so on, he would continually looped in this conversation and not be able to end it, and he would obsess on that (S-3).

When he was younger it would be mostly just smelling. He had to smell everything, your skin, your hands, whatever. He smelled or touched everything. He still does the smelling (S-3).

When he is overwhelmed by sights, sounds and feels, there are only certain clothes he won’t wear, his sheets have to be certain fabric. Shoes, he is very picky with because he has a tic with his toes. They have to be soft on top and he has to wear shoes that are too big for him so that he is able to have movement. His socks are the same way. They have to be a certain feel of them. I don’t even buy socks without letting him try them on. Like I buy socks for him, I pull out one sock out
of the bag for him to try on to see if they are OK. He’s very particular about that, too (S-4).

Several parents reported feeling deeply concerned about witnessing their child’s self-harming tics, or hazardous behaviors:

We share things (with the child’s pediatrician) like, “We think she’s hurting herself.” Then they’d up the dosage on the medication to try to calm the tics down a little bit (S-5).

For a while he did have a head/neck thing that was really painful (S-1).

I was driving them home and he was playing with a whole bunch of buttons and boom: he opened the car door, out here, where you’re coming down the four-lane road. That happened about four or five times (S-1).

The headache thing, the neck muscle thing, the teeth thing, he had a lot of things where if it had stuck around long enough, it would have caused damage, well permanent damage on the kid (S-1).

I have hot cookie sheets and it (touching behavior) scares me a little bit when she’s wandering around the stove (S-5).

The one tic that started it is really happening badly now is the hitting. He hits himself in the head, and it's always in the same spot, so that's very concerning to me. I’d say probably about two years. It has gotten worse as he has gotten older and stronger. It’s almost like a swelling that you see there now. And it's very difficult for me to see that (S-4).

As he got older, the tics got to a point where they physically hurt him where he would clear his throat over and over and over until he got a sore throat. He would sniff so much he would get a headache, and that stuff worried me, so I was seeing the doctor more often (S-4).

For a while, she would dig her nails into her forehead to the point where she broke the skin, and she had scabs all of her forehead. So she has done things that I know are painful and hurtful to her… …At home we saw a lot of self-injury type twitches. The way she twisted her neck… She did complete backbends. Like a gymnast wouldn’t do that well… She threw her neck back really hard and if she was sitting against something, she would whack the wall, and whack whatever, really hard. I don’t think that she’s had any really permanent damage at this point. For a while she did this with her fingers to the point where these knuckles were black and blue (presses outstretched fingers against each other, bending back the
fingers at the knuckles). I don’t know how she didn’t break her fingers doing what she was doing (S-5).

It affects his self-esteem tremendously. He feels like he can’t do things, he can’t do anything. He’s gotten depressed because of it, which I don’t think is even a clinical depression. It’s generally because of… because of life, and also getting very angry with himself. And that’s when this head hitting has started too (S-4).

A common experience, reported by interviewees, was contending with their rage attacks or emotional breakdowns. The following excerpts speak to this problem area:

Yeah, there’s a lot of taking out of his anger on them (siblings), and me, and just being angry at the Tourette’s basically (S-1).

…property damage, maybe rage attacks. He’d trash the room, trash the door. Oh, when does this stop? …Those were big; he’d like kick the door, or the furniture, was always the thing, but never people. It was rage attacks (S-1).

There are several holes in the walls. He’s broken two windows, but luckily he didn’t get cut severely at all (S-4).

He was really afraid of stuff. It started out like fireworks, he said like, “Are you going to die someday?” and I said, “Yes.” And he got like hysterical. That went for six months, just crying at night and that sort of thing… …That would go away for a year or so, then it would come back like, “The world’s going to end and the sun’s going to explode and you know it. Where are we going to be (S-1).”

I didn’t know to shut the door and walk away. He’d trash the room, trash the door. Oh, when does this stop, and then what I figured out, more close to what it was, rather than going in there with him, one time I said, “Dude, if you stop, I’ll take you to whatever movie is coming out.” He was always crazy, he would come up sobbing and apologize. And I’d say, “I guess we can go,” and he’d say “Go where?” And we had discussed the movie during the rage attack, but he didn’t remember at all. I don’t think he knew. I had read that kids can have amnesia during rage attacks. That was really something that he wanted to see, but he had no idea what I was talking about (S-1).

It’s when he gets angry. He will scream, he'll swear, he’ll punch his head, he’ll punch tables. Like he’ll get close your face to scream or he'll posture, but he won't hit. He's never hit someone when they go to restrain him, much like an animal trying to get out of a restraint. And that's the way I look at it. I know that a lot of people look at it. He's got all this energy when they're trying to hold him down (S-4).
She has what we have called meltdowns. Just something is not right and she goes into a corner in a fetal position and cries, and that has just compounded now with the Tourette's syndrome… She went away to a cabin with friends with very good friends who knew what to expect. And the house was tranquil. Everyone got along with a nice dinner and it was peaceful. She walked in and within five minutes, everything was in an uproar (S-5).

I had him cornered, like how most people put their children in corners, for a timeout. I literally had to keep my body against him to keep him in the corner (S-4).

To one degree or another, all but one of the interviewees stated that their child had displayed TS+ behavior that had a sexual component:

It has moved to a lot of very sexual things, and she likes to touch my boobs and she likes to touch her sister's body and it's just things that I have a really, really tough, tough time dealing with (S-5).

There was the booby thing for a while where she had that thing where she wanted to touch boobies, and particularly big ones had that affect on her (S-2).

Her Tourette's had a sexual component, which with her is fairly childish in its manifestation. She says, Wee, wee” and “Pooh-pooh” and for a while she liked to drop her pants and show her butt… She did tell a school personnel member to smell her ass one day (S-2).

She does this thing at home, one plus one equals two with her middle fingers. She has got this whole little poem thing going that she says over and over again using her middle fingers. It’s like, “Stop doing that!” …She's doing the middle finger a lot (S-5).

She was doing some of the sexual things she was grabbing my butt and squeezing it (in public). It could have been playful, someone could have interpreted it as having been playful, or whatever (S-5).

Parents were confused and frustrated as to the degree that TS behaviors are volitional. One parent in particular was troubled by the question as to whether her child’s behaviors were tic related and beyond her control, or whether the child was using her TS
as an excuse to act out or gain desired outcomes. This parent provided the following report:

I'm the “bitch” and when she's mad, that's the word that comes out. And is that a twitch or are you…, you know? I don't know that she knows the difference; I think it that it just comes…Sometimes saying (child’s name) doesn’t do it. But I’ll grab her. I'll try to snap her out of it and then she'll get angry, and she'll say, “I'm just twitching. You have to let me go.” You know, it's a struggle….She tells us she can’t (control her TS symptoms), but we see her do it. We went to a birthday party Sunday afternoon for her great-grandmother and a lot of people were there that she did not know. And she hardly did any tics. A couple of times she leaned over and said a couple of things into my shoulder, but it was five hours probably and I observed her doing almost nothing. We got home and it broke loose… …I think she is able to suppress and do much better. And sometimes at home, it is so disruptive and so nerve-racking. I would like her to suppress them a little bit and she doesn’t (S-5).

At another point in the interview, this parent shared:

…And she put her finger in it (her father’s plate of food) and he said, “Don't do that.” She was in one of her zones, and she took her fist and completely crushed his submarine sandwich and he was angry. And she said, “You can't be angry with me because that was a twitch.” Are there some things that she has to do, or can she always find things to do to substitute or delay it? That’s what we struggle with, with her. When there is something that she does that is very disruptive, if she would just walk away and go to her room it wouldn't be as disruptive, but she has not taken it upon herself to not cross that line. Where her line is at, and where our line is, is different (S-5).

This parent went on to describe an example where the child wanted a new cell phone, and it appeared to this parent that her child was intentionally using TS related behaviors as a means to manipulate her parents into buying her a newer model phone:

I said, “I’m not getting you a new one (cell phone). This one works,” and I said, “And, don't you dare think that you're going to break it and tell me it was a twitch.” The next time I came home and the cell phone is in about 35 pieces. She had broken it and then broken it again. I didn't know you could break a cell phone that badly (laughs and gasps in angst). So she insists it was a twitch. I think she believes it was, but I don't, so the cell phone’s in the bag and I'm not replacing it, and she’s upset, but that’s the way it goes. But how can I punish her for a twitch. See the gray hair (S-5)?
Another parent spoke of her child’s Social Anxiety condition being more debilitating than symptoms of TS.

I think the social anxiety part affects his life more than the Tourette’s because I think his Tourette’s is more, has milder symptoms that people notice than the social anxiety disorder that really affects his ability to associate with other people and enjoy life. He stuck out like a sore thumb socially. And the ability to follow the rules in the game and follow the game and the social anxiety because people were watching you can see definitely overwhelmed him… He has Tourette’s. It’s on the mild side. Social anxiety is definitely more on the moderate severe side…(S-3)

Grand Tour Question 2: How do parents experience their child’s TS+ in the home setting?

Theme A: Parent has contended with increased tics at home, due to tics being suppressed elsewhere.

Several of the participants reported that their children attempted to suppress their tics while in public (i.e., at school, etc.), only to reach home where the TS + behaviors were markedly more pronounced. The following statements illustrate this theme:

And sometimes she controls it (oral repetition of paragraphs of movie dialogue) and will we have gone away, within the last couple of weeks, we’ve gone away a couple of times for probably five or six hours, and we have seen her do very well at not having those outbursts (of verbalizations) in public, but she struggles at that, and when she gets home, watch out, because then it just flies (S-5).

We went to a birthday party Sunday afternoon for her great-grandmother and a lot of people were there that she did not know. And she hardly did any tics. A couple of times she leaned over and said a couple of things into my shoulder, but it was five hours probably and I observed her doing almost nothing. We got home and it broke lose (S-5).

When he was under a lot of stress or even, I heard it a lot when he was even by himself in his room in the evenings and even now, when he is in his own room. Our rooms are actually side-by-side. I can hear a lot more vocals ticcing or noises when he has his down time, he’s alone, he can let it come out and nobody’s going to comment about it (S-3).
I think when there are changes in the routine at school it definitely affects our home life because we get a lot of the behavior at home then, prior or post the activity (S-4).

**Theme B: Negative effects of their child’s TS+ condition on family functioning.**

A clear message delivered by all participants was that their child’s TS+ symptoms frequently had a dramatic negative affect on family functioning. As one parent bluntly put it, “She does upset the family…It (family functioning) is affected on a daily basis (S-5).”

It's definitely put stress on the family. Sometimes it's been frustrating because this child really has dominated my time and energy (S-3).

Other interview excerpts that further illustrate this theme are as follows:

She does take up a lot of our time, a lot of our time…If there is ever a fight, she has always been in the middle of it, always. If anything goes wrong, it's generally you can tie it back to the child…We (interviewee and her husband) spend a lot of time dwelling on her, deciding what we can do and how we can handle her… We spend a lot of time discussing her, which otherwise, we wouldn’t be (S-5).

We’ve planned vacations that we haven't gone on because she's been having a bad episode or things aren't good at the time so it's really it affected the whole family (S-5).

He would eat in front of me but not anybody else. It took a while to integrate him with that. But that is a requirement of family that we eat together every night together. Sometimes he won't eat much. You know, the head's sort of down and he won't eat much, and then he's my midnight buffet man (S-3).

…or at school, whenever there's a change in routine or structure, he comes home, and he is either very shut down doesn't want to participate in conversation. *(He)* doesn’t want to participate in family meals (S-3).

When he was younger he sort of obsessed about the weather and we would have to watch the weather Channel a lot. Then he would talk about do we get tornadoes here. And then he was stuck on tornadoes. He had to watch every movie about tornadoes. We saw the movie *Twister* a thousand times, and he would obsess about that. And even now he gets stuck on a movie if he goes to Blockbuster. He will rent the same video over and over and over again, even though there are 50 million movies (S-3).
I had to give up my home office because he had to have his own room. Which he’d have to do anyway, eventually. There’s no way he could share a bedroom at night with anybody, which is just fine (S-1).

Any changes in his routine just really puts him over the edge and we might see more ticcing then and hear excessive sniffing (S-4)...

There was a time that I was trying to go back to work and we tried to get daycare. She went through about five daycare providers in the course of about five weeks. (She) just wouldn’t have it… someone who’s not a family member, she doesn’t want to be at their house with strangers (S-2).

Even with the ADD, you’re pushed every day, to the end of your ability to cope. Before bedtime rolls around, I really try to keep my wife in check, because she’s worse about it than me. Her breaking points a little sooner than me, because she really doesn’t have the background. So I try to keep her in check, so I say, “Look, you really need to approach this differently because she’s really gonna take that behavior to school (S-2).

The last month of school she did not go to school, she had the vocal tics so bad she did not go to school… I’d tell my husband, you need to be available during those times. So there was a lot of planning that I otherwise wouldn't have had to do. You figure once they’re at school, they’re at school, you know, and you wouldn't have to worry about them, but…(S-5)

One parent reported that her child blamed herself at times for disrupting the family’s activities:

There was something else that we didn't go to because she just wasn't having a good day. I don't blame her, I don't say. “It's your fault,” but she has said already, “It's my fault we don’t do this,” or, “It’s my fault we don’t do that.” So it makes for a stressful household some days (S-5).

One interviewee stated that his family’s financial health had been dramatically affected by his child’s TS+:

And she (interviewee’s wife) can’t work, because she has to be here when the neurologist calls. That’s created a hardship. It’s not an unwillingness on her part to get a job, and it’s not really an inability to work, it’s the anxiety about what would happen if we’re not there to catch whatever happens to fall. So we’re always kind of always on call. And financial hardship creates stress. It creates an inability to get decent insurance, so then you have an issue with care. It just
creates all kinds of… And then you’re looked at because you’re driving an old car, and you’re looked down on by society who have their new shiny SUV, which I don’t care about. So you end up as somewhat as a societal outcast pretty much however you play it. And it’s not like you can sit down with people and say, “This is why I’m this way.” They’re not interested and they don’t care. Most people don’t care. I don’t care about them because I find them pretty shallow anyway. They’re all ghosts to me anyway… We took a real financial hit. Instead of working, I was going to meetings; I was at a hospital (S-2).

In one case, the child’s social anxiety disorder caused difficulties for the parent when she wished to go, as a family, in public:

I just think it's sort of a strain on your family life, because he has limited sometimes our ability to do family things as a family because of his behavior, and his refusing to go somewhere he's never been. I've had to schedule things a little bit better. I know that I can't do things at the last minute with him. I have to preplan and pre-warn him… He doesn't like to go to my sisters because usually when they go, there is a special event. Her husband comes from a very big family, and so when it's one of my niece’s or nephew’s birthday, a lot of extra people are there. Although he’s known them since I’ve gotten him, he just doesn't like that busyness. It's hard to make him go places so I've learned to adapt without hurting their feelings. I have to worry about not hurting their feelings because we get the behaviors and repercussions at home (S-3).

Another participant, as a means to compensate for the stress that TS+ brought to her family’s home life, took her family out of the home at times:

I’m rewarding my kids with trips and gifts, whatever. Not all the time, But I mean, “You’ve put up with a lot of crap lately; let’s get out of here. I’ll buy you whatever you want at Target, or let’s go to dinner (S-1).”

Theme C: Parent feels that child’s TS+ has negatively affected relationships among family members:

We didn’t have dinner together for two years (due to the difficulties of her child’s TS+), but then I figured we do other stuff together. I think there’s too many research studies said if you’re not eating dinner with your kids, they’re all going to get high (laughs) (S-1).

I felt like (child’s name) has demanded so much of my time that I felt like the brother got pushed off to the side and I know my mother gets frustrated with his behavior. He started getting physically aggressive with him (his brother) and at
times, needed discipline for that, and just very demanding of my time. He would get very jealous if his brother wanted some of my time (S-3).

She never calls me (interviewee’s first name), although for the last week, she has because when she's in this zone, it’s a different person … I’m the “bitch” and when she's mad, that's the word that comes out and is that a twitch or are you…, you know? I don’t know that she knows the difference; I think it that it just comes (S-5).

I think she has always felt somewhat alienated from them (her brother and sister), and there is only like two years difference between all of their ages. But she is just she has never really clicked with either one of them. I think this has probably alienated them more (S-5).

With her brother, it (TS) has probably alienated the two. He graduated (from high school) three weeks ago, valedictorian, and he is a great kid. We have a swimming pool, and they came over the other night. They came over and she started on one of them about his girlfriend's big boobs, and her brother’s friend knew that she had Tourette's, but he took Tourette's to be motor tics. Not these paragraphs of sexually… And (brother’s name) was like, ”Mom, make her shut up!” And I was like, “We need to go in the house.” And I separated her, and I told her that sometimes she needs to separate herself. And that doesn't do anything to help her relationship with (brother’s name). They (her brother and sister) feel like she gets cut a lot of breaks because of her Tourette’s. “It's not fair, she gets to do this and she gets to do that. She doesn't get punished as much.” I’m seen as caving in to her because I feel sorry for her or whatever. I hear that (S-5)

Two interviewees stated that their relationship with their spouse had been negatively affected by their child’s conditions:

Twice last fall, my husband and I were going away. One was at the beginning of the school year. In three days that week she had called me (from school to be taken home due to her TS+) and we decided we just could not leave town and so we didn't go (S-5).

I would say, bad, (referring to the affect their child’s TS+ had her relationship with her spouse) regarding this for years, for the whole bad thing where they go to work, and I go to work too. And because of my profession where all my responsibility, that typical thing, whereas if I get an article or leave a book out (on the subject of TS for her husband to read), he’s, “I just came from work,” or…and that just appalls me (S-1).
Grand Tour Question 3: How do parents experience their child’s relationship with peers and with other people in their child’s life?

Theme A: Parent wishes for their child to develop more peer relationships.

I wish he had a buddy. Or if he has one in school when he’s doing extracurricular stuff (S-1).

He loves people. It's almost like he needs people and he loves to be around people. The more people the better. He loves lots of friends he wants friends, but he has a hard time keeping them (S-4).

One parent, the maternal grandmother to the child (S-6), lamented that the boy was relegated to playing with children in the neighborhood that were nearly half his age. According to her, the boy was drawn to younger playmates because of his inability to make friends with his same-aged peers. She stated that he had no friends at school and that he was routinely made fun of and bullied by his peers.

Theme B: Parent concerned about their child being mistreated by others.

Interviewees provided numerous examples of their child being ridiculed, belittled, or harassed due to their TS+, as follows:

It's hard to make other people understand (my child's conditions) (S-3).

There have been a few times when it has been a place where it’s quiet and she would make a noise and somebody an adult or somebody will look around like, “What's wrong with that kid,” but it hasn't been to the point where I’ve felt like I've had to explain (S-5).

I think sometimes when he was doing a lot of vocal ticcing, or his friends would say why are you making that noise, you stop it, or if they hadn't seen him for a while there were doing it again they would say, “Oh, you’re still doing that (S-4)?”

Sometimes they didn’t understand, because they were young too. They would like mock him… There were a couple of kids last year that were… I don’t know why they were still in his classes, but they were failing, the two kids. But they were just mocking him, calling him, “Tourette Boy,” or whatever (S-1).
They make fun of the noises and the eye blinking. I've seen kids walk up to him and start doing that purposely to his face and teasing him. And it's just he won't speak up for himself, and that's frustrating to me... Sometimes he's an easy target because he doesn't speak up for himself and know we had a child who broke a new CD that he had because he was allowed to use a CD on the bus, but for no reason the child broke it. And he came off the bus sometimes with red marks because he was punched or hit. I had meetings with the school and they stopped, and the child said they were wrong and paid for a new CD for him. But that stigma sticks in his head, and it's bothersome (S-3).

One of his friends, they were on a bus once and later at night things were popping up and it was almost like a PSSA question: Do you do all of the swear words in one sentence? They were talking about it quite frankly, and that was in seventh grade, eighth grade, maybe. But he was a curiosity (S-1).

Evident in parental responses was a feeling of suffering, in response to the mistreatment their child received by their peers:

I've actually sat and watched without anybody knowing and watched how they'd (playmates at home) just go (teasing/taunting) at him and at him It’s hurtful (observing peers tease or ridicule her son). I mean I just I think sometimes I look at other kids. He tried out for a sports team in basketball and he stuck out like a sore thumb socially, and the ability to follow the rules in the game and follow the game, and the social anxiety because people were watching you can see definitely overwhelmed him (S-3).

Other kids, particularly little girls, are very cliquish, and they developed their cliques which she was never part of. She doesn’t fit in any social groups. No harm, no foul… you’re not missing anything (laughs). You just don’t it because you’re little. But boy, it was very sad, and very disturbing... The kids that are her own age are probably the worst on her because they recognize her as different. They quite possibly think of her as stupid because she doesn’t go to their classes, she doesn’t recognize the words that their learning to write, and spell, and use. It’s not part of her scenario. So that’s very sad, and can be hard to deal with (S-2).

In some cases, the child attempted to buy friendship through giving money or toys to children willing to play with them:

He gets his water guns out. They want the water guns. And one particular friend comes over, and he picks out the water gun that he wants, and that child could say I want that one or I'm not playing. And he will give it to him. He used to give them money. I had to hide his money when he was younger because he would
give the money to play with them candy, gum, cookies he would take anything without asking, because he wanted friends that badly (S-4).

I see that these kids only come around here (home) when they want something from him… He has supposed friends who do come around, but he is often taken advantage of. They want to borrow his games or his movies or other things. And that's the only time they seem to come around. They don't come around in the other time for social occasions to invite you out to do something or hang out (S-3).

One parent apparently felt that the quality of his parenting was being judged by others due to his daughter’s differences:

There’s no love in the icehouse, I'll tell ya. When you’re different, people don’t come out of the way and say “I don’t understand.” People come out of the way and say, “There’s something wrong with your parenting? What are you doing? Why is she like this? What’s wrong with her?” (S-2)

Unlike other interviewees, one parent stated that her teenage, female child was, in general, well supported by her close group of friends. This parent described her child as being very engaging and socially adept:

A couple of friends have made fun of her, but for the most part her friends have come to her defense and have supported her (S-5).

One child used his sense of humor as a defense mechanism against peer mistreatment, as the following story illustrates:

I didn’t know this was happening, but he was really shrieking at soccer and the kids would say, “Stop it.” He would say, “I have Tourette syndrome, you don’t even know what that is.” So there would be this big fight-argument. So he designed a T-shirt that my neighbors made. On the front it says, “I have Tourette syndrome,” and on the back it says, “Don’t worry; you have to be really smart to get it (S-1).”

Parents report that child’s TS condition has affected the family’s ability to participate in community activities, such as shopping, or flying when traveling:

Shopping is not generally something that we take our daughter to do. However, we can take her down the street to the hardware and grocery store and they love
her to death, because she has a relationship with them and she can walk the store by herself and not cause any problems. But if you take her to Walmart, you may get something very different. … Well, she might pull something off of the shelf and eat it. And she may unwrap it. There are for all appearances behavioral issues, but they don’t always manifest themselves. She can be a real bull in a china shop. I’ve taken her into antique shop where I had clients and I had her knock over a shelf and destroy things. But it’s not usually a behavior that plays out out of intent. It’s probably over stimulation. Plus there is a cat down at the local store. She goes to visit the cat. They give her a lollipop. They dig her. She’s a cool kid (S-2).

Early on, it was hard for me to take him anywhere. It was almost like when I would go into a store. I think there was so much stuff, part of the ADHD that it was very overwhelming to him (S-3).

When we go shopping at the store and there’s something in an aisle that he wants and there are a lot of people in that aisle, he’ll avoid the aisle. You try to go back later… Just that constant fleeting looks from side to side or looking around, you know. And I was up to the counter and paying for something and I heard a store employee come over and say keep an eye on that kid over there. You know, he might be a shoplifter because he is really scoping it out. I didn't say anything, but it really hurt. I just stood back and looked at him, and it's true. He did look like he could have been a shoplifter because he was constantly overly checking out his environment, who was around, and even now it affects his ability (S-3).

He came up behind me once in a grocery store and told me to, “Fuck off,” really loud, and I think this old man was like… My only issue with him is if people have a reaction to it and are judging you, tell them what’s going on, they already know something’s different so let the guy know that a whole generation of kids isn’t going around saying F-off to their moms (S-1).

God forbid you’re ever different, you know. I had cards made out, because we were traveling and we were flying and stuff, made out, like one of those little laminated cards, because he’s a big kid now, he’s about 6 ft. tall and I didn’t want to get arrested. I’ve heard what can happen. I’ve only heard a couple of bad stories, or whatever. So I have been prepared (S-1).

It’s been a challenge because that has definitely interfered with going for haircuts. He's a one or two haircut a year kid because people look at you when you go for a haircut (referring to the child’s social anxiety disorder) (S-3).

Grand Tour Question 4: How do parents experience their child’s school issues related to their TS+ condition?
Regarding parent experiences with school, as pertains to their child’s TS+ condition(s), multiple themes emerged from interviews. Notably, parents reported having put forth special effort to communicate with their child’s school personnel, in some cases actively teaching/training teachers in what to expect.

Theme A: Parent has made special efforts to communicate with school personnel, regarding child’s TS condition:

We've trained his teachers over the years, kind of preventatively, to ignore him. We tell them to just like ignore and redirect… I’d get in there early in the summertime and telling them and saying what’s up, and give them the article… The last time I had to meet with a staff, I thought it would be a couple, but there were 14 people in that room... I think it took a whole lot of time and energy to do the whole school experience right, and to train all the teachers and email them and stuff (S-1).

I was in constant contact with the school staff and personnel. I had to keep going up and fighting for him to..., you know I kept telling him them if there was a magic pill I would give him to be independent and speak out for himself, I would give it to him, but it’s not, so had to keep advocating for him because he does not advocate for himself, and to this day he does not advocate for himself.... So of course I called a conference to ask “Why wasn't I notified that he was failing in health?” I had to go up almost every week in distress and have huge team meetings and discuss how his how he might make these noises, but not on purpose, not to spite you or to irritate you he doesn't want his under a lot of anxiety, and he doesn't advocate for himself and we need to keep checking to make sure he is comprehending and getting it (S-3).

But every time he's changed schools or places which like every year at least, you almost have to go through everything again until they get it… They don’t take advantage of any of it (parent’s suggestions on how to work with their child) and the other 20% is the ones to try to do any kind of thing to help, any kind of help, any kind of suggestions that I would bring in to help.... I’ve walked in to do, they were doing a spelling for him on the computer and I said, “I'd like to come in because he’s been complaining about it,” so they let me come in (S-4).

We had informed all of the teachers so they knew what was going on… In the middle of sixth grade when she was first diagnosed, we corresponded either by phone or e-mail with the principal and all of her teachers. As it got closer, probably March, we again corresponded with all of the teachers, some of them personally, some of them via email, and said she is having vocal tics. That's all
what we did in the last four weeks of school hours or so. We called and said what
she is doing at home if she is doing that in school because it wasn't just the f-
word. It was the n-word and all kinds of words. So it's really not appropriate she
can't be in the class doing this. She told us she could not suppress them (S-5).

I'm very concerned. I'm not sure who works during the summer at school. I've
been trying to get a hold of the principal and get a hold of the school psychologist
and get something worked out and something in place before the school year
starts. I would like to push for some kind of contract… I never thought that I
would have to delve into special-education. I never knew what an individualized
education plan was. I'm having to educate myself, and part of me doesn't want to
force the school to do anything. I think they're willing to work with me, but part
of me says you better have your ducks in a line to make sure that your child is
going to get the academic support that they need when push comes to shove I hate
to go there, but at the same time, she needs her education (S-5).

In one case, the parent recommended to their daughter that she provide her
teachers and peers with information about her conditions so as to be an advocate for
herself:

We have suggested strongly that she be very open and tell everyone exactly what
it was. Her teachers were willing to let her do a presentation on Tourette's or
whatever to help the class understand. She, at first, did not want to do that. She
was very reserved and very… She didn't want to deal with it. As the school year
went on, she told more and more people and people, and the kids were very okay
with it. So she has talked to a lot of her friends about it. She was going to do a
project in science at the end of the year and she did hers on Tourette's syndrome
and yet she never went in to present it to her class. She is okay presenting even if
she is ticcing a lot (S-5).

Theme B: Parent has been frustrated when trying to communicate with school
personnel in order to ensure that their child was provided an appropriate academic
program.

The health teacher came in and said, “Well, he participated,” which was doubtful
“but he did not hand in a test.” So I questioned that. I said, “He brought it home
and he had no clue.” And she said, “Well, he's not supposed to bring that home
why would he bring it home?” And I asked, “Did you provide him any supports?
Could you modify it?” She did not even realize he was in learning support. And
the learning support teacher sat there and said, “I did not know he was in health
(S-3).”
Frequently, I would get calls from a school nurse, or from the teacher thinking he had pink eye, but it was from rapid eye blinking; his eyes would get irritated and become red, but it wasn't from an illness or a virus or anything. So sometimes dealing with that and having them understand it's from the tic (S-3).

They (school personnel) just don't really understand, or if they do understand, they can't get the higher-ups to give them the okay to be able to change something in the school to make it happen. But I do see a lot which was really amazing for me through all these years was these were emotional support teachers. Why do they not understand? Why do they not understand the disorders? I hate him going to school because they don't understand what's going on with him (S-4).

The following response was provided by one participant when asked if her son’s teachers were open to hearing her advice as to accommodations that would help her son learn best:

I’d say about 80% of them (teachers), absolutely didn’t, I mean they say that they wanted to. Probably about 20% were like, “I’ve been here about 20 years and I know exactly what I’m doing. I don’t want to hear anything.” And maybe like 60% would say, “Yeah, I want to hear what you have to say,” but then they don’t really do anything (S-4).

Two participants reported having difficulty getting school personnel to acknowledge their children’s TS+ condition(s). Apparently, since teachers didn’t notice symptoms, they were unable to recognize the children had special needs:

So we had a meeting with all the teachers. Her dad and I went and the teachers looked at us like we were nuts. They like said, we see absolutely nothing. She’s fine in class. She has lots of friends. We don't know why she's so upset. They thought we were crazy (S-5).

I mean the school, the school looks at us and says, “We don’t see any facial tics.” And we think, how can you not! What are you, ignoring them, because, I was talking to someone at TSA and he was telling me, “You have to videotape her,” I mean, you have to almost present evidence to the school in order to get them to understand (S-2).
One interviewee stated that due to his frustration and anger towards school personnel, he was advised to not attend school conferences. From that point on, he was represented at school meetings by his wife:

When the rep from the TSA group allied my wife, she asked me to not come to the meetings anymore, because she knew I had reached a point where I was going to release stress one way or another \(S-2\).

This same parent went on to explain his perception that school personnel had ulterior motives when making diagnostic and educational decisions in regards to his child:

My kid was evaluated by the school as being retarded. And when I asked the person who created the TSA, I asked him, I told him they thought my kid was retarded. He looked at me and said, “Oh yeah, that’s how they get their funding. He needed that so he could get funding. So now, any move that the school advises us to take, we assume, this is about funding, this is about perpetuating a career, this is about someone covering their ass so that their job doesn’t disappear or they don’t lose it. None of it is about my child. And that is disheartening to say the least \(S-2\).

Theme C: Parent was pleased with the school’s response to provide appropriate accommodations:

In some cases, school personnel were perceived by interviewees to have effectively responded to their child’s special needs. One participant explained that a multidisciplinary team meeting was held to brainstorm interventions for her child. At that meeting, the principal responded to the questions of whether to allow the child to independently go in the school building to a designated area where she could calm down:

One or two times she wound up going to the bathroom and crying in the bathroom by herself, and when we talked to an administrator at the school, he said, “No. She will always have a friend in every class to support her,” or whatever. So that was the school’s suggestion that she always have a friend in each class so that she is not walking through the halls crying, or whatever. They also offered her a room in the administrative wing, where she could go any time, which is kind of like
going to the bathroom, but a little more private. That was the room they also offered for her to go take tests in when she wanted to… She is very self-conscious about making noise or doing something to disturb the rest of the class. I don't think she actually took them up and to going to another room to take a test, but they made the offer (S-5).

Other interviewees also reported that in some situations, their child had received appropriate accommodations by responsive and caring school personnel, as follows:

I would say his teachers were very receptive, especially because I was really proactive... *(Helpful accommodations included)* preferential seating; permanent hall pass so that he never had to worry about asking to get up and go when getting up go for a walk, or getting a drink of water… It used to be sometimes that we'd let him sleep in *(at home)*. The less sleep he gets, the more he tics (S-1).

I think elementary school was pretty positive for him, his teachers were very understanding. He was still doing a lot of vocal ticcing at that time, and the teachers knew what it was or if he was under a lot of stress he would do more. They realize sometimes he needed more out of seat breaks. I've noticed that the teaching staff. Part of their inservices is that they get together with children that have learning disabilities with their team of teachers and they talk about the IEPs, and they are aware that they have IEPs and what accommodations might need to be made. And the parents are really involved in the IEP process for the next year. So I think that has been the big difference.

The one-on-one, anytime they were able to help them one-on-one. When they were able to read to him material that he needed to know, because when he reads the comprehension level is very high. But if somebody reads to him, it helps. When he is able to type things, using the computer... And in the school, when they would show the different movies, little movie clips to show exactly what…, it helped out tremendously (S-4).

The teachers have always been supportive of her especially over the last year, or they have allowed her to pick her seat. When she was doing the motor tics at the beginning of the school year they allowed her to sit in the back of the room, so she wasn't bothering and distracting other people. They give her a free pass to go to the bathroom anytime she wants. They have given her the option to take tests elsewhere... I had to get a note from a doctor saying that she could not go to school, but they did send a tutor to our home for an hour or two every day in order
to keep her caught up… Nobody’s (school personnel) come close to suggesting that she needs to be out of the regular classroom, at least at this point. None of the teachers said she can't be in here. The simple thing of letting her sit in the back of the class when she was doing the motor tics that was a big relief to her, because sometimes she would hit the desk and knock something. At this point I'm very, very, very pleased with the school's response. It has been very easy (S-5).

He's now in high school in 11th grade. Our new school district has been very accommodating. He's been very successful (S-3).

A mother of a gifted teenage boy stated that her child had been able to deflect attention from his tics by sitting in the middle of the classroom:

… or he would try to throw his voice. Preferential seating for him was always in the middle of the class. So people wouldn't know where the sound was coming from. You read in the side in the back or somewhere, no, dead center, masked (S-1).

**Theme D:** Parents were displeased with the school’s response to provide appropriate accommodations.

Two participants spoke at length about the shortcomings in the academic programs provided for her children’s schools. Problems included inattention to symptoms of sensory integration disorder, poor communication between staff members, and neglect in not addressing the day-to-day needs of their children:

I’ve walked in when they were doing spelling for him on the computer and I said, “I'd like to come in because he’s been complaining about it,” so they let me come in. My son got it started for me. I want to tell you it was the most boring… Like when they would say, “Stop!” And another thing is timing; If you try to time a child like this it makes him so much worse. And they still want to time him on everything. Can't they just leave him to himself? I actually started falling asleep, and it would go “stop” and scared me, it would scare me. You can imagine what it did to him… Sounds, definitely if there are a lot of sounds. Noise can do it. Sight… and I walk into a an emotional support class and it’s littered with stuff all over the walls. And I’m thinking, don’t they get this? The more stuff you have up, the worse it is. In fact, the one time I took out all of my pictures down in the living room. And I have blank walls and my child said, “All of this is so calming.” There are no pictures on the wall… They (teachers) just don't really understand, or if they do understand, they can't
get the higher-ups to give them the okay to be able to change something in the school to make it happen (S-4).

That was just the beginning of our weekly struggles of going up to the school and middle school. And several times he was supposed to go up to the nurse. You know, how they go for hearing and vision tests. He would never go to his appointment and they were getting a little flustered. And here again, he has difficulty telling time, and he will not initiate getting up and leaving the class even if he has a pass to go and he did not know where the nurses office was. So it was a matter of people getting frustrated without fully talking to him because if he would not know an answer or not understand something, he still does not raise his hand to inquire. He does not like to be the center of attention, whether it be good or bad, He just does not like that. He just sits there and smiles and that winning smile was getting him far. But now it's not and that's why I still need to advocate for him even though he is 17 years old, because he still does not self-advocate (S-3).

These parents also considered some teachers of middle school and high school neglectful in not actively responding to the day-to-day needs of their children:

His transition to middle school was more difficult I think because they require you to be more independent and sort of fend for yourself more… We changed school districts because I felt that we were not meeting his educational needs and was fallen through the cracks where he was. I think there wasn't enough communication between… because he is in learning support, but was mainstreamed for several classes. There was a lack of communication between the special-education staff and the regular staff… I was very frustrated so actually I made the choice to check out different school districts in our area. And I chose to move… He's quite vocal about his displeasure of going (to school). Not appropriately, at times, and that is interference I think for others to understand that it's not just, you know, sometimes teenage “I don’t want to go,” but really an anxiety issue for him. They (school personnel) were not accommodating him enough for the classes that he would they were requiring sixth-graders to take there was no support for that but yet he needed that because I kept trying to show them. This class expectations up here, this is where his cognitive abilities are as for your testing and everything else. This gap we need to fill in what adaptations can be made, but they just didn’t seem to get it, and I was continually… and that's why we chose to move (S-3).

I know if I am very overwhelmed are having a hard time, the last thing I'm doing is trying to get someone attention, may I please do this? If he could simply walk up and walk out the door and be in the hallway to relax. But they (teachers) would wait and make them go through all of this other rigmarole, until he got out of the hallway and he was explosive. So then it was like well see he gets
explosive in the hall. Well yeah, because you’re not letting him go out when he needs to go out… They felt like a lot of his behaviors were just were not because of his disorder and it was really sad. Even though we have these disorders, he still needs to learn to do it this way. And that bothers me too because I think everybody learns differently… I just don't understand why they don’t allow like, especially if you put him in the back of the class, put them in the back of the class where other people can't see him bouncing up and down (when seated on rubber ball).

And I don't look at him as sometimes being learning-disabled. I think it's teaching disabled…They are saying that he is having trouble in this and I find something that helps why are they so… not wanting to even try. It's very, very difficult for me in that aspect… It’s like them trying to, and I understand that he can be distracting to other people, but on the other hand, they are very much distracting to him, especially in an emotional support class because everyone has their own issues… Constantly, and it’s gotten to the point that they make fun of everything from his tics to anything because they know that he is not one of those children who… He wears his feelings on his sleeve, so he is very much a target. He is an easy target for others to pick on so that he gets in trouble or he reacts. And the hard part is that you get the kids in school, who sneakily, behind the adults back, are able to like pick on him when he reacts he is the one getting in trouble and the other one isn’t. They never believed him. He would come home crying saying why don't adults believe children when they are telling them something (S-4).

What she tells me now is she hates school. That’s a fairly recent manifestation. School was probably not boring to her in the beginning. It was new, it was different, and there were kids there. Now, I don’t think she gets as much interaction with the kids because she’s disruptive. Which is really what she’s after is she just wants to play with the kids. I don’t think the curriculum is structured in any direction towards what she needs, which is art, music, she needs to be able to maybe flutter from one station to the next and you teach her within the confines of what she’s willing to learn. It’s impossible for us to evaluate what the hell’s going on at school because they’ll send us an evaluation home that says, “5, 5, 5, 4, 5…” and then tell us how bad she’s doing, and the information that they send doesn’t jibe with the meetings that we have. And it doesn’t always jibe with what’s going on at home. She’s still a kid. They are so scared of stepping out of the box that I’m not sure they even care what happens to her. We had her on one drug where she would come into school and sleep in a bean bag chair and they would evaluate her as “5’s,” which is high as she could get. She’s asleep. Well how are you teaching them to read or write? It’s not a church. It’s not a hospital. It is not a clinic. It is not a laboratory. It’s a ‘frickin’ school. Teach her to read, write, and do math...(S-2).

The absolutely most helpful thing was when I finally pulled him out of school, out of the complete school system, and said, “I want homebound schooling.” And they (school officials) were saying, “We can’t do this (homebound schooling)
forever (S-4).”

Theme E: Children refused school.

He’s not a runaway child, but he would literally walk out of the school to get away to calm down because he would feel like people were constantly on him for something…. He absolutely hates school. I hate him going to school because they don’t understand what’s going on with him (S-4).

He was trimming his socks every time when the bus was coming and we would have these big fights about why he was doing it. It was like really irrational and stuff. He couldn’t get out the door, he was doing crazy stuff. So that was disruptive (S-1).

Although this particular participant was “very, very, very pleased” with the school’s willingness to make needed accommodations for her child, the student rejected middle school for an extended period of time due to the humiliation and embarrassment she felt as a result of her intense tic behaviors (including coprolalic verbal tics).

Eventually, she received homebound instruction:

She was so uncomfortable that she was just a basket case. She did not want to be there (school), and that was the point that we requested a tutor come to the house… When she does not want to go to school it’s terrible to push your kid out the door with tears in her eyes, telling her, “You can do this.” And then I come to work and worry and wait for the phone call all day long. The first couple of weeks (of school) was horrible, because I just knew… This last year, until we got things settled down, every other day, every day the phone was ringing and I had to talk her through it or go get her, or get somebody to go get her. She came home (during school hours) probably the first three weeks of school. She called me, eight days, I had to go pick her up, because she was crying, she was upset… The last month of school she did not go to school, she had the vocal tics so bad she did not go to school. I think she had 26 days that she missed during the school year and 20 of them would have been in the last two months of school. She just stayed home or she would call me after two hours (while at school) and say, “You need to come and get me; I can't do this (S-5).”

Theme F: Parent was concerned with their child’s limited ability to participate in extra-curricular activities.

The kids would holler. He almost made a basket, which I was so proud of him, but it was in the wrong basket. It didn't go in, thank goodness. But after that,
surprisingly enough, he did try basketball again. And that was after we had moved and it was a different league and he had improved his motor skills and was practicing and the proudest moment of my time came when… Usually when he got the ball he would sort of freeze with big saucer eyes like, “What do I do now?” But he actually dribbled the ball and passed it several times through the game because he usually didn't play very long. And one of the boys after the game said to him, “you were the only one playing good defense tonight, good job.” And it actually made me cry because he always sort of stuck out. The whole team would be running and he would still be by himself and think, oh…, but he’s not a big sports team player. Now he uses excuses like, “Oh, it’s stupid. I’m not going to do that.” But what it boils down to is that he has a hard time following the rules and keeping up (S-3).

He would not ride the bus. He did ride the bus before I adopted him when he was younger, but siblings rode the bus with him so he knew them. He would say that he doesn't know anybody and people look at you when you get on the bus (S-3).

Sometimes when he had really bad fatigue, he was really like wiped out and maybe not want to do things. Or not always do a longer field trip, or something after school or whatever it was, because he would be afraid. He got a little reclusive for a little while (S-1).

From the school point of view, the schools… all look at this as a privilege and if his behaviors don't match up, then he cannot do or go to gym with the kids can’t go to the cafeteria. I would always stay there and make sure that because I knew how he could get overwhelming for his peers or even some of the coaches so I would attend and stay there at all his practices and all of his games, but it did get to a point because he was one of the more difficult children, the soccer team actually said that they don't have room for him anymore. Like I would call and say…, or he would try out. “No, he didn't make it (the team).” Because of his behaviors, they just didn't understand him (S-4).

The team was very supportive, but she didn't go the last couple of weeks, because she was yelling out things and she just wasn't comfortable doing that on the court. She couldn't seem to suppress it. There have been events or things that she has not gone to because she was having a bad day. And that does happen, with more regularity now than it used to. Generally speaking, I don't see where her Tourette's has slowed her down (in school activities) (S-5).

Theme G: Parents struggled with homework problems related to their children’s TS condition.

Participants were in agreement that at times, their children’s conditions made
homework challenging:

I’m sure were times in those couple of years that we’ve said, “Let’s forget it.” Because there’s been so much going on for those solid two or three hours at night. And he was so tired, and you can’t read when you’re that (inaudible). And you’re not breathing right anyway and it was hard for him to eat and stuff. But I’m sure there were times when we said forget it (i.e., complete homework) (S-1).

You know, definitely, doing homework when he was younger was a challenge. We were up and down on the chair, on the floor, all over, but and around was really a challenge for him, but not so much anymore (S-4).

It literally only would take five minutes once he could finally do I, it would only take five minutes, but would take us two hours some nights, where he would sit down to do it…. I would actually write for him, he told me the answers. I would read for him. And just getting him to do that little bit of homework… He would get very upset and crying when he would do homework. It was almost like over-needing to please the teacher to make the teacher happy. And that's when I realized the erasing. He would erase over and over again until they got holes in the paper. I tried everything from doing it right after school to… And we found out, no, he needs a break right after school, because it's just too much. He needs to go run. Then I tried doing it later in the night but then he was too tired. It's like we had to find this middle ground (S-4).

I did think she did struggle more toward the end of the school year because I think she has suppressed her tics during the school day when she just didn’t get it, and then she would come home and try to do her homework, it was that much more frustrating for her. I think with working so hard to suppress everything the tics and things at school, and being so self conscious, she is not catching what the teachers are saying, and that concerns me. And she’s trying to do her homework and I asked her, “Didn't you hear this lesson. Don't you understand how to do this?” And she will say, “Dah-di-dah.” She's not catching it at school so homework has been much more difficult for her (S-5).

It (homework) is a waste of time, to put it bluntly. It’s gotten better lately and she seems to have a desire to do it. She likes to do it with her older brother. He seems to have more success with it. Obviously, for me, I couldn’t even tolerate it. It was enough for me to sit down here and even fill this out. With dyslexia, it tires on me pretty quick (S-2).

And here it's like, “Okay, we need to do your homework by this time. You get an hour or two hours. You can go run to do what you want, and it is time for homework.” But it would still be that the battle and I don't know what was really going on in his head that made it seem so difficult for him, or if it was just all the trauma from being at school (S-4).
Theme H: Parent reported being accused by school personnel of child abuse due to child’s sexual behaviors exhibited at school.

Unique to one participant, his 6-year-old daughter’s sexualized behaviors caught the attention of school personnel. Consequently, the father became the subject of an investigation of criminal misconduct, sparked by the child’s school’s phone call to a state child protection agency. His interview responses were colored by his obvious anger towards those individuals from school that, in his opinion, unjustly instigated the investigation.

The child’s sexually oriented behaviors included pulling down her pants at school, exhibiting herself to other children, and touching the breasts of female teachers. These behaviors, among others, led to an investigation of sexual molestation, initiated by the child’s school. The interview transcript revealed this child’s parent’s feelings towards school personnel who gathered information from the school side, and who made the phone call to the investigating agency:

But you try to sit in on a school meeting when you’re the focus of this anger, and this anxiety, and this misunderstanding. They don’t want to hear it. When I went into this meeting, knowing that I was the focus of this meeting, and not only was I the focus of it, but now every male in our inner circle was under this suspicion by us. And I didn’t know what my wife was thinking of me, even though she was aware of what we had gone through. And that day, when we came home from that meeting (and I was upset), and I mean jump across the table and grab school personnel members and give them the beating that I think they should have had as a child, upset (S-2).

I consider them complete egotists, who were only interested in perpetuating their own myth, and funding the program that pays their bills, and keeps their insurance for their kids intact, while they destroy my family, because they don’t like me. Because I don’t like them. And I’ve told them, “I don’t like you, and I don’t have to like you, and I don’t think you know what you’re doing. I don’t have to listen to you. This is my child. Only one person, well, only two… (including his wife),
we decide what treatments we pick for this child (S-2).”

According to this parent, a psychiatrist requested the authority to take control of medication management for his daughter. This was another point of contention. The participant considered the psychiatrist too inexperienced to carry this responsibility:

We reported to school that we had stopped these medications, and the school personnel reported us to social services for neglect, who had already accused us of molestation, and neglect, and a whole lot of other things… Three years she’s been doing this, and she wants to take over my child’s medication? I was incensed; it was dangerous. It was reckless. And when you express that to them, they get their hackles up and they want to do battle more…If you’re that unwilling to listen to what we’re saying, and maybe give us the benefit of the doubt, we don’t need you there. If you’re not an asset and an ally, you’re an adversary. I don’t have time for them. I don’t have time to stroke the psychologist’s ego, I don’t have time to make the doctor’s career something she can retire on…(S-2)

A complicating factor was that the psychiatrist was part of the sex abuse investigation:

First, the… …psychiatrist came at us with a completely combative, and completely off-the-wall, from the wrong angle, and immediately, we wanted that person out of the picture (S-2).

Summing up his ordeal with his child’s school, this father made the following statement:

We were looking for allies. We were looking for some help anywhere we could. And we got our nose pushed in it instead. And it’s unfair, and I suspect we’re not the only ones… No one has considered how the parents of one of these children, what they go through. Why would they, we’re the enemy. We’re the boogeyman. We did something. We’re under suspicion. Why wouldn’t we have to suffer (S-2).

And at that point (once the investigation was launched), we (my wife and I) unified as a component, because we felt like a wedge had been driven between us, and they were going to divide and conquer and find the boogeyman. But there is no boogeyman; there’s only Tourette’s (S-2.)

Additional Finding:  Parents are affected on an intrapersonal level by their child’s
Tourette’s Syndrome Plus condition

In the interview protocol, one line of questioning tapped the intrapersonal experiences of raising a child with TS+. In general, parents reported that their lives were made considerably more difficult due to their child’s condition(s). Themes that emerged included some parents feeling responsible for their child’s condition, feeling overwhelmed by having to provide counsel to their child, and feeling alone in the meeting their child’s unique social/emotional needs. The cumulative affect, according to all parents interviewed, was that raising a child with TS had taken a toll on their own mental and physical health. While all parents stated that at times they had a negative outlook on their child’s condition and their child’s future, some parents regarded their child to be endowed with personal “gifts” that compensated for their condition(s).

Theme A: Feeling personally responsible for their child’s Tourette’s Syndrome Plus condition.

Two of the participants acknowledged feeling that they were personally responsible for their child’s TS condition, stating:

I felt responsible for quite a long time. I guess even now, partially because I was diagnosed after (my child) was born. He was about a year and one-half years old and I was diagnosed with depression and anxiety. I’m also a recovering alcoholic of 13 years (S-4).

Referring to his genetic contribution, one parent stated, “Well, obviously it’s my fault. It comes from my family (S-2).”

Another parent described how her husband related differently than she did to their child’s TS disorder. This individual reported that although she and her husband did not feel responsible for the condition, her husband felt that he should be able to “take care of”
the symptoms of TS and comorbid disorders:

My husband and I struggle with it. My husband took it personally, but he's the man. He is supposed to be able to fix everything and he can't fix this. He has struggled with that a lot over the last year and a half, and it’s like, “She shouldn't have to deal with this. I should be able to take care of this.” Well…. I don’t know how he deals with it other than just, he talks like that. But I'm not sure. We've talked about it a lot (S-5).

*Theme B: Parents felt drained by having to provide emotional support to their children.*

According to parental reports, their children suffered due to the symptoms and related social-emotional difficulties at home, in the community, and at school. As such, all parents related the toll that it took on them to have to frequently buoy their child’s self-esteem. For example, one participant extolled, “I loved him for who he was at the beginning, and I still do. It gets frustrating as a parent (S-4).”

Another mother reported that she was frequently in the position of acting as a counselor to her son:

I had to take a more…, I don't want a say a friendship role, but I think counselor or something like that… …He gets a lot more attention (*than his siblings*), but he needs more attention… I told him pretty early, what it was. And I told him, “You know how your mind works really hard and you know everything and you’re not going to forget anything. And it’s kind of working against you and it keeps repeating the same movement of the same thing, so it’s kind of a double edged sword…” One of his friends asked him at school what it was and was it contagious. So he said, “Don’t worry, you have to be really smart to get it.” So we really tried to…. you know, I tried to twist it positive, which is really hard sometimes (S-1).

The following example emphasizes the emotional drain felt by some parents when trying to help their child maintain a positive outlook on life, despite the difficulties of living with TS:

Some days, she embraced it (*her TS*), like, “I am bigger than this. It's not going to
get me. I’m going to,” you know, “beat it,” whatever, “I’m going to manage it.” She would write. She's a writer. She would write these stories about how she's going to be okay, and then there and were days when she was like depressed. And “I will never have a family. I will never have kids. I will never be able to drive.” She made things worse than any 13-year-old, or 12-year old at the time should ever have to deal with, and things like that… It was heart wrenching… She has not been consistently one way or the other for more than a week since she had the diagnosis. She's been back and forth, I think she's being positive and things are going pretty well and then she goes downhill again… And I’ve had to tell her that time and time again because she will say, “I can't deal with this,” and I said, “Yes you can. You're not given more than you can handle.” So sometimes I wonder why, but I try to be positive for her (S-5).

Theme C: Parents felt alone in caring for their child.

Four of the six parent interviewees claimed to have feelings of aloneness in trying to meet the unique needs of their child. One individual stated, “It was pretty much a solo effort (S-1).” Another participant explained in some detail the important role that she had played in the child’s life:

I have had a very bonding relationship and we have been bonded and everybody else in this life has disappeared. I'm the only one that has been a constant and consistent in his life. He doesn't cope very well at all. He gets very emotional and he starts crying and it is called a sissy a crybaby and mama's boy. One staff member called him that in a hospital one time. He actually said to him the kids look at you as a mama's boy, and I called the person above him and said this is very inappropriate. You don't use those kind of terms to a child like this. I know that you think, and also it is true that he and I have had a very bonding relationship and we have been bonded and everybody else in this life has disappeared. I'm the only one that has been a constant and consistent in his life. What may seem like a mama's boy to him is I'm the only person with whom he feels safe (S-4).

Sadly, one parent, a biological grandmother to the child, seemed to be desperate for agency intervention to address her 14-year-old son’s social-emotional problems (e.g., raging, social isolation, immaturity, inappropriate sexual behaviors, etc). In fact, during my initial phone contact with this individual, she stated that her participation in the study
was driven by her need to consult with me about agency assistance/intervention. “I can’t help him myself,” she exclaimed. “He needs help (S-6).”

Participants were questioned as to the extent they had received support from family members in the care of the child with TS+. Those participants who had family members in their lives (5 out of 6) reported feeling supported. However, at times, other members of the family, were deemed “unsupportive” in their actions or attitude:

My family has been very supportive (S-3).

My boyfriend who has been was very wonderful with him and understands what he is going through. Actually, there have been times when I’m on the phone with him at the residency and I’m getting so worked up. I say, “Here, talk to my boyfriend.” And my boyfriend can get him finding a solution, calm him down, laughing. So he (boyfriend) does a wonderful job with that (S-4).

If she needs to go somewhere, he’ll (her brother) drive her. He will do whatever. He has picked her up at school when I been in a meeting and couldn't pick her up. I’ve called him and he's taken her home spent the afternoon with her so she wasn't by herself. So he is very caring. They're both (both siblings) supportive of her when she's having a really rough time. I’ve seen her sister try and de-escalate her by talking to her, or rub her back or working with her (S-5).

Not uncommon was the report that individuals living in the family would become intolerant at times of TS related behaviors. Based on one parent’s report, her mother had difficulty accepting the child’s difficulties and became irritated by her grandchild’s TS symptoms:

My mother would always say, “It’s bothering me (the grandchild’s tics), take his carbs away. If you don’t stop it, punish him,” and all that stuff (S-1).

Theme D: Parent felt that their own mental and/or physical health has been negatively affected due to child’s Tourette’s Syndrome Plus conditions.

A common experience expressed by participants was the mental anguish and
physical exhaustion felt due to the relentless job of dealing with the problems associated with their child’s TS+. This was particularly true of two interviewees who reported that their ability to effectively deal with their children was compromised due to their own neuropsychiatric disorders:

This past weekend was a struggle for me with him to try to stay to remain calm and not get caught up in his emotions and when he goes home. I literally could sleep 12 or 14 hours just to because I feel so worn out and then my emotions, and then I’ll start crying, because it’s like I try so hard to make things work…That’s why he’s in residential again, I got to a point where I was just totally overwhelmed having my depression (S-4).

Another interviewee spoke of how the ordeal of having been accused of sexually molesting his daughter had taken a toll on his own health:

This whole thing was huge, huge! I’m not afraid of big guys, and I’m not afraid of big situations and danger, and I’ve walked down streets that, believe me, you have no business walking down…. But this (accusation of molestation) was a monster that was very foreign to me. Well suddenly you’re in the spotlight and under the magnifying glass. And I’m sure some of that is just perceived, but that perception is enough to cause enough paranoia and trepidation where you don’t want to interact with people. And I spent a good two years as a hermit… So you end up as somewhat as a societal outcast, pretty much however you play it. And it’s not like you can sit down with people and say, “This is why I’m this way.” They’re not interested and they don’t care. Most people don’t care... And that’s when I started to tic again, which I hadn’t done in years and years, and am still doing now. And shortly thereafter, was hospitalized with diverticulitis, which is a stress related, intestinal disorder. Not to mention, a loss of income, a loss of moral, a loss of self-esteem, a loss of identity, feeling that all eyes are on me, in the neighborhood, in the community, in the school… So I really watch myself as far as back-sliding, I call it “skating the edge of the razor blade;” I’ve always called it that. You can fall off at any second and be completely crazy, and I mean certifiable, straight-jacket, shock treatment, incarcerated crazy in my family. You can be that. It exists. And I don’t want to be. Too much on the line...(S-2)

This same man also spoke about how his own neuropsychiatric conditions, similar to his daughter’s conditions, had allowed him to remain more in control than his wife when dealing with their daughter’s behaviors. According to this man, when compared to
his wife, he was able to relate to his daughter’s behaviors in a less critical manner:

We have to be very careful with saying things like, “god damn it,” and stuff like that. Even with the ADD, you’re pushed every day, to the end of your ability to cope. Before bedtime rolls around, I really try to keep her (my wife) in check, because she’s worse about it than me. Her breaking point’s a little sooner than me, because she really doesn’t have the background (experience with TS+). So I try to keep her in check. So I say, “Look, you really need to approach this differently because she’s really gonna take that behavior to school (S-2).

For most parents, the relentless role of being a caretaker for their child with TS+ exacted cost on their own mental and physical health. The following excerpts illustrate this point:

I’m sure it didn’t do a good job with it (mental and physical health of interviewee). Just that chronic, every night, every couple of hours… (S-1)

I looked at that Prozac bottle for a few days and thought maybe I should take some myself… I am a “stress eater.” …sometimes I think about her and I get stressed and I eat…. it’s tough…it’s stressful… But I guess there are worse things that I can do with all that stress… We can live with this. Some days I think we can’t, but we will live with this (S-5).

Theme E: Parents’ outlook on their children’s Tourette’s Syndrome Plus conditions vacillated at times between feelings of despair and of hope for a bright future.

Although the transcripts were laden with strong emotional reactions from parents, across the interview, the parents, at times, referred to how their child’s condition(s) have been an emotional rollercoaster for them. One parent, typical of other interviewees, shared her feelings about a moment when her child was agonizing over the difficulty of life with tics, stating, “It was heart-wrenching (S-5).” Feelings reported by parents ranged from relief, to anguish, to even rage:

And I think, can he have this stuff forever? You read the books and they say, yeah, he’ll have it forever, kind of thing. Well, how much, when, where…? I kept thinking, no, he can’t (live in her home forever) (laughs). So I think he’s going to have it for a long time, forever… He’s managed it so far. I have to wonder about
college. I'm not sure how it will affect a roommate or how I figure we'll get him in somewhere, and if we have to ask for a private room and he'll be really happy. I'm concerned, but I’m not losing sleep (S-1).

I think he's going to be successful and Tourette’s is not going to really interfere with that (S-3).

The one thing that concerns us now is that he may have a tendency to use his disorders as a way to say, “I can't do this or I can't do that (S-4).”

I put it (child’s TS+ condition) in perspective, looking at friends of mine that have much, much bigger things than mine, and I decide it's not that bad. You will survive this. And my hope is that it slows down as she reaches puberty and in later teens. I don't know..., that's my hope (S-5).

Several interviewees spoke of the resilience their children had shown, not seeing themselves as victims of TS+:

He’s lucky, really lucky I guess. He’s a fighter, I guess, of course he fights me constantly (laughs). So that must help. He’s not like a big victim rolled up in a ball somewhere (S-1).

Even until today, I don't think he sees himself as a person with Tourette’s Syndrome. Quite honestly, I think he accepts himself for who he is and that's what he does. And really, you know, when I contacted the Tourette's Association for information or activities and things, he is not really interested. He doesn't really associate himself with being different (S-4).

Inspirational to me were the comments of parents regarding the inherent gifts their children possess that far outshine the problems associated with their disorders. The following excerpts are representative of other comments that highlight this point:

This stuff (TS+), on some level it’s not even important. It should be ignored, it should be celebrated. I’ve never met a normal person who I even thought was interesting. I just want to slap them and say, “Why are you normal? Aren’t you bored? My god, how can you live that way. And of course they’re not normal either. It’s just an illusion you know…(S-2)

I knew if any of our three children had this diagnosis, she would handle it the best. She is just that kind of a kid. She has always been a kind of, been a special kid. Everyone who has ever dealt with her, her teachers, everyone has said that
there's something about her. She's very engaging. I always dreamed she would do big things. She just has something about her and always has. I questioned whether this would affect that, or if she will embrace this and go further because of it (S-5).

**Exhaustive Descriptions**

Parents of children with significant TS+ symptoms experience intensely difficult challenges in the process of providing physical, psychological, and emotional support to their child. Finding medical help and treatment for their child is complicated due to the complex nature of TS+. These parents often feel irritated, deeply troubled, embarrassed, or frightened when having to witness and live with the odd, aggressive, obnoxious, sexual, or self-harmful symptoms of their child’s TS+.

The symptoms associated with the child’s TS+ condition(s) are perceived by parents as having a daily, negative impact on family functioning, which may result in quarreling, excessive noise in the household, upsetting family routines, etc. Parents have to endure intensified TS symptoms in the home due to tics being suppressed in other environments. Furthermore, family relationships are adversely affected at times, which, depending on the circumstances, may result in tension, hostility, jealousy, and resentfulness among household members.

Children with TS+ may be the victims of misunderstanding and mistreatment by peers and community members, enduring bullying, name calling, scrutinizing stares, ostracizing, etc. Witnessing these social problems causes emotional torment for the child’s parent, who mourns the absence of normal social relationships and social/emotional development in their child.
Parents of children with severe TS+ conditions at times find it necessary to become an advocate for their child at school in order to contend with their child’s school related problems. Advocacy efforts include educating school personnel about their child’s TS+ conditions(s), requesting adjustments and accommodations in their child’s educational program/placement, reporting bullying behaviors against their child, and struggling to modify the school’s expectations for the completion of homework. In short, these parents feel the need to become an authority in their child’s neuropsychiatric condition(s), and in special education and school policies, in order to assist their child in gaining social-emotional safety and academic success in school.

Parenting a child with TS+, through attempts to help their child navigate the home, community, and school environments, has an adverse affect the parent’s own social-emotional health. At times, these adults experience distress, worry, social isolation, disrupted home and work schedules, and tension in their own relationships with other family members. At the same time, parents are deeply committed to their child’s well being, and recognize that along with their child’s challenging health problems, their child is also endowed with special, endearing gifts that give hope for a bright future. 

*Statement of the Fundamental Structure of the Construct Being Investigated*

The following statement is a condensed version of the exhaustive descriptions. Gained through the process of eidetic reduction, this statement reveals the fundamental structure of the construct being investigated, namely, the lived experience of parenting children with TS+:
Parents of children with severe TS+ experience extreme degrees of suffering as a result of their child’s unique behaviors and needs. More specifically, parents feel irritated, deeply troubled, embarrassed, or frightened for their child when witnessing their child’s TS+ symptoms and are troubled by the negative impact these behaviors have on family functioning and relationships. Additionally, these parents mourn the absence in their child of normal social relationships and social/emotional development, and feel deep anguish when their child is a victim of bullying, teasing, and ostracism. Parents feel fearful, at times, that their child is being poorly educated, misunderstood, or mistreated at school. Furthermore, parental suffering, related to the affects of parenting a child with severe TS+, adversely affects the parents’ own mental health.
Findings of this phenomenological study reveal that the role of parenting may be extremely challenging when raising a child with severe TS+ symptoms. As reflected in the exhaustive descriptions (see pages 90-91), these parents are impacted by their child’s medical needs, social-emotional deficits, and problems in the home, community, and school environments. An important additional finding was that parents reported that their own mental health was negatively affected as a direct result of their child’s ordeals. In this chapter, I will reflect on each of the major areas of findings and contrast these findings to existing literature. Secondly, I will identify limitations of this study. I will then conclude this chapter by making recommendations for further research in this area.

Reflections on Major Findings

Living with the symptoms of Tourette’s Syndrome Plus.

Based on the results gleaned from the first area of questioning, parents of children with significant TS+ symptoms experience intensely difficult challenges in the process of providing physical, psychological, and emotional support to their child. For example, interviewees reported struggling to gain a diagnosis for their child at the onset of their
child’s TS condition. Two parents remarked that their child’s physician was unwilling to diagnosis the child without witnessing the tics first hand. I have read of this situation, referred to as the “elevator phenomenon.” Parents, having seen tics in their child, take the child to a physician for a diagnosis. The child does not tic during the examination, perhaps due to self-consciousness, and some volitional control of her or his tics. Once the parent and child leave the examination room and reach the elevator, where the child is less self-conscious, the tics resurface with a vengeance.

It is understandable that doctors might have difficulty diagnosing TS+. There are no clear boundaries set in the diagnostic criteria for TS for tic behaviors, as to frequency, intensity, or type. As well, tics can be difficult to observe, especially if physicians have misconceptions about what behaviors constitute a tic. For example, doctors might mistakenly look for coprolalic behaviors as evidence of TS, or diagnose a child with TS who presents with self-stim behaviors (stereotypies characteristic of pervasive development disorders). Other doctors might not give a diagnosis of TS without there being evidence that the condition causes the individual “significant distress,” a criterion that was stricken from the 1994 version of the DSM-IV. These examples highlight some of the difficulties associated with the challenge of making a diagnosis of TS, possibly leading to frustration and confusion among parents seeking a diagnosis and possible medical assistance for their child.

Although parents reported feeling shocked or in a state of disbelief when a diagnosis was given, most stated they felt relieved in that their suspicions had been confirmed, they had an explanation for their child’s behaviors, and they knew that TS
was not a fatal disease. This reaction was somewhat inconsistent with the expectation of Kubler-Ross (1969) who expected that after receiving such news, parents could be expected to experience a grieving cycle (see page 17). It should be added, however, that most participants in this study had been dealing with their child’s conditions for a number of years since their child’s diagnoses were given.

Complicating the diagnosis and treatment of TS can be the presence of symptoms of comorbid disorders. Consistent with reports in existing literature (Leckman and Cohen, 1999), all of the participants stated that their child was found to have multiple disorders that, in most cases, presented greater problems for their child than symptoms of TS, as found by Carter, et al. (2000).

Given the constellation of symptoms of co-occurring disorders, pharmaceutical treatment can be difficult to manage. This problem was strongly endorsed by nearly every interviewee. I, too, was treated with veritable panoply of medications over the last 10 years to alleviate concurrent symptoms of TS, OCD, GAD, ADHD, etc. Looking back through my personal records, various physicians from several branches of medicine (namely neurologists, general practitioners, psychiatrists, and psychologists) introduced 11 different medications, some concurrently. I can say from my experience that the medication haloperidol was a nightmare, literally and figuratively. I vividly remember walking the streets of my small town attempting to maintain some sense of sanity. Symptoms of a sharp and intense depression were my chief complaint, which, obviously to me, induced as a side effect of that drug. Other problems brought on by haloperidol were cognitive blunting, nightmares, somnolence, and, strangely, claustrophobia. In fact,
I was unable to sleep beneath the sheets on my bed for weeks on end. Most concerning to me is that children who are medicated with such powerful drugs are less able to articulate to caregivers how their bodies and minds are affected. These children may present with fewer problematic externalizing behaviors from their parents and teachers perspective, but may be suffering internally.

Consistent with research (albeit scant) were reports by parents who were deeply disturbed by witnessing, on a daily basis, TS+ symptoms in their child that appeared odd, offensive, or frightening. As shown on page 54-55, these behaviors included “weaponized tics,” (such as shrieking in others ears, hitting, pushing their hand in another’s food, etc.), raging (punching walls, kicking doors, etc.), the utterance of coprolalic tics at the dinner table, hazardous behaviors, (e.g., compulsively opening the car door while driving), and public displays of sexual behaviors. While most behaviors are well described by research in the field of neuropsychiatric spectrum disorders, the incidence of sexualized behaviors was higher than I expected. In fact, four out of the six interviewees stated their child had displayed sexual behaviors while in the presence of others. Perhaps due to some parents feeling embarrassment or shame, in three cases, it wasn’t until I had turned off the tape recorder that these accounts were given. Such behaviors included exhibitionism (in the case of two older boys and one younger girl) towards other family members or peers, copropraxia (i.e., gesturing with the middle finger), and touching another girl’s breasts or buttocks. Presumably, sexual behavior may be the result of an intermingling of symptomology, characteristic of impulsivity in ADHD, complex motor tics, and OCD. As to the association with TS, this disorder has
been described as a condition of disinhibition. However, the knowledge of which neurobiological mechanisms are most directly involved in producing such complex behaviors has, thus far, eluded research scientists.

As previously mentioned, one parent when interviewed expressed his contempt for school personnel who had interpreted his child’s sexualized behaviors as a manifestation of sexual abuse. A full range of professionals convened at a series of school meetings to investigate this matter and to intervene. The girl’s father, who maintained his innocence, was infuriated that school personnel were unaware that sexually inappropriate behaviors are not uncommon among children with TS+. School officials that were involved in this case notified a state child abuse agency which investigated the charges. According to the father, the case worker from that agency did not press charges against him. Instead, she became an advocate for him and his child at future school meetings. Fearing he would become violent during a meeting, the father chose to not attend follow-up meetings at school. He asked his wife to attend instead. His story sounded like a living nightmare. Indicative of the degree of rage felt by this person, he stated, “If they (school personnel) fell off the face of the earth and sunk into hell, I’d want video so I could watch it over and over so I could pause it on the good parts. That’s how I feel about it.” Although this man’s story may seem unique, he may not be alone. Dr. Roger Freeman, Clinical Head of the Neuropsychiatry Clinic at British Columbia Children’s Hospital, Vancouver, B.C., a noted researcher on TS, commented in his Internet blog site on this subject. His blog is dedicated to “Concepts applicable to an understanding of Tourette’s and comorbid disorders that are often unavailable in books.”
Quoting from Dr. Freeman’s blog:

Sexualized Behaviors: This is a tricky subject. Some children or adolescents will show behaviour that looks sexual, and nowadays someone is likely to assume that there was sexual abuse or molestation as the basis for this. However, this is not necessarily so! Tics can take this form without any interference from outside, but this may require expert assessment (Freeman, R.D., 2007).

Some parents themselves felt confused about what behaviors were controllable by their child (i.e., behavior driven), and what behaviors were a manifestation of the child’s TS+. This problem speaks to the point, as discussed in the literature review section of this study, that tics may be, in part, volitional (Bullen & Hemsley, 1983). In the case of one participant (discussed on page 60), she was convinced that her daughter was manipulating her into purchasing a new cell phone after the daughter broke the old phone into pieces. The girl was emphatic that her destructive impulse was tic related. “How can I punish her for a tic?” her mother exclaimed. This example exemplifies the difficulties spoken of by all study participants: How do I know what is a tic related behavior, how should I regard such disturbing behaviors, and what can I do to improve my child’s behaviors.

*Effects of Tourette’s Syndrome Plus on the Family at Home.*

In another area, the symptoms of TS+ condition(s) were perceived by parents as having a daily, negative impact on family functioning, which adversely affected family relationships. Based on a scan of existing literature, this topic is largely unexplored by researchers. As previously noted, Zinner (2004) found that children with TS hold back their tics during the school day for fear of teasing. Consequently, these individuals may
display heightened symptoms of tics and emotional disturbance when they arrive home. This phenomenon was well substantiated by parent participants in this study. They generalized this effect to their child withholding tics in multiple environments, leading to pronounced tic behaviors and emotional volatility in the home environment. In the words of one parent, whose report was similar to most others, “They (school personnel) would force him to stop during school time, and his tics would just fly out like crazy when he got home. All this rage, and all the tics from them forcing him to be in this mold all day long at school…(S-4).”

Backing the findings of Hubka, and colleagues (1988) (outlined on page 18), parents provided a plethora of stories substantiating that the lives of their family members, as well as family relations in the home, had been negatively impacted as the result of their child’s TS+. In a resounding chorus, participants in unison decried the disruption to home life functioning. As detailed in the Results section, daily schedules were affected, meals were eaten away from the table, vacations were cancelled, quarreling was a nightly event, etc. In short, discord and turmoil was the norm in some parents’ homes, which was a condition blamed on their child’s TS+ problems. Here again, it appears that no one disorder’s symptoms explain the cumulative effect on household disorder, rather, the problems seem to stem from the confluence of difficulties within the child. These difficulties might include the need to release tics that are withheld during the day, frustration from mistreatment by peers, low self-esteem, depression, anxiety, symptoms of CD or ODD, OCD, impulsivity/hyperactivity, or sensory defensiveness.
Relationship issues.

A third major finding of this investigation was that, in every case, parents mourned the absence of normal social relationships and social/emotional development in their child, in that their children with TS+ were reported to have frequently been the victim of peer bullying, teasing, and ostracism. Although some of this social mistreatment stems from the school environment (Abwender et. al. 1996), parents reported their child’s problems with peers were pervasive issues that plagued their child at home, in the neighborhood, and in the community settings. As outlined in the previous section of this report, parents told heart-wrenching stories of their children being used by neighborhood “friends,” who extracted money and toys in exchange for their company, who teased and taunted their child, and, in one child’s case, took advantage of her sexually. Social conditions for these children were no better in the community setting, where one boy was barred from participating in a local sports league, and another child was taunted by two bullies with the phrase, “Tourette boy.” A parent who was a grandmother to the child, sought out the assistance of the “Big Brothers Big Sisters of America” group because of her concern for her son’s inability to make friends. In general, parents expressed deep anguish over the emotional abuse suffered by their children.

Based on excerpts from interview transcripts, parents may experience discomfort, shame, or embarrassment while accompanying their child in public when their child exhibits TS+ behaviors. As has been well documented in this study, severe tic behaviors are somewhat unpredictable, and can be alarming to others. The symptoms of associated
disorders, in confluence with tic behaviors, may accentuate this problem. Bystanders, who may be unfamiliar with the symptoms of these disorders may view such behaviors as bizarre, disturbing, and/or alarming. As reported by the parents in the present study, bystanders can be intolerant of children with TS+. This problem may to be due to these children appearing otherwise normal, and yet exhibiting socially aberrant behaviors, and to a lack of awareness among the public that TS+ behaviors are a manifestation of a disability.

In this study, parents provided numerous accounts of behaviors exhibited in public by their child that might have been disturbing to bystanders. Examples include one boy who shouted, “Fuck-you,” towards his mother at the checkout lane, another child repeatedly grabbed her mother’s rear-end in the mall, and another who was suspected by store personnel of shoplifting because of his furtive glances, made to avoid social contact. Arguably, if most people saw a person in a wheelchair, they would immediately assume that individual has some form of disability, would have sympathy for that person, and would make allowances for that person’s behaviors. However, from the public’s point of view, it is not obvious from outward appearances that children with TS+ have a neuropsychiatric disorder. To cope with the problem of public awareness and intolerance for TS, one parent interviewee had cards made up to distribute to the public, explaining that her son had TS. She also developed a sense of humor around this issue. She provided an account of a trip that her family had taken to a national park to visit underground caves. At one point during the tour, her son shrieked loudly, whereupon the others on the tour screamed and ducked, thinking they were being attacked by bats. Clearly, the
unusual and unpredictable nature of TS+ symptoms, coupled with a lack of knowledge among the public of these disorders, can make outings a emotionally traumatic event for parents and their children with TS+.

*School related issues.*

A pronounced area of concern, according to the reports of all parent interviewees, centered on school related problems that arose as a result of their child’s TS+ symptoms. All parents felt the need to become an authority in their child’s neuropsychiatric condition(s), and in special education and school policies, in order to advocate for their child. Based on parent responses, some children seemed to achieve better results from their advocacy efforts than others. From my perspective, those results appeared to depend on the severity of the child’s disabilities, the willingness of school personnel to heed the parent’s admonitions, and the parents ability to be an effective spokesperson. Three parents were relatively satisfied with the school’s responses in providing helpful accommodations for their child. Three other respondents expressed extreme frustration and anger towards school personnel, charging that their school did not provide a safe social-emotional environment and a quality program that was responsive to their child’s special needs.

Regarding positive reports of school responses, two parents made specific references to a range of accommodations that benefited their children. Specifically, both students were allowed to leave the classroom when needed so as to be able to retreat to an isolated room in the school in which to tic. As mentioned, one junior high school-aged girl was provided a student helper that ensured her safe passage to another secure area.
Helpful to those children was the knowledge that if need be, they could tic in private. Teachers were instructed to ignore tic related behaviors. One parent noted, “It was the little things…” that most helped her son in school, such as preferential seating, a permanent hall pass, and flexible schedule. According to his mother, this boy utilized his own creative strategies to deflect attention from his tics, including sitting in the middle of the classroom, and “throwing” his verbal tics. Although her son is in a gifted educational program, he was issued a 504 plan, ensuring that supports would be made available if needed, across grade levels, teachers, and classrooms. These accommodations are included in lists of school supports published by TSA. Other strategies used to support these students included the choice of completing written assignments by computerized word processing, and taking tests in private rooms, removed from extraneous stimulation, where the student can feel free to tic without being noticed by, or disturbing, other students. Notably, both of the aforementioned parents, who reported being most pleased with the efforts made by their child’s schools, hold Masters Degrees. They also endorsed being highly involved at the schools by educating teachers, intervening in problem situations, and closely following their children’s progress.

Other parents were critical of a lack of supports, and supportiveness by teachers and administrators, at their child’s school. Complaints included classrooms that had excessive sensory stimulation (e.g., lights, noise, and visual stimuli), too much written work, excessive homework, unrealistic expectations for academic performance, inappropriate teaching methods, and a lack of flexibility in academic programming. These deficits suggest a lack of insight by teachers into the needs of children with TS+,
and rigid adherence to teaching practices. I am reminded of teachers I have met that when asked to adjust their classroom routine, complain, “I can’t be expected to change my way of teaching because of one student.” It is no wonder these parents felt the need to change schools, or even, in one case, to insist on homebound instruction. In my estimation, these parents lacked the skills needed to persuade the child’s school to make adjustments. In the words of one interviewee, “They (teachers) just don’t really understand, or if they do understand, they can’t get the higher ups to give them the okay to be able to change something in the school to make it happen (S-4).” This parent underscores the point made by the research conducted by Miranda, Presentacion, and Soriano (2002), who found that the most significant impediment to teachers working effectively with students with ADHD was teachers’ lack of knowledge about this disorder. Arguably, this is equally true, if not more true, of TS, given the relatively low incidence rate of TS.

One key to working with school personnel is to not expect the school to implement a laundry list of strategies, some of which might not be needed for their child to succeed. In that the symptoms of TS+ vary from child to child, it is important that parent’s assess the needs of their own child, carefully select the interventions strategies that address those needs, and present these to teachers in a patient manner. This recommendation is substantiated by Shimberg, (2003) who advised that the single greatest strength that a parent can bring to bear on gaining accommodations at school for their child is knowledge. If changes are not welcomed by the classroom teacher, I would suggest parents involve the building’s Instructional Support Team, and consider
implementing a 504 plan. This latter step is particularly important for children in secondary schools who are subjected to multiple teachers and classrooms.

*Intrapersonal effects of TS+ on parents.*

Parenting a child with TS+, through attempting to help their child navigate the home, community, and school environments, had an adverse effect on the parent’s own social-emotional health. This finding echoes the research results of Hubka, et al. (1988), and of Wamboldt, et al. (1996) (see page 17). The emotional drain experienced by parents was clear in both the words and affect of parent participants. I, too, was emotionally drained after listening to the litany of daily problems and challenges shared during each parent interview. Although some parents seemed more confident than others in the future success of their child, all spoke of difficulties that at times during their parenting years, tested the limits of their endurance and patience. As predicted by Zinner (2004), parents bore the brunt of the child’s stress and hostility in the home environment. This phenomenon is consistent with the findings of Christie and Jassi (2002) that provided evidence that parents experience more problem behaviors in their child than do teachers. Seemingly, parents are more in tune with their child than classroom teachers. As noted above, parents live with the child in the home and community ecologies when nerves are worn and words flow free.

The cumulative stress of caring for a child with TS+ appeared to me to have taken its toll on parent participants. Two parents joked about needing to self-medicate. Two other parents stated that their marriages had suffered as a result of the parenting load. One of these individuals had been diagnosed with severe depression and felt unable to have
her child live in the home (at the time of the interview, the child was in a partial hospitalization setting due to the severity of his self-injurious tics and raging behaviors). She relied on her boyfriend to handle phone calls from the boy when he was upset.

Cooper, Robertson, and Livingston, (2003), made the point in their study that parents of children with TS had higher levels of psychiatric disorders than parents of children with asthma. While the present investigation was not designed to fully investigate the degree of parental pathology, interview transcripts did provide context for such mental health disturbances, given the difficulties that beset these parents on a daily basis.

**Limitations**

This study was limited with regard to elements of its design, scope, and implementation. Regarding limitations to the design, it was unclear whether redundancy of data was achieved due to the difficulty of recruiting parent interviewees. The problem of questionable saturation of data was exacerbated by the approach of attempting to capture a wide range of parental experiences across multiple ecologies of their child’s life. With regard to sampling procedures, five of the six children, represented by their parents, were between the ages of 11 and 17. The sixth child was six years of age. Thus, although the majority of parents had parental experiences with a teenager, a number of years had elapsed, in many cases, since their child had experienced TS symptoms at their worst (10.5 years of age, statistically). As well, parents of older, teenaged children are less likely than parents of preteen children to recall their experiences around the time of their child’s diagnosis, and their child’s elementary school years.
Pertaining to the interview process, it was unclear how forthcoming parents were as to their children’s problems. For example, one interview was held, at the request of the parent, in a public coffee house. Another impediment to parents providing uninhibited and honest responses in interviews was the fact that two interviews were conducted in the participants’ homes, where there were other family members present in adjoining rooms. Thus, talk of more personal matters, such as sexual behaviors, might not have been fully and openly addressed by these parents. In the case of two interviews, I was alone with a female parent in her own home. Here again, these individuals might have been more reserved in their descriptions had we been in a more public, yet private setting, such as a private office in a school.

**Recommendations for Future Research**

Although the current study provides new contextual information regarding the rearing of children with TS+, many areas of study may be spawned from these results. For example, one useful area of investigation might be directed towards the strategies that parents use as coping measures to make their role easier, or more effective. In another vein, more direct lines of questioning to parents might better reveal which disorder(s) in the spectrum of neuropsychiatric disorders, is most debilitating for their child, from the parents’ perspective, and what activities in the child’s life are most affected by those condition(s). As discussed in the current study, parents that are armed with knowledge of their child’s area of disability are best equipped to affect change in their child’s educational environment and program. Research is needed into how parents can best attain that knowledge.
Conclusion

The purpose of this study was to explore the lived experience of parenting a child with TS+. Based on responses to interview questions, parents of these children experience extreme degrees of suffering as a result of their child’s unique behaviors and needs. More specifically, these parents have struggled to gain medical attention and effective treatment for their child. They also experience frustration, angst, embarrassment, and fear when witnessing their child display odd, violent, sexual, or offensive TS+ related behaviors. Furthermore, parents contend with disruptions to their family life and relationships among household members. Parents also mourn for their child when she or he is bullied, mocked, ostracized, or mistreated by peers, or others in the community. Undoubtedly, parents who raise children with disabilities other than TS+ experience added hardships. Parents of children with TS+ may face additional burdens, however, due to the unpredictable nature of TS+, and the fact that most children with TS+ do not look atypical. An especially troublesome aspect of these parents’ lives is having to advocate for their child’s emotional safety and academic progress in the school environment. Finally, parents’ own mental health suffers from the stress and strain of their difficult role in their child’s life.

The benefit of this study was to bring an awareness of parents who experience unique problems associated with raising a child with TS+. While some research has explored general aspects of TS through quantitative research methods, this study is the first of its kind to investigate the lived experience of parents of children with TS+, through qualitative means, centering on the parenting experience. It is hoped that the
information yielded in this investigation will bring a new understanding of the suffering these parents endure, and serve to inspire further research that can improve these parent’s lives, and in turn, the lives of their children.

The final words belong to one of the parents of this study, to whom I’m deeply indebted:

What I feel is pride, success, the ability to overcome. That’s what I feel. This (TS+) is not a death sentence. It’s not even a jail sentence. It’s wonderful. I’m blessed. I’m blessed because I’m dyslexic. I’m blessed because of my brain and that I’m learning disabled. I create beauty all day long. That’s what I do for a living. I create beautiful things. I’m not a demon, and neither is my daughter. She makes beauty too. I know that people can come through this (S-2).

Follow-up Interviews

As prescribed by Colaizzi (1978), follow-up interviews were conducted with study participants (in March and April 2008) as a means of member checking (described on page 48). I used that opportunity to question participants as to the academic and social progress of their children. Subject one stated that her son was doing well in school, having been a finalist in an historical information contest. She added that his TS condition was most noticeable at home in the evening, but that at school, he had grown in his ability to blend in with his peers. He has plans to attend college and study history or library science. The six-year-old female child of subject two continued to struggle at school. Based on her parent’s report, a second psychiatric appointment was scheduled by school personnel in order to inform placement decisions. School officials, as well as her parents, have been frustrated with the child’s lack of academic progress in her current placement.
Another parent (S-3) reported that her son continues to struggle, although she recently helped with his last Individual Education Plan meeting at school. As such, he is anticipating transitioning to the work world within the following two months. This mother noted that she is relying heavily on state services to provide him assistance in gaining an education in a trade, and in procuring work. She revealed her concern that her son might not do well with the transition in that he is sensitive to change. Subject four stated that her son was “doing better” due to a medication change to haloperidol. She added that the medication was helping his tics, especially his self-injurious tics. This mother mentioned that she was working to build her son’s self-esteem and coping skills. She credited her live-in boyfriend with helping in this effort due to his being a “male figure” who frequently engages her son in play activities, and his helpfulness in dealing with her son’s problems. Reportedly, subject five’s daughter successfully participated in school for most of the school year. Unfortunately, she recently experienced a reemergence of severe coprolalic tics, resulting in this child receiving home-bound instruction. Subject six, primary parent to her 14 year old grandson, stated that he was doing “better” because he recently changed medications. She also stated that he was improving with age. Reportedly, he is involved more with his same-aged peers despite his social anxiety disorder. She also mentioned that her grandson frequently reports feeling self-conscious about his tics. Apparently, he feels bad when his friends ask him, “Why are you doing that (ticcing)?” This parent also stated that most of his current teachers don’t seem to know that he has TS, and that his grades have dropped.
GLOSSARY

**Chronic Tic Disorder (CTD):** less severe than TS, this disorder is characterized by at least one motor tic, or, at least one vocal tic, lasting longer than 12 consecutive months.

**Complex Tic:** a tic that involves a coordinated group of tics, involving multiple muscles, or, in the case of complex verbal tics, the utterance of words or sentences

**Comorbidity:** the presence of one or more disorders that occur in conjunction with another disorder more frequently than would be expected by chance. In the case of TS, ADHD, OCD, learning disorders, mood disorders are frequently found to co-occur.

**Coprolalia:** a form of complex vocal tic, whereby the individual involuntarily utters curse words, ethnic or racial slurs, or socially inappropriate phrases or sentences

**Echolalia:** a complex vocal tic, characterized by the involuntary repetition of part, or all, of what someone else has just said

**Echopraxia:** a complex motor tic characterized by involuntarily copying someone else’s action(s)

**Simple Motor Tic:** an involuntary, rapid, sudden movement (e.g., blinking; wrinkling of the nose; shoulder shrug; head jerk, etc.)

**Palilalia:** a complex vocal tic characterized by the involuntary repetition of one’s own words
**Parent:** one who raises and nurtures a child, who may be a single (unmarried) male or female, a biological father or mother, a step-parent, an adoptive parent, a grandparent, or those in a same-sex relationship

**Primary Parent:** When two or more parents were known to be involved in the child’s life, the primary parent is defined as the parent who has taken responsibility for greater than 50% of the day-to-day parenting duties, such as getting the child to school, taking care of the child’s health care needs, etc.

**Tourette’s Syndrome:** a neuropsychiatric childhood disorder characterized by multiple motor tics and one or more vocal tics.

**Transient Tic Disorder:** the mildest form of tic disorder, characterized by tics lasting for at least four weeks, but for no longer than 12 consecutive months.

**Vocal Tic:** an involuntary verbal noise, such as a sniff, bark, grunt, or words
## APPENDIX A

### EXAMPLES OF SIMPLE AND COMPLEX MOTOR AND VOCAL TICS

<table>
<thead>
<tr>
<th>Simple Tics:</th>
<th>Motor</th>
<th>Vocal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye blinking</td>
<td>Sniffing</td>
<td></td>
</tr>
<tr>
<td>Mouth-opening</td>
<td>Throat-clearing</td>
<td></td>
</tr>
<tr>
<td>Grimacing</td>
<td>Grunting</td>
<td></td>
</tr>
<tr>
<td>Finger Movements</td>
<td>Screeching</td>
<td></td>
</tr>
<tr>
<td>Rapid bodily jerks</td>
<td>Clicking</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Complex Tics:</th>
<th>Motor</th>
<th>Vocal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tossing head/Shoulder shrug</td>
<td>Syllables, words, or phrases, such as “whuwh,” “no,” “what’s that,” or “I told him so.”</td>
<td></td>
</tr>
<tr>
<td>Thrusting arms</td>
<td>Echolalia (repeating other’s sounds or words) or palilalia (repeating one’s own sounds or words)</td>
<td></td>
</tr>
<tr>
<td>Jumping up/touching floor</td>
<td>Copropraxia (obscene gestures or sexual touching)</td>
<td></td>
</tr>
<tr>
<td>Copropraxia (obscene gestures or sexual touching)</td>
<td>Coprolalia (uttering profanities; racial epithets)</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B

DSM-IV-TR TIC DISORDER CLASSIFICATIONS

I. Diagnostic Criteria for Transient Tic Disorder (307.21)
   A. Single or multiple motor and/or vocal tics.
   B. The tics may occur many times a day, nearly every day for at least four
      weeks, but for no longer than 12 consecutive months.
   C. Onset before age 18 years.
   D. The disturbance is not due to the direct physiological effects of a
      substance (e.g., stimulants) or a general medical condition (e.g.,
      Huntington’s chorea or post-viral encephalitis).

II. Diagnostic Criteria for Chronic Motor or Vocal Tic Disorder (307.22)
   A. Single or multiple motor or vocal tics, but not both, have been present at
      some time during the illness.
   B. The tics occur many times a day, nearly every day, or intermittently
      throughout a period of more than a year. During this period, there was
      never a tic-free interval of more than three months.
   C. Onset before age 18 years.
D. The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington’s chorea or post-viral encephalitis).

III. Diagnostic Criteria for Tourette’s Syndrome (307.23)

A. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently.

B. The tics occur many times a day (usually in bouts), nearly every day, or intermittently throughout a period of more than a year; and during this period, there was never a tic-free interval of more than three consecutive months.

C. Onset before age 18 years.

D. The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington’s chorea or post-viral encephalitis).

Department of School Psychology
The Ohio State University

PARTICIPANTS NEEDED FOR RESEARCH

“The Parenting Experience of those who have Children with Tourette’s Syndrome”

Have you had intense parenting experiences due to your child’s Tourette syndrome condition (and possible other related disorders)? We are looking for volunteers to take part in a study of the parenting experience of those who raise children with Tourette’s Syndrome, with a focus on the child’s school and home experiences.

As a participant in this study, you will be asked to participate in two interview sessions with the primary researcher. The first session will last approximately two hours and the second session will be a phone conversation lasting approximately one-half hour.

In appreciation for your time you will receive $30.
For more information about this study, or to volunteer, please contact:

Roger Sasnett
at
(614) 256-2578
Email: roger@sasnett.com

This study has been reviewed by The Ohio State University’s Institutional Review Board.
APPENDIX D
INTERVIEW PROTOCOL

Introductory Statement:

“Thank you so much for participating in this interview. I would like to ask you some questions about your child’s TS condition, his/her experiences at school, your experiences with the school, and how these experiences may relate to your child’s diagnosis. The session today will be audio taped. Please know that what you choose to share here today will be kept strictly confidential. No one else will have access to this tape, and the tape will be kept in a locked cabinet. Your words may appear in a report that represents my doctoral dissertation; however, your name, the names of other family members, the names of teachers or schools, and/or any other identifying information, will not be revealed. You are welcome to end this interview at any time, and you are welcome to not respond to any questions that you do not care to answer.”

Demographics Questionnaire (see Appendix D)

“To begin with, I would appreciate your filling in the spaces on this questionnaire that provides me background information about you and your child.”

Grand Tour Question 1: How do parents experience the symptoms of their child’s TS+ condition(s)?
Possible Prompts:

1. “What was it like for you and your family when you first learned your child had TS?”
   a. “What was your child’s reaction to hearing that he/she had TS?”
   b. “What was it like for you when you first learned that your child had TS?”
   c. “How did this news affect your family?”

2. “How do you feel about your child’s condition(s) now?”

3. “How did your relationship with your child change following the diagnosis?”

4. “Have you or your spouse in any way felt responsible for your child’s TS (ADHD, OCD, etc.)? If so, in what ways?”
   a. “Who else in your immediate or extended family has a history of TS or other mental health problems?”

Grand Tour Question 2: How do parents experience their child’s TS+ in the home setting?

Possible Prompts:

1. “How has your child’s school experience affected the way your child behaves at home?”
   a. “What is completing homework like for your child and for your family?”
   b. “What is your child’s attitude like towards school?”
   c. “How does his/her attitudes towards school affect your family?”
   d. “How has your child’s school experience affected his/her relationship with her/his siblings?”

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2. “Has your child’s TS condition affected your mental or physical health, and if so, how?”

3. “How has your child’s TS condition affected her/his relationship with his/her siblings?”

4. “How has your child’s TS condition affected your functioning in the home?”
   a. “How has your child’s TS condition affected your relationship with your other children?”
   b. “How has your child’s TS condition affected your relationship with your spouse?”

Grand Tour Question 3: How do parents experience their child’s relationship with peers and with other people in their child’s life?

Possible Prompts:

1. “How has your child’s TS condition affected his/her relationship with friends?”

2. “What is it like for your child to be out in public, considering his TS condition?”
   a. “How do others react to his/her TS symptoms?”
   b. “How does your child feel about the reactions of others to his/her TS symptoms?”
   c. “How does your child cope with other people’s reactions to his/her symptoms?”
   d. “How do you handle the situation where other people react to his/her symptoms?”

Grand Tour Question 4: How do parents experience their child’s school issues related to their TS+ condition?
Possible Prompts:

1. “How has your child’s condition(s) of TS (ADHD, OCD, etc) affected him/her academically?”
   a. “Overall, how do you feel about the progress your child has made academically?”
   b. “How well do your child’s school grades reflect their academic abilities?”
   c. “What changes have your child’s teachers made in the classroom or curriculum to accommodate his/her TS (ADHD, OCD, etc.)?”

2. “What is your child’s relationship like with his/her teachers at school?”
   a. “How does your child feel about his/her teachers?”

3. “What is your child’s relationship like with his/her classmates?”
   a. “Talk about incidents, if any, of your child being the victim of teasing or bullying.”
   b. “How do you feel about the way your child has been treated by his/her peers at school?”
   c. “What guidance has been given your child as to his/her relationship with peers?”

4. “Talk about times that you have felt the need to intervene in your child’s school-related problems, and ways that have you been able help your child with his/her problems at school.”
   a. “How successful do you feel you have been in getting your child’s needs met at school?”
b. “What feelings come up for you when you think about the problems your child has faced at school?”

5. “How has your child’s condition(s) of TS (ADHD, OCD, etc.) affected his/her participation in school activities (e.g., bus, cafeteria, library, assemblies, extracurricular activities, school sports, etc.)?”

6. “What would you like the personnel and students at your child’s school to know about TS, and about you and your child?”

7. “What other school-related issues haven’t we discussed?”
APPENDIX E

PARTICIPANT QUESTIONNAIRE

Thank you so much for your participation in this study. This questionnaire will ask you to answer some questions about your child’s Tourette’s Syndrome condition, his/her experiences at school, your experiences with the school, your child’s social experience, and your family’s experience with Tourette’s Syndrome.

Please know that what you choose to share on this questionnaire will be kept strictly confidential. No one else will have access to this information, and all documents and tapes will be kept in a locked cabinet. Your words may appear in a report that represents my doctoral dissertation; however, your name, the names of other family members, the names of teachers or schools, and/or any other identifying information, will not be revealed. You are welcome to not respond to any question that you do not care to answer.

Directions: Complete a separate questionnaire for each child in your household that has been diagnosed with Tourette’s Syndrome.

Date: ________________________________

Name of parent: ________________________________

Name of child with Tourette’s Syndrome: ________________________________
Child’s birthdate: ________________

How many children do you have living in your family at home? ________________

When was your child first diagnosed with Tourette’s Syndrome? ________________

Who made the formal diagnosis of Tourette’s Syndrome? ________________

Where was the diagnosis made? (City/town; name of hospital/clinic)

________________________________________________________________________

How severe would you say that your child’s TS condition is? (Circle One)

Mild    Moderate    Severe

Please describe your child’s symptoms of Tourette’s Syndrome (at the present time).

________________________________________________________________________

Has your child been diagnosed with a learning disability? Please give details.

________________________________________________________________________

Has your child been diagnosed by a doctor or psychologist with another psychological,
behavioral, or medical conditions besides Tourette’s Syndrome?

(Circle: yes or no).

If yes, circle the condition shown below and the severity of his/her symptoms.

<table>
<thead>
<tr>
<th>Disorder (Circle all that apply)</th>
<th>Severity (Circle One)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention Deficit Hyperactivity Disorder (ADHD)</td>
<td>Mild    Moderate    Severe</td>
</tr>
<tr>
<td>Hyperactive Type</td>
<td></td>
</tr>
<tr>
<td>Inattentive Type</td>
<td></td>
</tr>
<tr>
<td>Combined (Hyperactive and Inattentive)</td>
<td></td>
</tr>
<tr>
<td>Condition</td>
<td>Mild</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Obsessive-Compulsive Disorder (OCD)</td>
<td></td>
</tr>
<tr>
<td>Mood Disorder</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td></td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td></td>
</tr>
<tr>
<td>Generalized Anxiety Disorder</td>
<td></td>
</tr>
<tr>
<td>Panic Attacks</td>
<td></td>
</tr>
<tr>
<td>Phobia</td>
<td></td>
</tr>
<tr>
<td>Separation Anxiety</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

What other conditions besides Tourette’s Syndrome do you suspect your child may have?
APPENDIX F

CONSENT FOR PARTICIPATION IN SOCIAL AND BEHAVIORAL RESEARCH

Protocol Title: Parenting Children with Tourette’s Syndrome
Principal Investigator: Roger H. Sasnett, M.Ed.

I consent to my participation in research being conducted by Roger Sasnett of The Ohio State University.

The investigator has explained the purpose of the study, the procedures that will be followed, and the amount of time it will take. I understand the possible benefits and risks, if any, of my participation and my participation. I also understand that the information obtained from this study will be used for research purposes and that other steps have been added to verify the validity of the results. This information was provided to me verbally by a Roger Sasnett. I have been informed that I may participate in the research without having the data included in the data analysis, but by signing this consent form, I know that the data collected on me will be included with the analysis. I know that I can choose not to participate without penalty to me.

I have had a chance to ask questions and to obtain answers to my questions. I can contact the investigator at (614) 256-256-2578. If I have questions about my rights as a research participant, I can call the Office of Research Risks Protection at (614) 688-4792.
I have read this form or I have had it read to me. I sign it freely and voluntarily. A copy of this form has been given to me.

Print the name of the participant:

__________________________________________________

Date: _______________ Signed: ________________________________

(Participant)

Signed: ________________________________

Signed: ________________________________ Signed: ________________________________

(Principal Investigator or her representative) (Person authorized to consent for participant, if required)

Witness: ________________________________

(when required)
APPENDIX G
FIELD NOTES

Date:

Participant Number:

Time Interview Began:
Time Interview Ended:

Interview Location/Description:

Person(s) Present:

Physical Description of Participant:

Participant’s Affect at Beginning of Interview:

Participant’s Affect during Interview:

Participant’s Affect after Interview:

Interviewer’s Impressions:
LIST OF REFERENCES


