

TOURETTE SYNDROME IN ADOLESCENCE: HOW IT IMPACTS AN
ADOLESCENT'S EXPERIENCE OF THEIR FAMILY, PEERS, SCHOOL, SELF-
CONCEPT AND VIEW OF THE FUTURE.

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ABSTRACT

This exploratory study investigated the experiences of adolescents with Tourette Syndrome (TS) and its impact on their family, peers, school, self-concept and view of the future. The focus on adolescents was deliberate since TS typically emerges in childhood, with tics at their worst during adolescence. A qualitative analysis of eight semi-structured interviews was completed using a grounded theory approach to capture the main themes that emerged from the adolescents' responses. The results of the study identified several main themes that these adolescents experienced which included: more adverse experiences with TS than positive ones, pervasive misconceptions about TS symptoms, a desire for more understanding of TS by the public, understanding and supportive families experiencing increased stress, academic challenges requiring accommodations, the active suppression of tics in school and in public, complex social interactions with peers, overall positive self-concepts impacted minimally by TS and a positive outlook on the future, fueled by resilience. These themes were thoroughly discussed within the context of existing research findings in the TS literature. The study's limitations were also considered given its small sample size comprised exclusively of all adolescent males from a clinical population. Implications for future research were discussed and suggested that the scientific community recognize the importance of qualitative research in understanding what it means to live with TS and to design experiments that broaden this part of the literature to ensure that TS will be more thoroughly understood and treatment will become more holistic.

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CHAPTER I

Introduction

“I finally apprehend the magnitude of the background noise that I have been experiencing for decades... the people around me do not share my tics because they do not hear the drumbeat. They do not feel the sensations without sources, do not have irresistible urges to pause in midsentence, do not receive strict internal commands to trace with their eyes in midair the shape of each of Aristotle’s regular solids, and so on in endless, bewildering variety... Finally and most important, I feel convinced that this complex challenging enigmatic internal world is the obvious core of Tourettes” (Hollenbeck, 2001).

Tourette Syndrome (TS) is both a public and private experience. The outside world serves as witness to the involuntary body movements and vocalizations, known as tics, that plague the person with TS. These tics vary in how seemingly natural and conspicuous they are, ranging from simple eye blinking and throat clearing to complex body gyrations and echolalia, the repetition of other people’s words. The forcefulness of their expression inevitably influences how much attention they garner from casual observers in everyday public settings. Having TS requires one to acknowledge this unwelcome companion as an inevitable part of their public life.

Privately, the person with TS is bombarded by involuntary sensations akin to tension, pressure and itching in a particular part of the body that serves as an abrupt alert to the imminent expression of a tic. These fleeting sensations, known as premonitory urges, wax and wane in their frequency and intensity, making it difficult to predict how often they will occur. Sometimes, they allow enough of a warning that the person is able to suppress the tic altogether, while other times to mask the tic in a more adaptive

expression, in the hopes of it going unnoticed. These premonitory urges are just a portion of the private experiences of people with TS, experiences that will be explored further in this investigation.

The public and private experience of TS becomes more of a challenge when considering the fact that the disorder typically emerges in childhood, with tics at their worst during adolescence, and a formal diagnosis required before the age of 18 (Leckman, Bloch, Scahill & King, 2006). Adolescence is a period of considerable upheaval, centered on major physical and psychosocial changes. Erik Erikson (1968) describes adolescence as a development stage in which the adolescent is charged with solidifying their identity by altering and replacing identifications made during childhood to assimilate new identifications that are congruent with the adolescent's desired social role. Erikson (1964) encapsulates the experience of adolescence in the following way:

“The growing and developing youth, faced with this physiological revolution within them, and with tangible adult tasks ahead of them are now primarily concerned with what they appear to be in the eyes of others as compared with what they feel they are, and with the question of how to connect the roles and skills cultivated earlier with the occupational prototypes of the day.”

Not only are adolescents are charged with the task of experimenting with and solidifying their identity, but also separating from their parents in a healthy manner, seeking acceptance from their peers and beginning to pursue romantic relationships, among others. These major developmental milestones occur all while the adolescent undergoes significant growth spurts and hormonal surges in a very public way.

Statement of the Problem

Now consider the adolescent with TS. Not only are they charged with the numerous psychosocial developmental hurdles that confront all adolescents, but they do so when their tics are at their worst. This is further complicated by the fact that a diagnosis of TS is often accompanied by comorbid disorders including: Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Oppositional Defiant Disorder (ODD), mood disorders and non-OCD anxiety disorders (Center for Disease Control and Prevention, 2009; Coffey & Park, 1997; Singer, 2005). The combination of TS being at its worst, and potentially accompanied by comorbid disorders, forces the adolescent to negotiate how they ultimately incorporate TS into part of their emerging identity.

The subjective experience of the challenges confronting adolescents with TS has not been well investigated. Most of the research involving TS has explored the etiology of the disorder, medication for the management of tics and behavioral therapies including Exposure and Response Prevention (ERP) and Comprehensive Behavioral Intervention for Tics (CBIT). Advances in these three areas have helped individuals with TS and their families better understand potential causes for the disorder, provide a reduction in symptoms, and teach behavioral techniques to more effectively manage the expression and impact of tics.

However, this research neither addresses the unique experiences of individuals with TS, nor the impact that it has on their daily lives during the critical developmental period of adolescence. For instance, it is highly likely that the experience of a 13-year-old male with TS and OCD, preoccupied by arm jerks, barking and hand washing

compulsions is different from the 17-year-old female with TS only, who constantly makes squeaking noises and blinks excessively. The aim of this investigation is to explore and come to a deeper understanding of how such differences and similarities influence adolescents with TS. In one study that has actually investigated the qualitative experiences of young people with TS, Cutler et al. (2009) urge:

“Future research could usefully explore the meanings that children give to TS, and further investigate the influences on the process of acceptance. It would be interesting to investigate whether age and developmental stage influence their ability to conceptualize their TS in this way.”

This investigation embodies the spirit of these authors. It documents the subjective accounts of a group of adolescent males with TS in order to gain a more comprehensive understanding of their unique experiences with the disorder. It allows each adolescent to tell their story of TS, giving voice to the impact it has had on their experiences with their family, school, peers, self-concept and view of the future. It aspires to capture the core of what it means to each adolescent to have TS, while allowing for the uniqueness of each experience. It is the hope of this author that these compelling stories of TS will serve as a springboard for more emphasis on the importance of qualitative research with respect to TS.

CHAPTER II

Literature Review

Tourette Syndrome

Tourette Syndrome (TS) is a neuropsychiatric disorder characterized by the presence of both motor and vocal tics. Tics are sudden, repetitive, stereotyped motor movements or phonic productions that involve discrete muscle groups (Leckman et al., 2006). Both motor and vocal tics are each divided into one of two categories, simple or complex. Simple motor tics are sudden, brief, repetitive, meaningless movements that usually last one second or less in duration. Common examples include eye blinking, facial grimacing, mouth movements, head jerks, shoulder shrugs, arm and leg jerks (Leckman et al., 2006). Complex motor tics are sudden, repetitive, stereotyped movements of longer duration that can appear to be purposeful in nature. Examples include touching, hitting, smelling, jumping, bending, gyrating and these tics can have a dystonic character (Singer, 2005). Simple vocal tics are fast, meaningless sounds and noises that include sniffing, throat clearing, grunting, barking and squeaking (Leckman et al., 2006). Complex vocal tics include syllables, phrases, echolalia (repetition of other people's words), palilalia (repetition of one's own words) and coprolalia (uttering of obscene words). While coprolalia is one of the more distressing and recognized tics, it occurs in only about 10% of people with TS (Singer, 2005).

According In the DSM-IV-TR (2000), Tourette's Disorder is the most impairing diagnosis in the category of Tic Disorders. A diagnosis of Tourette's Disorder requires the presence of multiple motor tics and one or more vocal tics occurring many times a day, with the onset of the tics occurring before the age of 18. The presence of these tics

must last for more than one year and have no tic-free interval lasting longer than 3 consecutive months. The remaining three tic disorders include Chronic Motor or Vocal Tic Disorder, Transient Tic Disorder and Tic Disorder Not Otherwise Specified. Chronic Motor or Vocal Tic Disorder is diagnosed with the presence of one or more motor or vocal tics occurring many times a day, but not both. Tics have to be present for more than 1 year to warrant diagnosis. Transient Tic Disorder is diagnosed when motor or vocal tics have been present for at least 4 weeks, occurring many times during the day, but for less than 1 year. Tic Disorder Not Otherwise Specified is diagnosed when tics do not meet criteria for any specific Tic Disorder. Examples of such a diagnosis include tics lasting less than 4 weeks or tics with an onset after the age of 18.

Phenomenology. The cardinal feature of TS is the waxing and waning of both motor and vocal tics in their frequency, intensity and duration. Motor tics usually begin between the ages of 3 and 8 years, with transient periods of intense eye blinking or some other facial tic. Vocal tics can also begin as early as 3 years of age, yet typically they follow the onset of motor tics by several years. These motor and vocal tics arise in bouts over the course of a day and change in severity over weeks and months (Leckman, 2002). The frequency and intensity of tics are usually worse during periods of excitement and fatigue. Typically, these tics multiply and worsen by early adolescence so that even during the waning phases the tics are troublesome. In most people with TS, the course of worst-ever tic severity is age dependent and usually falls between 7 and 15 years of age, after which there is a steady decline in tic severity (Leckman et al., 2006). Studies of adolescents and young adults have demonstrated that tics disappeared in 26% of participants, diminished substantially in 46% of participants, stabilized in 14% of

participants and increased in the remaining 14% (Singer, 2005). In many cases, vocal tics become increasingly rare or can disappear altogether, while motor tics can be reduced in both the number of tics and their frequency (Leckman et al., 2006).

While most TS symptoms are easily observed by others, there is an internal sensory experience that remains private to the person with TS. Premonitory urges are an internal feeling of an increasing need to perform a specific tic that is temporarily relieved once the tic has occurred (Fahn, 2005). Such sensory urges include tension, pressure, itching or tingling (Singer, 2005). Leckman (2002) argues that these urges, and the internal struggle to control them, can be as debilitating as the tics themselves. Research has shown that premonitory urges typically show up 3 years after the onset of tics and that while nearly 90% of tics are preceded by these urges, tics involving more automatic behavior, such as eye blinking, do not have urges that precede them (Leckman et al., 2006). Premonitory urges are localized to discrete anatomical regions that can be easily identified. Examples include the throat, shoulders, hands, midline of the stomach and front of the thighs and feet (Leckman et al., 2006; Singer, 2005). In some cases, premonitory urges can be as distracting as the tics themselves. This is true in the case of some adults that are partially able to resist tics, but are left with the distraction of the premonitory urge. Researchers suggest that these urges may account for a part of the attentional problems that plague those with TS (Leckman et al., 2006). The recognition that tics may be a voluntary response to an involuntary sensation has led some researchers to classify tics as “unvoluntary” rather than involuntary (Singer, 2005). This term helps clarify that while a person may be able to volitionally and temporarily suppress a tic, the tic itself will eventually have to be discharged. Complicating this

“unvoluntary” nature of tics is the evidence that even when an individual with TS is able to intentionally suppresses a tic, there is an increase in their urge to tic (Himle, Woods, Conelea, Bauer, & Rice, 2007).

Prevalence. Once thought to be a rare disorder, the prevalence of TS has significantly increased over the years. More recent prevalence estimates suggest that there are between 31 and 157 cases per 1000 in children between the ages of 13 and 14 (Leckman, King, Scahill, Findley, Ort & Cohen, 1998). Other researchers have claimed that the overall prevalence rate for adolescents is about 1 to 10 in 1000 cases (Kurlan, McDermott & Deely, 2001). A 2009 Morbidity and Mortality Weekly Report (MMWR) conducted by the Center for Disease Control and Prevention (CDC) estimated the prevalence rate for receiving a diagnosis was 3 in 1000, as per parent reporting. A diagnosis of TS was approximately three times as likely for boys compared with girls and approximately twice as common in children between the ages of 12 and 17 compared to those between the ages of 6 and 11. Non-Hispanic white children were twice as likely as non-Hispanic black children and Hispanic children to have a parent-reported diagnosis of TS (CDC, 2009).

Genetics. As the prevalence rates for TS has increased over time, so has the evidence suggesting that TS has a strong genetic etiology. TS aggregates strongly in families, suggesting that family members share either genetic or environmental risk factors that contribute to its manifestation (Keen-Kim & Freimer, 2006). The morbid risk of TS among relatives ranges between 10% and 15% and the rate of other tics ranges between 15% and 20% (Walkup, LaBuda & Singer, 1996). More robust support for the genetic contribution to TS is provided by the results from twin studies. Price, Kidd,

Cohen, Pauls & Leckman (1985) found an 86% concordance rate for chronic tic disorder in monozygotic twins compared to 20% in dizygotic twins. Other studies have found that monozygotic twins show approximately 50% to 70% concordance for TS, whereas dizygotic twins display only a 9% concordance rate (Hyde, Aaronson & Randolph, 1992). While these studies suggest a strong genetic contribution, they also highlight the role of the environment in contributing to TS because the concordance rates for monozygotic twins are far from 100% (Keen-Kim & Freimer, 2006).

Comorbidity. While managing the barrage of tics brought on by TS is difficult enough, the majority of people diagnosed with TS have at least one comorbid disorder to contend with. Results from the recent MMWR show that among children ever diagnosed with TS, 79% of them were also diagnosed with at least one co-occurring mental health or neurodevelopmental condition. The study found that 64% of children had been diagnosed with attention deficit hyperactivity disorder (ADHD), 43% with behavioral or conduct problems, 40% with anxiety problems, 36% with depression and 28% with developmental delay affecting the child's ability to learn (CDC, 2009). These results are consistent with an abundance of research. It is suggested that between 50% and 75% of children with TS will have comorbid ADHD (Comings & Comings, 1985) with other studies presenting an even wider range from 21% to 90% (Comings & Comings, 1987). Obsessive-compulsive behaviors have been reported to occur in about 20% to 60% of people with TS, with some studies reporting a co-occurrence of 89% (Robertson, Trimble & Lees, 1988; Singer, 2005). Multiple studies have an increased incidence of anxiety and depression in people with TS. A study of 100 children and adolescents found that 76% met the criteria for a mood disorder and 67% met the criteria for non-obsessive-

compulsive anxiety disorders (Coffey & Park, 1997). This high rate of comorbid disorders simply adds to the challenges and difficulties already faced by a person diagnosed with TS.

The Psychosocial Impact of TS

Family. The impact of TS goes well beyond the motor and verbal tics that plague the child diagnosed with it. Its impact is felt through the entire family. Minuchin (1974) views the family as a self-regulating unit where stress in part of the family is seen as affecting all other members. Recent research has corroborated this by demonstrating that the parents of children with TS have more marital difficulties, substance abuse, family conflict, lowered quality of parent-child interaction, and higher levels of parenting frustration relative to parents of children without TS (Storch, Merlo, Lack, Milsom, Geffken, Goodman & Murphy, 2007). One can infer that these negative outcomes for the parents have adverse effects on the child with TS and their siblings.

Other research suggests that TS has more of a negative impact on families than that of other chronic diseases. Bawden, Stokes, Camfield, Camfield & Salisbury (1998) found that the mothers and fathers of children with TS rated their families as less cohesive than did mothers and fathers of children with diabetes. Cooper, Robertson & Livingston (2003) found that parents of children with TS experienced greater caregiver burden and were at greater psychological risk than parents of children with asthma.

The prognosis for families dealing with TS is poorer when accounting for comorbidity. Children with TS and ADHD are at increased risk for internalizing and externalizing symptoms and problems adapting in social situations when compared to children with TS (Carter, O'Donnell, Scahill, Shultz, Leckman & Pauls, 2000).

Wilkinson, Newman, Shytle, Silver, Sanberg & Sheehan (2001) demonstrated a clear positive correlation between the number of comorbid disorders that a child has and negative impact it has on the family. Using the Family Impact Scale (FIS), a 34-item questionnaire that consists of statements regarding the way in which an ill family member has affected the family, children with TS only had significantly lower scores than did those with comorbid conditions. Wilkinson, Marshall & Curtwright (2008) replicated these results by showing that parent-reported stress is significantly higher when a child has TS and one or more comorbid disorders.

The strain placed on the parents of children with disabilities is so great that the phenomenon of caregiver burden has emerged. Caregiver burden is the sensory-perceptual reaction to the circumstances of giving care to a person in need of help (Edge Schoeder & Remer, 2007). Using the Caregiver Strain Questionnaire (CGSQ), a 21-item self-report measure that assesses objective strain, internalized subjective strain, and externalized subjective strain in caregiver of children with behavioral and emotional problems under the age of 18, these researchers found that caregivers of children with TS experience this strain. This strain is exacerbated by a lack of perceived social support and increased symptom severity (Edge Schoeder & Remer, 2007). A conclusion drawn by this study is that strain not only affects the caregiver, but the caregiver-child relationship and ultimately, the child with TS. Lee, Chen, Wang & Chen (2007) found that parents of children with TS had greater overall stress if they were below the age of 30, suggestive of less experience in their parenting role, and had a low family income, making them less likely to seek the medical attention they need. In sum, the findings of

these studies paint a picture of a difficult family life for those with TS, with no family member being inoculated from its impact.

Peers. The involuntary movements and vocalizations brought on by TS complicate the interactions of children with the disorder and their peers. There is robust research that chronicles the difficulties these children have socializing with and being accepted by their peers. Stokes, Bawden, Camfield, Backman & Dooley (1991) conducted an investigation into the social adjustment and peer relationships of children with TS, ages 8-15, by gathering data directly from their classmates using the Pupil Evaluation Inventory (PEI). The PEI is a sociometric questionnaire used to assess peer relationships in children in grades 1-9, focusing on the factors of Likeability, Aggression and Withdrawal. The results showed that children with TS were viewed as significantly more withdrawn, more aggressive and less popular than their classmates. Additionally, thirty-five percent of the children with TS received the lowest rating in the class on one or more of the factors on the PEI. It was demonstrated that the children's severity of tics did not explain these problems. Stokes et al. (1991) suggest that children and adolescents with TS may be handicapped in mobilizing their social coping skills effectively, either because of their lack of insight into their social handicaps or as a direct result of the disorder itself.

Hoping to replicate these results, Bawden et al. (1998) compared peer relationships, social skills, self-esteem, parental psychopathology and family functioning of children with TS, ages 7-15, to a group of children with diabetes mellitus. Using the PEI to gather data from classmates about both groups' behavior and peer relationships, the TS group was shown again to be at high risk for poor peer relationships. Further, this

group was at higher risk for having poor peer relationships than the group of children with diabetes mellitus, suggesting the presence of a chronic disease alone does not account for the peer relationship problems in children with TS. These peer relationship problems appear to exist independent of parental psychopathology and family dysfunction as assessed by the Minnesota Multiphasic Personality Inventory-2 (MMPI-2) and the Family Assessment Measure-3 (FAM-3). These findings suggest that poor peer relationships are connected to specific features of TS.

Other studies have confirmed the difficulties in socialization for children with TS. Carter, O'Donnell, Schultz, Scahill, Leckman & Pauls (2000) used the Vineland Adaptive Behavior Scale (VABS) to measure the personal and social sufficiency of children with TS and ADHD, TS only and control subjects. Results showed that the TS and ADHD group was at an increased risk for problems in social adaptation compared to the other two groups. When both the TS and ADHD and TS only group were aggregated and compared to the control group, the aggregated TS group had significantly more difficulties on the socialization domain. Dykens, Leckman, Riddle, Hardin, Schwartz & Cohen (1990) also used the VABS to assess adaptive functioning in a sample of medication-free children, ages 7-14, with TS only and TS and ADHD. The data from both groups revealed a level of social functioning that fell considerably below chronological age expectations, suggesting that many children with TS show a delay in social adaptation compared to other areas of adaptive functioning.

With many studies using quantitative data to chronicle the social difficulties of children with TS, a recent study used qualitative data to bring these problems to life. Cutler, Murphy, Gilmour & Heyman (2009) studied the impact of TS on Quality of Life

(QoL) in children with TS, ages 8-18, using both quantitative and qualitative means. The study used 90-minute focus groups, facilitated by one researcher and one psychologist, asking questions of the participants to guide the conversation. This conversation was audio recorded, transcribed and analyzed to reveal emerging themes. Under the theme of *struggling to fit into society's expectations of normal behavior*, these children with TS revealed being different from their peers causing them to be a target for bullying and teasing. In turn, this bullying and teasing led to aggressive and violent reactions on the child's part, causing them to get into trouble: "They like call me Tourettehead and stuff, I just end up kicking them or something, as I just get really angry and start kicking them and they start punching me, doing that back. And I end up falling out with them" (Cutler et al., 2009). Other children worried about what their peers thought of their TS: "If I do the noises they're like 'oh that Tourette's isn't it' and I think [few words inaudible] and I'm scared they'll start thinking I'm weird and my relationships will go. I'm scared of that" (Cutler et al., 2009). This qualitative data helps invigorate the many quantitative study results that have demonstrated a dearth of positive peer interactions in children with TS.

Presented with such strong evidence documenting the socialization difficulties of children with TS, researchers are developing new interventions to combat it. An example of this research is that of Marcks, Bernlin, Woods & Davies (2007) on preventative disclosure. This strategy attempts to counteract the stigma that people with TS face in social situations by disclosing information about their condition, preventing others from forming negative impressions. The study examined the survey results of 369 college students that read a vignette about a character exhibiting symptoms of TS, with half of

the students in the preventative disclosure condition and the other half in the control condition. The results supported the hypothesis that preventative disclosure would significantly reduce social rejection related to TS symptoms. The authors suggest that preventative disclosure may mitigate people's concerns about their TS symptoms and increase their comfort in social situations (Marcks et al., 2007). Developing such strategies is a critical component of helping children with TS improve their socialization difficulties.

School. In addition to the socialization difficulties experienced by children with TS are the academic challenges confronting them. Studies range with respect to the impact TS has on academic performance, with most demonstrating a negative one. Hagin & Kugler (1988) found that 16% to 68% of children with TS function below expected educational levels for academic skills. A survey of 200 children and adolescents with TS revealed that 36% experienced learning problems, 22% had a learning disability, 18% reported poor grades, 12% needed to repeat a grade and 8% were in full-time special education classes (Erenberg, Cruse & Rothner, 1986). Comings, Himes & Comings (1990) found that there is a five times greater requirement for special education services in children with TS than there is in the general population. Ferrari, Mathews & Barbas (1984) found the children with TS have difficulties in tasks requiring visual-motor coordination, perceptual organization, short-term memory and numerical reasoning.

While there is ample research to bolster the claim that TS plays a role in a child's academic difficulties, there is a caveat that requires attention. Shapiro, Shapiro, Young & Feinberg (1988) suggest that the intellectual and academic functioning of children with TS may be due to the problems of attention and hyperactivity associated with ADHD.

Dykens, Leckman, Riddle, Hardin, Schwartz & Cohen (1990) set out to test this hypothesis by assessing the intellectual, academic and adaptive functioning of TS children, ages 7-14, with and without Attention Deficit Disorder with Hyperactivity (ADD-H). The study used Wechsler Intelligence Scale for Children Revised (WISC-R) and Woodcock-Johnson Psychoeducational battery to measure intelligence and academic functioning, along with the VABS to measure social functioning. The results showed that children with TS manifested a relative strength in the ability to think conceptually in an abstract, logical manner and a relative weakness in mental, numerical reasoning (Dykens et al., 1990). TS children with ADD-H scored significantly lower on the performance IQ than did the TS only group, causing the researchers to suggest that children with ADD-H may have more difficulty completing tasks requiring both perceptual organization and visual-motor integration (Dykens et al., 1990). This finding is consistent with the work of Sattler (1988) who found that children with ADD-H generally tend to score lower on tasks of perceptual motor skills than children without the disorder. It is apparent that problems with attention and hyperactivity both complicate and contribute to the learning difficulties that are present in children with TS.

Tic suppression may also play a role in the learning difficulties experienced by children with TS. Tic suppression, the temporary and willful prevention of one's tics, is a phenomenon that has been demonstrated in children with TS by using positive reinforcement (Himle & Woods, 2005). There is debate among researchers about whether or not tic suppression causes a rebound effect, a paradoxical increase in tics after efforts to suppress end (Marcks, Woods, Teng, & Twohig, 2004). Tic suppression has been linked to one's attentional abilities; namely the ability to anticipate a premonitory

urge and divert one's attention to prevent the tic from occurring. This ability to have some control over one's tics by attending to them may interfere with a child's ability to focus in the classroom. Cutler et al. (2009) found that children needed to suppress their tics to fit in with others and avoid negative attention:

“Because when I look at people, they are really odd ones just like [demonstrates a facial tic] and when I look at people and I don't know them I try and keep them in, but if you do do them they like look at you and stare at you, it's really annoying.”

Additionally, Cutler et al. (2009) showed that the child's struggle to control tics was attention consuming and prevented them from giving their full attention to external events, such as school. One child participant stated:

“I think the reason I can't remember is like sometimes I don't know what I'm doing because I'm thinking 'oh no the Tourettes is bad ohh got to control it control it, control it' and I might ask just to go to the toilet so I can do it and then I've missed like 20 or 25 min of the lesson.”

It appears as though the role of tic suppression, in addition to the role of ADHD, should be included in any investigation measuring the impact of TS on a child's academic functioning.

Self-Concept. With an abundance of evidence to suggest that children with TS have more difficulties with their family, peers and school performance, it is important to consider its impact on their self-concept. Self-concept is the total picture of how an individual perceives or understands him or herself, his or her attributes and how an individual perceives others' perceptions of him or her (Parker, 2010). Self-concept can

be thought of as a multifaceted construct that is hierarchical in nature, with global self-concept at the top and subcategories underneath that influence each other, as well as an individual's overall sense of self (Shavelson & Bolus, 1982). Subcategory examples include academic, social, emotional, physical, and athletic perceptions of oneself. A subcategory such as academic self-concept may be further divided into subject-specific domains, such as math, science, reading, and social studies. These subject-specific self-concepts work together to inform an individual's overall sense of academic self-concept, which, in turn, is part of the larger global self-concept construct (Pajares & Schunk, 2001). It is important to clarify the difference between self-concept and self-esteem, as the two constructs are often used interchangeably in the research literature and cause confusion (Strein, 1995). Self-esteem is a subcategory of self-concept that enables a person to establish a sense of value or self-worth (Rice & Dolgin, 2005). Thus, self-concept and self-esteem are not one and the same and should not be used interchangeably.

Self-concept begins to develop when young children begin to see themselves as unique individuals. As they grow and mature, a child's self-concept gradually increases in complexity and perceptions of their abilities become more organized (Parker, 2010). A person's global perception of self is fairly stable, yet domain-specific self-concepts are influenced by self-assessments, idealizations, contextual experiences, and evaluations by significant others, such as parents, peers, and role models (Shavelson & Bolus, 1982). There is general agreement that parents, teachers and peers provide information and feedback that shape the formation of an adolescent's self-concept (Harter, 1999). Being susceptible to this influence is particularly prevalent during puberty, as young adolescents

begin making thorough evaluations of themselves and their abilities through both self-assessments and intense social comparisons (Rice & Dolgin, 2005). Consequently, adolescents' domain-specific self-concepts, with respect to intelligence, social skills, and athletics, are more fluid and open to both positive and negative influences (Schunk, 2000).

While one's global self-concept has been demonstrated to be fairly stable, researchers have data to suggest that it may be vulnerable to change during the transition to middle school (Barber & Olsen, 2004). Eccles, Wigfield, Flanagan, Miller, Reuman & Yee (1989) found general declines in global self-concept for adolescents transitioning in the middle grades, with self-concept reaching its nadir immediately after the transition. Contrarily, Chung, Elias & Schneider (1998) found that young adolescents' self-concept either remained stable or increased as they entered middle school. Parker (2010) added to the complexity of these results by demonstrating that middle school adolescents had an initial increase in their self-concept as they entered middle school, followed by a decrease in their self-concept to pre-study levels and even lower. Harter's (1998) research demonstrates that many of the domains of self-concept drop during early adolescence and then rebuild slowly during later adolescence, in a flat, U-shaped curve. In a two-year longitudinal study that measured the self-concept domains of 518 Canadian high school students using the Harter's Self-Perception Profile, Shapka & Keating (2005) found that most domains of self-concept increase with age, while perceived scholastic competence decreases. This study revealed that boys had higher perceptions of appearance and athletic competence, while girls had higher perceptions of their close friendship abilities and social acceptance. Using a hierarchical regression analysis, it was revealed that

appearance was the most significant predictor of overall general self-worth for both boys and girls.

The fluctuating nature of self-concept during early adolescence has important implications that greatly shape their future. Individuals with low self-concept have been shown to have less positive characteristics in the domains of cooperation, persistence, leadership, anxiety, expectations for future education and peer interactions when compared to peers with high self-concepts (Hay, Ashman & van Kraayenoord, 1998). Parish & Parish (1991) found that adolescents with low self-concept have higher incidences of behavior problems, inattention, depression, or a history of negative life events and report lower attachments to their parents. Fuligini & Eccles (1993) argue that adolescents with low self-concept are thought to be more influenced by and more attached to their peers than their parents. These adolescents who felt strongly about perceived excessive parental control ignored parental rules, schoolwork, and even their own talents in order to be popular with their peers. While some research presents peer influence as an impediment to a healthy self-concept, other researchers deem it the psychologically necessary step of individuation. In this process, adolescents remain emotionally connected to their parents but progressively use their peers to become more independent and autonomous and engage in more adventurous behavior away from their parents. During this stage, parents remain a source of advice and of economic and social support, where adolescents use their parents as reference points to validate their behavior and self-concept (Hay & Ashman, 2003).

View of the Future. Mounting evidence suggests that TS adversely impacts both the child with the disorder and their family members. As mentioned, the families of children with TS report increased stressors including marital conflicts, substance abuse and increased parental frustration (Storch et al., 2007) and these stressors are exacerbated when comorbid diagnoses accompany the TS diagnosis (Carter et al., 2000). In addition to family stressors, children with TS have difficulty socializing with and being accepted by their peers (Stokes et. al., 1991). Bawden et al. (1991) found that children with TS were at higher risk for having poor peer relationships than a group of children with the chronic disease, diabetes mellitus. These children have also been shown to feel different from their peers, causing them to be a target for bullying and teasing (Cutler et al., 2009). Such difficult social interactions are not the only challenge facing children with TS at school. Comings et al., (1990) found that there is a five times greater requirement for special education services in children with TS than there is in the general population. This prognosis worsens for children with TS and other comorbid disorders. Dykens et al. (1990) found that TS children with ADD-H scored significantly lower on the performance IQ than did the TS only group. Consistent with this finding is the work of Sattler (1988) who found that children with ADD-H generally tend to score lower on tasks of perceptual motor skills than children without the disorder. This combination of increased stressors at home, school and with their peers undoubtedly shapes the view of the future for each child with TS.

Research has demonstrated that there are two general paths that children take with an eye toward the future. One of these paths is dark and uninviting. Here, children attribute negative life events in the world to internal, stable and global causes leading to

feelings of hopelessness and depression (Seligman, Kaslow, Alloy, Peterson, Tanenbaum & Abramson, 1984). Additionally, these authors found that children who endorsed this attribution style were more likely to be depressed 6 months later and have a mother who modeled this negative attribution style for them (Seligman et al., 1984). This reformulated theory of helplessness and depression postulates that humans make attributions about negative life events that are internal or external, stable or unstable, global or specific. The former positions lead to hopelessness and depression while the latter positions significantly reduces a person's chances of having depression (Joiner & Wagner, 1995). Hence, children who adopt internal, stable and global attributions to negative events are more likely to be depressed. Joiner & Wagner (1995) offer a simple example of a child who fails a test and makes these deleterious attributions. First, the child making an *internal* attribution will explain the cause of this negative event in self-referential terms like, "I failed the test because I am stupid." Alternatively, a child making an *external* attribution might say, "I failed the test because the class clown distracted me." Second, a child making a *stable* attribution explains the failure in terms of permanent factors, whereas an *unstable* attribution explains the event in terms of temporary factors. "I failed the test because I am stupid" is a *stable* attribution since "being stupid" is a relatively permanent state. In contrast, "I failed the test because the class clown distracted me" is an *unstable* attribution, because the class clown's distracting behavior is temporary. Last, a *global* attribution explains the cause of negative events in terms that are pervasive across situations, whereas a *specific* attribution explains events in limited terms. Thus, the attribution "I failed the test because I am stupid" is global because "being stupid" is likely to influence many situations.

Contrarily, “I failed the test because the class clown distracted me” is a specific attribution since the class clown is unlikely to affect many situations outside of the classroom. As a result, a child with an internal, stable and global attributional style is more likely to blame themselves for their failures and other negative events, leading to an increased risk of hopelessness and depression.

The peril of a child adopting this negative attribution style is that in normal development, a child’s attributional styles appear to stabilize around the age of 12 (Gibb, Alloy, Walshaw, Comer, Shen & Villari, 2006). Further, studies of the attributional style of sixth graders and high school students have yielded almost identical 1-year re-test correlations as those reported in adults (Gibb et al., 2006). This cognitive inflexibility that increases with age can also be exacerbated by a child’s social environment. Rose & Abramson (1992) hypothesized that social and peer-related events such as teasing, rejection, and humiliation are more likely to contribute to the development of negative attributional styles than other types of life events. McDougall, Hymel, Vaillancourt & Mercer (2001) found that peer rejection, and its effect on depressive cognitions, predicts the development of low-self esteem that reinforces a negative attribution style. It is clear from this varied research that a negative attributional style will negatively tinge a child’s view of the future.

The other path toward the future is a more desired one. Children that walk down this path are guided by a sense of optimism and supported by positive social relationships in their environment (Schonert-Reichel, Buote, Jaramillo, & Foulkes, 2008). In a study of 1,402 students in grades 4 through 7, Oberle, Schonert-Reichel & Zumbo (2011) found that trait optimism, supportive and positive relationships with peers, non-related adults in

the community and a strong sense of school belonging were significantly and positively related to life satisfaction, a critical aspect of happiness in early adolescence. Oberle & Schonert-Reichel (2010) found that optimism in children has been shown to positively predict peer acceptance, while it has been negatively related to peer victimization, rejection and loneliness (Deptula, Cohen, Phillipsen & Ey, 2006). Further, research has demonstrated that optimism longitudinally predicted lower levels of childhood depression and externalizing problems while pessimism predicted higher levels of anxiety and lower levels of academic competence among third through sixth grade children (Ey, Hadley, Allen, Palmer, Klosky & Deptula, 2005). Kumpfer (1999) found that dispositional optimism is an essential resource in positive adjustment that has been related to successful adjustment, especially in the contexts of stress and adversity. Gilman & Huebner (2003) demonstrated that high levels of life satisfaction in youth were positively related to interpersonal relations, positive relationships with parents, and hope, and negatively related to depressive symptoms, anxiety, and a negative attitude towards school and teachers. In sum, children that are optimistic and have supportive family, school and social relationships are more likely to be satisfied with their life and have a positive outlook on their future.

Research Questions. The aim of this study was to investigate the experiences of adolescents with Tourette Syndrome (TS) across multiple domains. Specifically, this study investigated the impact of TS on these adolescents' experiences with their family, peers, as students, on their self-concept and its impact on their plans for the future. Eight adolescent males, ages 12-17, were interviewed using a semi-structured interview created by this study's author. The interview focused on gathering data across the five identified

domains using a qualitative case study design. The broader goal of this study was to expand the literature on TS to include more qualitative research that demonstrates the far-reaching impact of this neurological disorder on the adolescent's psychological experience. This study focused on answering the following questions:

1. How does TS impact this adolescent in their family?
2. In what ways does TS impact this adolescent with their peers and social situations?
3. In what way does TS impact this adolescent in their school setting?
4. What has been the impact of TS on this adolescent's self-concept?
5. How has having TS impacted the adolescent's plans for their future?

CHAPTER III

Methodology

Participants

Nine boys with a diagnosis of Tourette Syndrome (TS) were interviewed for this study at the Rutgers' Psychological Clinic. Informed consent was obtained from each of the participant's parents, as well as assent from the participants before the study commenced. Participants with serious psychiatric disorders, such as psychosis and bipolar disorder, along with those having developmental disabilities were excluded from the study. These conditions warranted exclusion from the study since they were likely to have an additional impact on experiences of adolescents that goes beyond that of having TS. While this study focused specifically on the impact of TS on adolescents' psychosocial experiences, comorbid symptoms that are common in the TS population were included in the study. These symptoms include the inattention, hyperactivity and impulsivity of Attention Deficit Hyperactivity Disorder (ADHD), the obsessions and compulsions associated with Obsessive-Compulsive Disorder (OCD) and defiant behavior associated with Oppositional Defiant Disorder (ODD).

Of the nine boys interviewed, one interview could not be used because the participant's parent misinformed the Principal Investigator (PI) of the participant's age, which was revealed after the interview took place and therefore the participant did not meet the minimum age requirement. With respect to the eight remaining participants, 63% (n=5) were Caucasian, 25% (n=2) identified as Other and 12% (n=1) were Hispanic. The average age of the participants was 14 years, 11 months old, with an age range from 12 to 17 years old. Thirty-eight percent (n=3) of the participants were in the 11th grade,

25% (n=2) were in the 8th grade, 12% (n=1) were in 9th grade, 12% (n=1) were in 7th grade and 12% (n=1) were in 6th grade. Of the eight boys interviewed regarding their classroom settings, 63% (n=5) were in mainstreamed classrooms while receiving classroom accommodations, 25% (n=2) were in mainstreamed classrooms without receiving accommodations and 12% (n=1) were in a self-contained, special education classroom. Out of these five participants in mainstreamed classrooms while receiving accommodations, 60% (n=3) received testing modifications, 40% (n=2) utilized the Resource Room, 40% (n=2) had a classroom aid, 20% (n=1) received Occupational Therapy services and 20% (n=1) received social skills training. In order to measure the participants' current levels of tic severity, frequency, and impairment, the Yale Global Tic Severity Scale (YGTSS), a clinical rating instrument for measuring tics, was administered. Of the eight participants, 50% (n=4) scored in the more severe category, 38% (n=3) had scores in the moderate range while 12% (n=1) scored in the mild category. The mean score on the YGTSS was 28.6, with a range of scores from 5 to 50. Regarding DSM IV-TR diagnoses, 50% (n=4) of participants were diagnosed with TS only, 25% (n=2) were diagnosed with TS and OCD and 25% (n=2) were diagnosed with TS, OCD and ADHD. Accompanying these diagnoses, 38% (n=3) of participants were taking psychotropic medications to reduce their symptoms. Of the three participants taking medication, 67% (n=2) were taking 2 medications, while 33% (n=1) took 3 medications. The classes of these medications included 3 antihypertensives (42%), 2 antidepressants (29%) and 2 antipsychotics (29%).

Measures

This study utilized various measures to collect data from subjects. A brief Demographics Questionnaire (Appendix C) was given to the parent(s) to fill out while the participant was interviewed. This questionnaire requested demographic information of the participant including their age, gender and ethnic background. Further, it asked about the participant's grade level, classroom type and what, if any, types of school-based services are received. Finally, parents were asked to list any current psychotropic medications the participant was taking.

A semi-structured interview (see Appendix D), developed by the PI, was used to collect information that served as the principal data for this study. The interview included various open-ended questions about the participants' experiences with TS with respect to their family, peers, school, self-concept and view of the future. Other questions sought to obtain information about the age at which the participant was diagnosed with TS; what tics emerged first; what the participant believes are the most common misconceptions about TS; and what the participant wants others to know about their experience with TS.

The Yale Global Tic Severity Scale (YGTSS), a clinical rating instrument for measuring tics, was administered to each participant in the study. The YGTSS (Appendix E) scores provided the current levels of severity, frequency, and impairment of each participant's tics. This measure has an inter-rater reliability of 0.78 for the total motor score, 0.91 for the total phonic score, 0.84 for the total tic score, 0.80 for the overall impairment score, and 0.85 for the global severity score (Leckman, Riddle, Hardin, Ort, Swartz, Stevenson, et al., 1989).

Procedures

Participants for the study were recruited through both the Tourette Syndrome Program (TSP) at Rutgers University and the New Jersey Center for Tourette Syndrome (NJCTS), a non-profit organization that provides referrals and services for children, families and professionals dealing with TS. New clients seeking treatment at the TSP were informed of the opportunity to participate in the study when they scheduled their first appointment. During their intake interview, the clinician presented the client with the study's flyer (Appendix A) and confirmed the client's interest in participating. If the client volunteered for the study, the clinician contacted the PI with the client's contact information. Clients already receiving treatment at the TSP were also informed of the opportunity to participate in the study by their clinician. If the client volunteered for the study, the clinician contacted the PI with the client's contact information. Participants were also recruited from an e-mail advertisement (Appendix B) sent out by the NJCTS. Interested participants contacted the NJCTS and gave permission for the organization to contact the PI with the client's contact information. The study did not offer compensation for participation.

Prospective participants were contacted by the PI and informed of the study's purpose and procedures. The PI reviewed the study's inclusion criteria to confirm their eligibility. After participants confirmed their eligibility, an appointment was scheduled to conduct the in-person interview. Participants' parents signed an informed consent (Appendix F) before beginning the interview. The participants themselves signed an assent (Appendix G) after its content was fully explained by the PI and before beginning the interview. A copy of both the consent and assent were made for the participant

before the interview began. Upon the completion of the signatures, the parent was given a demographic questionnaire (Appendix C) to fill out while the participant was interviewed using a semi-structured interview (Appendix D) developed by the PI. The semi-structured interview was audiotaped for the purposes of transcription and subsequent data analysis. Finally, the YGTSS (Appendix E) was administered to participants to generate a severity score reflecting the participants' current tics.

Treatment of Data

All study participant material that included identifying information such as the consent, assent and demographic information forms were kept in a locked storage cabinet at the TSP. From here, each participant was assigned a unique numerical identification code that served as the only form of identification on participant response materials including the semi-structured interview transcript and the YGTSS. A master list of the participant's identifying information and corresponding code was kept in a password-protected document on the PI's computer, as well as the digital audio files that contained the interviews. No one other than the PI had access to identifying information. Three years following the completion of this research, all documents and files with identifying information will be destroyed.

Data Analysis

This study used a qualitative research method to gather content-rich data from adolescents with TS, describing its impact on their experiences with their family, peers, school, self-concept and view of the future. After comprehensively reviewing the TS literature and learning that the majority of studies in this area are focused on and informed by quantitative data, it seemed necessary to utilize a qualitative method that

would allow these adolescents to convey their unique stories and experiences with minimal methodological restraints. Strauss & Corbin (1990) explain a core aspiration of qualitative research:

“The aim is to give an honest account with little or no interpretation of—interference with—those spoken words or of the observations made by the researcher. While this particular group of researchers hold that the informants’ views of reality may not reflect the “truth,” nevertheless the subjects’ views are reported in the spontaneous and meaningful ways that they were actually expressed. The philosophical principle underlying this approach is that by presenting this faithful account, the researcher’s biases and presence will not intrude upon the data.”

By adopting this methodological approach, this study was designed to encourage the participants to be as honest and reflective about the questions that were posed to them to help fill in the gaps of the TS literature. This need for more qualitative research in the TS literature is supported by researchers who are actively conducting quantitative studies. Cutler et al. (2009) argue that, “future research could usefully explore the meanings that children give to TS.” Consistent with this type of thinking, this study sought to interview adolescents with TS “to gain novel and fresh slants on things about which quite a bit is already known” (Strauss & Corbin, 1990). By adding qualitative data to the robust trove of quantitative studies, this study will help to generate hypotheses to inform future research and influence clinical practice.

This study utilized grounded theory, a specific type of qualitative research methodology that was developed by Glaser and Strauss in the 1960’s (Strauss & Corbin,

1990). The main purpose of using grounded theory is to develop theory that is informed by research questions that give the researcher the flexibility and freedom to explore a phenomenon in depth (Strauss & Corbin, 1990). There are three phases of data analysis included in grounded theory: open coding, axial coding, and selective coding (Strauss & Corbin, 1990).

Open coding “is the part of the analysis that pertains specifically to the naming and categorizing of phenomena through close examination of the data” (Strauss & Corbin, 1990). The design of this study’s semi-structured interview is reflective of open coding. It sought to investigate the impact of TS on the adolescent’s experiences with respect to five specific areas: family, peers, school, self-concept and view of the future. The interview incorporated open coding into its structure as it consisted of five clusters of questions in each area to help generate the data necessary to explore the phenomenon more deeply and in a manner that captured each participant’s unique story. In doing so, five general categories and subcategories of data were already set up allowing for themes to begin emerging as each participant told their respective story.

Axial coding is the next part of the analysis where the data are put back together by making connections between the categories. This is made possible by utilizing a coding paradigm that involves conditions, context, interactional strategies and consequences. By identifying these relationships, the data will reveal pattern and themes that exist in the data set (Strauss & Corbin, 1990). This study utilized axial coding by taking the broken down data from each question in the open coding portion and putting them together using a summary sheet for each question that combined the participants’ responses to the specific question. From here, general themes began to emerge.

The final part of grounded theory is selective coding, where categories that were already identified in the axial coding phase are further collapsed under the main categories to form the core categories of the model (Strauss & Corbin, 1990). Core categories are the central phenomenon around which all other categories are integrated. In this study, categories that emerged in the axial coding phase on the summary sheet were refined and more precisely fit into core categories. These core categories revealed the main themes that emerged from the responses of the participants regarding the impact of TS on their experiences with their family, peers, school, self-concept and view of the future.

CHAPTER IV

Results

In this section, the participants' responses to each question on the semi-structured interview will be outlined. As mentioned, the interview was constructed in a deliberate manner to focus on the impact of TS with respect to five sections: family, school, peers, self-concept and view of the future. Further, the qualitative experience of having TS itself is explored and the subsections that emerged under all of these domains are reported.

The TS Experience

The first question on the semi-structured interview asked, "What is it like to have TS?" This question was deliberately open-ended, inviting the participants to describe their unique experience with TS in whatever way they chose to. Of the eight participants interviewed, 63% (n=5) reported that their experience with TS has been a negative one. One of the 17-year-old participants stated, "It's annoying. That's the only way to describe it... there's always like an itch that you can't scratch... like a mosquito bite." A 16-year-old participant described his TS experience as one of limitation, "I felt like I was being kept back by TS a bit... it was like I had to do the tic and then move on." Another 17-year-old participant described his frustration not with TS itself, but with the medication used to mitigate the tics, "It makes you feel terrible. Like sometimes it doesn't even do anything to the tics." The three other participants reported less negative experiences with TS. 25% (n=2) reported having mild cases of TS that did not adversely affect them. A 14-year-old participant reported, "It really doesn't affect me that much or I don't let it affect me." Similarly, a 13-year-old client reflected, "It can be kind of

annoying but like you have to deal with it. Like you don't have any control over it.”

12% (n=1) reported having both a negative and positive experience with TS, “Bad things are it gets in the middle of my life. The good things are I feel special about having tics.”

When asked about the age at which they were diagnosed with TS, the participants revealed a mean diagnostic age of 8 years, 10 months, with a range from 6 years old to 14 years old. All but one participant 88% (n=7) recalled their initial tic. Of these seven participants, 57% (n=4) reported a motor tic while 43% (n=3) reported a vocal tic. Among the motor tics, blinking, sniffing, head jerking and foot shaking were reported, while each of the three participants described their vocal tic as distinct, non-functional noises.

Participants were next asked if they had ever experienced stress from having TS, 75% (n=6) of the participants reported yes, while 25% (n=2) reported no. The participants offered a variety of definitions for stress. One 17-year-old participant described it as “something that worries you,” while another 17-year-old participant responded, “Well, just not happy. Just upset. Just overwhelmed.” A 12-year-old participant likened stress to, “like emotions all bottled up, like excitement bottled up.” A 13-year-old participant that did not report feeling stress described it as, “frustrated, like annoyed.”

In response to a question about the positive aspects of having TS, 63% (n=5) reported that there are indeed positive aspects. One 13-year-old participant reported that having TS, “teaches you that like there are harder things in life. Life's not, like always fair. Some people have it worse some people have it better. But like it teaches you how to deal with things.” A 17-year-old participant reported “the job I work at school, they cut

me slack because of the way I react. They won't fire me but they'll warn me cause they know I have that problem." The remaining 37% (n=3) reported that there are no positive aspects of having TS. One 13-year-old participant spoke of an injury related to his TS:

"I don't think there's any positive things about it because I'm always falling and getting hurt from it. I've got this scar right here; it was like bleeding. I think I got that last year, it was like from a door. It was from a doorknob. It was sharp and I did a tic and it just opened it (pointing to a scar on his arm)."

Participants were then asked if TS prevented them from doing things that they believe they could do if they did not have TS. Four of the participants (50%) responded no it had not, while four others (50%) reported feeling that TS had prevented them from doing things. The 13-year-old participant that injured himself from his tics stated, "It used to prevent me from doing a lot of sports especially running." A 17-year-old participant reported his pessimism about the impact of TS on his ability to get a job, "If I didn't have Tourettes, I could do more obviously. It would probably help me get a job." Another 13-year-old participant reported a negative influence on his school performance:

"Maybe having the opportunity to do a little bit better in school. Like instead of getting A's and B's maybe getting all A's or something like that. Get like really good academic scores, like I feel like I haven't been able to do that in the past few years. "

Misconceptions

The participants were asked if there were any misconceptions by the public about TS that they would like to see cleared up. Seven of the eight participants (88%) reported that were misconceptions that needed to be addressed, while one participant (12%) said

there were none. Five of the seven participants (71%) that reported the presence of misconceptions focused specifically on coprolalia, the involuntary swearing, use of obscene words or derogatory remarks that have been reported in nearly 10% of TS cases (Singer, 2005). A 17-year-old participant was adamant about changing this misconception:

“The cursing. People always think that like what’s going to happen; like I’m going to scream profanities and stuff like that. No, I’m not going to do that.

That’s always the first question I get asked. Yeah, it really gets on my nerves.”

A 16-year-old participant recalled an incident during a class biology project:

“One group had to do the neurological system and one of the disorders they chose was Tourettes. I heard a couple of people in the background say, ‘Do they say,

“Shit! Fuck!” all the time?’ I was like, ‘No they don’t.’”

A 14-year-old participant shared his experience of dealing with this misinformation and providing facts about TS to uninformed others:

“Well a lot of people think that having TS is like randomly blurting out words. It is kind of like the stereotype for TS like, I guess, because a lot of people think that. But I just told them that’s not it and if they ask why I’ll say “I have it” or if it’s just a random person will say I did some research on it, cause both of them are the honest answer.”

While most of the participants wanted the misconceptions about coprolalia cleared up, two other participants (29%) stated they want others to know the facts about TS. A 13-year-old participant wants others to know that his tics are involuntary and difficult to manage, “ Depending on the kind of Tourettes you have. For me, I have a movement

disorder. I want them to know it's really hard not to do a lot of things." Another 13-year-old participant wants others to know that living with TS is a challenge that requires a lot of work, "It's a hard life and you've got to work through it. It's not like one thing (tic); you're going to have more than one thing. You can have one thing and it can be anything."

The participants were asked if there was anything that would be helpful for people to know about what it is like for a person to have TS. All eight participants (100%) provided a variety of responses, with three participants (38%) expressing their desire for others to know how difficult it is to have TS. One 13-year-old participant stated, "That it can affect your life and it is kind of hard so like, that's really it. Just like to know how hard it can be." A 14-year-old participant expanded on this point:

"I'd like them to know maybe like how hard it is for some people. It's not hard for me, so I really wouldn't like them to be in my footsteps cause they won't really get an idea of what it's like. Maybe someone who has it harder, that needs to take medication or something like that maybe they should just like, see like it's really hard for them. Maybe they should get a different idea what it's like."

A 16-year-old participant with TS and OCD reported, "I would like for people to know that people with TS always have that temptation to do their tics and OCD rituals." One 17-year-old participant wants others to know about the natural ebb and flow of TS symptoms, "Like a rollercoaster. Like it has ups and downs. It's been good sometimes and really hard to deal with others." Another 17-year-old participant offered a simple request for those people who encounter a person with TS, "Just pretend like nothing's happening. Just treat them like they're normal."

Impact on Family

The participants were asked a series of questions about the extent to which they believe their having TS has impacted their family. In response to a question about whether or not their family understands their TS, 100% (n=8) reported yes they do. When asked about how their family came to learning about TS, 100% (n=8) reported the doctor that made the diagnosis informed and helped educate their family. Additionally, 50% (n=4) reported that their family had done research on their own to educate themselves more thoroughly on the disorder. The 14-year-old client reported, “We watched the video together as a family and we learned about it and that’s how we got our understanding.” Six of the eight participants (75%) sought treatment at the TSP which provides a parent support group, while the other two participants (25%) reported that their parents had attended an outside support group:

“My mom went to a place near (redacted) Medical Center to learn about it in a group form type of thing, where she was like with other parents that had kids with it and they talked about it and kind of learned off each other’s knowledge about it.”

Next, participants were asked about whether or not they believed that having TS caused their family to have stress. One participant did not respond to this question due to an unintentional omission by the interviewer. Six of seven participants (87%) responded yes, TS did cause family stress, while 13% (n=1) reported that it did not. The 16-year-old client that responded yes qualified his answer, “Yeah. Like they have to pick me up. We have to go here (Rutgers Psychological Clinic), get me medication and then pay for all that. So yeah, I think it did cause some stress.” A 13-year-old participant

stated, “It would be kind of like stressful, not like it wouldn’t stress them because I’m doing the tics, but it stressed them because of me not learning.” The participants that responded yes were then asked how this made them feel. The 12-year-old participant reported feeling “guilt” because his parents “are caring about me and making me do my best.” One 17-year-old participant vividly recalled his feelings when he was younger, “I was young and it got me pissed off.”

Further attempts to understand the perceived impact on the family were made by asking the participants if their family had to change in any way because of their TS. Five of the eight participants (63%) said no their family did not change, while three (37%) said yes, it did lead to change. Of the participants that responded yes, a 17-year-old participant reported that his family became more “understanding” of him after educating themselves about TS, while a 13-year-old participant reported that he and his brother miss sporting events in order for him to receive treatment. “My brother has wrestling and baseball so like it’s not his fault that he has to miss out.” This anecdote provides a helpful transition into the next question.

The participants were asked if having TS caused any conflicts with their siblings and extended family members. Four of the respondents (50%) responded yes it had, while the other four (50%) responded no it did not. For those four that responded yes, all of their reported conflicts (100%) were with their siblings and not their extended family. A 17-year-old participant reported that he was teasing his brother for the way he was eating his hamburger causing his brother to retort, “Why don’t you go to your psychiatrist?” A 13-year-old participant reported a similar instance where he teased his brother about repeating his words and his brother responded by focusing on his tics:

“Like I used to tease him about that and he got really angry and started to tease me about the tics and then we start cursing at each other and he hurts me.” While some reported teasing, one 16-year-old participant that responded no to the question conveyed a sibling’s display of empathy. “My sister was like ‘I don’t want him to have it (TS) again’ and started crying. I wasn’t sure why because she never did that before... she probably felt like she was actually feeling sadness for me because I had TS.”

Each participant was asked if their parents ever disciplined them for exhibiting a tic thinking it was a behavior done on purpose. Four of the eight participants (50%) responded yes they had been disciplined, three (38%) responded no they had not, while one (12%) could not recall either way. One 17-year-old participant reported that when he engaged in a tic, his parents “just told me to stop doing it and started getting mad, but they would never punish me.” The 16-year-old participant recalled a specific incident:

“I was in church in fifth grade and I couldn’t stop, they were like thinking I was clearing my throat, they thought I was like singing a tune from a video game, because I used to love this one video game. And they were thinking ‘Oh great. He’s singing the tune from that video game.’ That’s what they thought... They would like say stop or they would just like nudge me to make me stop. I’d say I can’t stop.”

Another 17-year-old participant reported, “Well, even after I got diagnosed my dad, he would like yell at me for doing it.”

The final question posed to each participant asked if having TS caused any problems for their family that would not be caused for a person without TS. While some of the previous answers alluded to perceptions of TS creating family stress, sibling

conflict and some participants being disciplined for exhibiting tics, all eight participants (100%) responded no. In short, having TS caused no particular problems that would not have been caused otherwise.

Impact on School

Consistent with the previous section, participants were asked various questions about the influence of TS on their school experience. First, participants were asked whether or not having TS had affected their ability to learn in class, to study and their grades. Six of the eight participants (75%) responded yes to this negative influence, while two participants (25%) responded no. All six participants (100%) that responded yes cited having difficulty concentrating either on lessons in the classroom or when attempting to study at home, resulting in worse grades for some. One 13-year-old participant stated:

“It would be harder for me to concentrate because it was a pretty loud vocal tic so I wouldn’t be able to concentrate and sometimes I would have to like leave cause I do understand that other kids have to learn too. It’s not like all about me.”

Another 13-year-old participant reported, “I don’t study because of tics, I’m always doing them and I just can’t pay attention in class.” As a result of not being able to study, “Like my grades have dropped a lot since they (tics) got worse.” A 17-year-old participant acknowledged that he would concentrate more on preventing his tics than his academics, “Like I’ll try to concentrate on stopping (the tics) more than learning.”

The impact of TS on school performance was further explored by asking each participant if they receive accommodations to help them learn. Consistent with the previous question, six of eight participants (75%) received accommodations to help them

learn better, while two participants (25%) were in mainstreamed classrooms without receiving accommodations. Of the six boys interviewed regarding their classroom settings, 83% (n=5) were in mainstreamed classrooms while receiving accommodations and 17% (n=1) were in a self-contained, special education classroom. Of the five participants in mainstreamed classrooms while receiving accommodations, 60% (n=3) received testing modifications, 40% (n=2) utilized the Resource Room, 40% (n=2) had a classroom aid, 20% (n=1) received Occupational Therapy services and 20% (n=1) received social skills training. A 14-year-old participant that does not receive accommodations reported that his tics do not factor into his learning in class to the point that “I think a few of my teachers this year don’t even know I have it (TS).”

With respect to the impact of TS on their classmates, participants were asked if a classmate has ever complained about their tics. Seven of eight participants (88%) reported that classmates have never complained about their tics, while one participant (12%) stated that a classmate did indeed complain. A 14-year-old participant spoke of his accepting classmate, “Like I said, a friend once asked me about it, ‘Why do you do that?’ I just said, ‘Obviously I can’t help it, I just do it.’ And they’re like, ‘OK.’ And they just accept it.” The 16-year-old participant spoke of a less than accepting classmate that persisted in asking, “‘Why do you keep doing that?’ Although he knew, he’d just keep on, ‘Why do you do that?’”

Next, participants were asked if they believe that their tics bother their classmates. Five of the eight participants (63%) responded no their tics did not bother their classmates. Two participants (25%) stated their belief that their classmates were bothered by their tics. A 17-year-old participant responded, “I really don’t care most of

the time” when asked how he felt about his tics bothering his peers. A 13-year-old participant that said yes responded in a different manner:

“Maybe a little bit secretly but I mean like, I’m not trying to be mean, but it would be like kind of distracting to me. Like I would be a little frustrated if someone else was doing that and I understand that because like you’re there to learn and it might frustrate them a little. Like they understand that I can’t control it.”

One participant (12%) reported that his tics bothered classmates in the past, but does not currently do so. He stated, “I remember the last time it bothered me... like sixth grade. That was like high times with tics. It probably did bother them then. Yeah, I kept on feeling they were watching me. A zoning in, trying to see what I’m doing.”

Next, participants were asked if they actively suppress their tics while at school. Six of eight participants (75%) reported that they did indeed actively suppress their tics while at school. A 17-year-old participant stated, “If I’m doing the tic, I can do the tic and pay attention (in class). But when I want to control it (the tic), then I have to just focus on one thing.” The 12-year-old participant reported on the consequences of suppressing his tics:

“It itches yeah. I usually get a tingling feeling and sometimes when I try resisting, some part of me, some part of my body starts hurting, like cramping a little bit.

It’s strange actually.”

Two of the eight participants (25%) reported that they did not actively suppress their tics. A 13-year-old participant reported that he did not do so to avoid the negative consequences of suppression, “Well, if I prevent myself from doing the tics it will

probably get saved on for later and then when I do it later it's gonna be worse." Another 17-year-old participant reported that he does not suppress his tics in school but, "I try to suppress them while I'm in public."

The final school-related question posed to the participants inquired about what the teachers and school staff members know about their TS. Seven of the eight participants (88%) reported that their teachers and school staff know of their TS diagnosis, while one participant (12%) reported that he never informed his teachers or school staff members. Out of the seven participants that informed teachers and school staff, 100% of participants reported that their parents were responsible for educating them. A 13-year-old participant stated, "I'm on a lot of medication, so they (teachers and staff) know what's going on." The 14-year-old participant said of his mother:

"She'll go to my teachers and she'll have a meeting with them and she'll say this is what he has, this is what he does; he can't help it or anything and they'll ask questions and they'll kind of like talk about it."

A 17-year-old participant that reported, "I never told them" also stated that in some classes, classmates and presumably teachers easily observe his tics. "If it's a lecture in class like history, I do it (tic) a lot."

Impact on Peers

The following section addresses the impact of the participants' TS on their experiences with peers. Of the eight participants that were asked about whether or not their peers knew of their TS, 100% (n=8) reported yes they do. When asked about how their peers reacted to their TS, the participants offered a variety of responses. Three of the eight participants (38%) reported that their peers were curious about their TS,

prompting them to ask questions of the participant. The 16-year-old participant reported of his peers, “Oh, like they would ask what I did. Like how did I experience it... I told them what I would do.” The 12-year-old participant shared a similar account, “Some of them don’t know it so they just ask why I do it.” Two participants (25%) described their peers as being understanding of their TS. A 13-year-old participant said, “They were really nice about it. They didn’t talk to me about it and they didn’t like act like I was different from them.” Similarly, a 14-year-old participant encapsulated his peers’ reaction as, “They’ll be like, ‘Oh, ok.’ Because to them, they might not know exactly what it is really. They’ll just be like, ‘Well, you have it so it shouldn’t be that bad.’” One participant (12%) reported using humor with his peers regarding his TS. “We just joke around about it. I mean it’s not like I’m getting made fun of or like bullied or anything... I kind of make it a joke myself.” The two remaining participants (25%) reported that they were teased by their peers, with some intentionally imitating their tics. This specific issue was addressed by the following question.

The participants were asked if their peers had ever teased them for having TS. Five of eight participants (63%) reported yes, their peers teased them, while three participants (37%) reported never being teased. A 17-year-old participant that reported having his tics intentionally mimicked in elementary and middle school said, “Yeah, it bothered me. That’s all. Like I didn’t know what to do.” A 13-year-old participant gave his reaction to being repeatedly teased by a peer:

“He’s like, ‘Oh, look at (participant), he’s like this (mimicking his tic).’ I got really angry and like I told you before I get pissed off really easily... so if I

wanted to punch the kid I wouldn't have done it because I would have gotten in trouble in school.”

Another 17-year-old participant reported of his peers, “Some do it (mimic his tics) on purpose, some understand. The ones that aren't my friends will do it on purpose.”

A similar, yet more generic question was next posed to the participants.

Specifically, participants were asked if they thought having TS caused them to be treated differently by their peers. Five of the eight participants (63%) stated no, while two participants (25%) said yes and one participant (12%) said yes in the past, but not currently. The 12-year-old participant that considered being treated differently as a positive, “I think I'm respected more. They were nicer to me than they could have been.” The 17-year-old participant described his being treated differently as a negative experience, “I've been treated differently. Mistreated.” A 13-year-old participant that reported being treated differently in the past, but not currently, said his peers would ask “Are you ok?” out of concern when he engaged in tics. “I just told them to treat me fine, like treat me normal” and he reported that his peers have obliged.

The participants were last asked about potential social benefits to having TS. First, participants were asked if they thought that having TS ever helped them make friends. Seven of eight participants (88%) reported that TS did not help them make friends while one participant (12%) said having TS did help him make friends. This participant reported that he had made multiple friends at Camp Bernie, a weekend retreat for kids with TS and their families supported by the NJCTS. Next, participants were asked if there were any positive social aspects to having TS. Six of seven participants (86%) stated there were no positive social aspects to TS, while one participant (14%) said

yes. One respondent did not answer this question due to an unintentional omission by the interviewer. Speaking about the positive aspects of meeting others with TS, a 17-year-old participant said, “I mean like meeting other people with it. Like that’s good. Like just to see like the difference between me and other kids that had it.”

Impact on Self-Concept

The following cluster of questions sought to identify each participants emerging self-concept and to learn to what extent, if any, that having TS has impacted its formation. From the outset, the eight participants were asked to describe what they like about themselves and 100% of participants were able to identify positive attributes. Four of the eight participants (50%) described themselves as “nice” and “friendly.” One 13-year-old participant offered, “I feel that like I’m nice to people... I’m friendly, like I’ll talk to anyone, like I don’t really care. Like I wouldn’t treat you differently either.” Another 17-year-old participant offered a similar sentiment, “I’m a nice person I guess... I don’t know, I have a good heart, I guess (laughs). I don’t want to be cocky about anything.” Three of the eight participants (38%) identified themselves as possessing a hard work ethic, with one 17-year-old participant stating, “I just want to be the best that I can.” One participant (12%) identified his intellect as a positive trait:

“I like that I can understand things easily, cause I hate not understanding things, so I’ll try and look it up cause I’ll ask a question and some people will be like ‘I have no idea’ and I’ll be on the computer for three and a half hours just researching things.”

The 16-year-old participant identified multiple positive attributes about himself, “I’m a pretty interesting person. I like history and I work hard as much as I can. Like I do push

myself for academics, sports. I try to figure out things like if I find a story, I like to go deeper into it.” Additional positive attributes offered by the participants included adjectives such as “creative” and “athletic.”

The next question sought to learn if there was anything that the participants wished they could change about themselves. Five of the eight participants (63%) reported yes, they had something they wanted to change, while three participants (37%) did not seek any changes. Of the five participants that wanted to make a change to themselves, three (60%) of them sought to rid themselves of TS. A 13-year-old participant bluntly asserted, “I’d probably change that I don’t have Tourettes.” A 17-year-old participant spoke pointedly about his belief that not having TS would improve his comfort level in social situations around new people, “I’d be more comfortable... I avoid... I feel funny talking to people.” The 16-year-old participant had multiple requests for self-change, “I wish I could obviously be thinner and have that power to eat anything I want and to not gain a pound.” He added, “One thing I would change about myself would be to be more outgoing.... and sometimes I wish I could know when to talk to people because sometimes I think I should not talk to them and then talk to them.” The 14-year-old participant that did not seek any personal change summed up his reasoning, “It doesn’t matter if I have TS or I don’t. I wouldn’t get rid of it or anything. It’s not bothering me. So if it’s not broken, then why fix it? That’s kind of my mentality.”

Participants were asked if having TS has impacted their view of themselves in any way. Five of the eight participants (63%) reported that TS had no impact, while three participants (37%) reported yes it had impacted their self-view. Of the three participants that said yes, two (67%) reported that TS has had a positive impact. A 13-year-old

participant reported that his having TS makes him feel more “creative” and “unique.”

Another 17-year-old participant spoke of the positive impact of TS in terms of helping him develop resilience:

“It’s just kind of made me a stronger person I guess, like having to go through... like it used to be really bad. And I don’t know, like conquering that and like it not being so bad anymore, like having the tics bad anymore... I don’t know. I feel like I can over come it. “

One participant (33%), a 13-year-old, reported that TS has had a negative impact on his self-view while recalling a vivid memory at a sporting event:

“Well actually, I feel like, I remember the first wrestling match I ever had I felt like, cause I did the tics, well we did laps, I felt like I didn’t deserve to be part of the wrestling team.”

Impact on the Future

The following section aspired to learn the future plans of the participants and to ascertain whether or not TS has impacted these plans in any way. All eight participants (100%) reported having plans for the future, with a range of goals from the immediate future to the distant future. A 17-year-old participant spoke of his occupational aspiration, “I would like to own my own business for like a landscaping business and do like landscaping architecture.” Currently, he has a small side business and reported, “We actually have 15 houses... right now, we mow the lawn weekly and clean up the houses. We’ve done a couple of jobs, mulching and rocks.” Four clients (50%) reported their specific aspiration to attend college. A 13-year-old participant reported, “I really want to

go to Harvard University. I really want to become a heart doctor. Yeah, it's one of my big goals." The 14-year-old participant had similar aspirations:

"My plans for the future are to go high school. Next year I'll be in the high school and then go to college and learn a science of something, whether it be computer science or just any type of science really. That will probably be like a better decision in the future where I'll kind of know what I want to do. But it will definitely be in the science field."

In addition to attending college, another 13-year-old participant reported of his plans, "Try to do well in school, be nice to people and have a lot of friends." The 16-year-old client had a more particular agenda for the near and distant future:

"My plan for the future is to get a girlfriend, get into graphic design, lose about twenty pounds and make a library of my favorite books. This is my dream of when I grow old and wrinkly, I'll have a massive library in my house."

Interestingly, this participant was one of four participants that reported "graphic design" as their future occupation.

With all eight participants reporting having plans for their future, they were asked if having TS impacted it any ways, positive or negative. Six of the eight participants (75%) reported that TS did not impact their plans for the future. The 13-year-old participant, and aspiring cardiologist, conveyed his optimism for his future with TS based on the story of a surgeon with TS:

"No, because I remember one, I think Dr. (redacted), he told me and I watch movies where doctors have Tourettes and they perform surgery. So everybody had something. I guess I'll have to deal with it."

A 17-year-old participant offered this perspective, “I mean if I ever become famous or something, I’ll be known as that person with Tourettes, I guess.” Two participants (25%) reported that TS did in fact impact their plans for the future. This 17-year-old participant said of the impact, “It’s usually negative. Like I said, more doors are closing for me.” The 12-year-old participant suggested that his future may be adversely impacted by TS as he related a story about a friend with TS, “Well people might reject people with TS... this guy I know is trying to get a job and he has TS and they won’t accept him... because he made loud noises and he had TS.”

CHAPTER V

Discussion

This study investigated the qualitative experiences of adolescent males with TS across multiple domains. Specifically, it examined the impact of TS on these adolescents' experiences with their family, peers, school, self-concept and view of the future. This chapter discusses themes that emerged from the adolescents' responses to questions pertaining to the overall TS experience, misconceptions about TS, its impact on the family, peers, school, self-concept and view of the future. Emergent themes from these interviews included: more adverse experiences with TS than positive ones, pervasive misconceptions about TS symptoms, a desire for more understanding of TS by the public, understanding and supportive families experiencing increased stress, academic challenges requiring accommodations, the active suppression of tics in school and in public, complex social interactions with peers, overall positive self-concepts impacted minimally by TS, and a positive outlook on the future, fueled by resilience. The study's limitations and implications for future research are discussed in this chapter.

Adverse Experiences

With the intention of capturing the essence of the TS experience in an unbiased manner, the first question of the semi-structured interview simply asked the participants, "What is it like to have TS?" Answers to the question revealed that for the majority of participants, the experience has been challenging. Responses centered on the TS experience being "annoying," with the persistent feeling of the premonitory urge likened to a mosquito bite that can never be itched. Other responses describe having TS as one of "limitation," with a participant feeling like they had "to do the tic and then move on."

Such responses suggest that to have TS is to be held captive by its temporary command over one's body and mind before being able to proceed with any volitional act. It is a constant companion that serves as a reminder that control over one's body and mind will be a battle.

Frustration and challenges posed by TS were not limited to the experience of the tics themselves, but also to the psychotropic medications that have been enlisted to quell them. A participant focused his frustration with TS on the side effects of the medications he took, "It makes you feel terrible. Like sometimes it doesn't even do anything to the tics." This particular participant had taken multiple antihypertensive, antipsychotic and antidepressant medication for his tics, ADHD and OCD. "I've been through so many like I forget what they were." Side effects shared among these distinct groups of medication include: dizziness, drowsiness, headache, decreased appetite, nausea, vomiting and constipation among others (PubMed Health, 2012). This participant has since stopped taking all medication, as he believes the costs do not outweigh the benefits.

Stress was another common experience that challenged these participants with TS. With a wide range of definitions for stress including, "something that worries you," being "overwhelmed," "upset," and having "emotions all bottled up," participants experienced stress related to TS in experiences with their family, peers, at school and other social settings that will be highlighted in subsequent sections. The stress that is caused by TS is a double-edged sword since stress itself is a well-known trigger for exacerbating tics (Leckman, 2002; Singer, 2005). This fact about TS is critically important in treating TS, by helping bring awareness to those stressors and emphasizing stress reduction as a part of treatment.

For some participants, their experience with TS has been restrictive, preventing them from doing things they believe they otherwise could do if they did not have TS. For instance, one participant did not play sports for a certain period of time as he dealt with a tic that caused him to frequently fall to the ground. Another participant felt that his grades were lower than they could have been since he had not been able to concentrate on class material due to the distraction of his tics. One final participant, who does not plan on attending college, stated his belief that if he did not have TS, he would be able to get a better job in the future. Of the four participants who reported being held back, three were between the ages of 12 and 13 and the 17 year old outlier was the lone student in special education. It seems sensible that younger adolescents that have less experience with managing their TS and an adolescent with a documented learning disability would find the TS experience to be one of restriction.

Pervasive Misconceptions

Having barely finished asking the participants if there were any misconceptions about TS they wanted to be cleared up, their answers were quick and decisive. The majority of participants immediately seized the opportunity to identify coprolalia as being the most egregious misconception. Again, coprolalia is the involuntary swearing, use of obscene words or derogatory remarks reported in nearly 10% of all TS cases (Singer, 2005). Participants' reactions to these misconceptions ranged from experiencing anger, "That's always the first question I get asked. Yeah, it really gets on my nerves." to irritated clarification, "I heard a couple of people in the background say, 'Do they say, 'Shit! Fuck!' all the time?' I was like, 'No they don't.'" These emotional reactions are

very understandable considering how often they have been in the position to either answer or educate this popular misconception.

It is not difficult to identify why such pervasive misconceptions about coprolalia occur when considering how the media portrays TS. For instance, a 2007 South Park episode entitled, “Le Petit Tourette” has one of its main characters, Eric Cartman, feign having TS and coprolalia for his own comic relief. He strolls around the school hallways and sits in his classes arbitrarily cursing and directly insulting his peers, all while sheepishly blaming it on TS. When one of his close friends confronts him on faking the coprolalia, he admits to doing so as it is, “a magic cloak that makes me impervious to getting in trouble” (Le Petit Tourette, 2012). Similarly, a 2002 “Curb Your Enthusiasm” episode entitled, “The Grand Opening” centers on a chef with TS having an outburst of coprolalia in front of a packed dining room on the restaurant’s opening night. The crowd reacted with stunned silence. In a state of panic, Larry David blurts out random profanities to provide cover for the chef and many patrons join him with their own unique array of profanities. In the end, the entire room is a buzz with laughter and Larry is impressed with his spontaneous intervention (HBO, 2012).

Both of these shows are staples of American comedy with South Park in its 15th season and Curb Your Enthusiasm having completed its 8th. They reach millions of people with each viewing and subsequent viewings of particular clips on the Internet. Their respective plotlines shape the public perception of TS, with their heavy emphasis on coprolalia, misrepresenting what a more typical TS experience is like. While the “Curb Your Enthusiasm” episode provided no factual information about TS, the “South

Park” episode did so, much to the surprise of the national Tourette Syndrome Association (TSA):

“Despite our pre-airing trepidations, we do concede that the episode was surprisingly well-researched. The highly exaggerated emphasis on coprolalia notwithstanding, for the attentive viewer, there was a surprising amount of accurate information conveyed. The scripted input from parents, a neurologist, peers and the therapy session with the "TS children’s support group" all served as a clever device for providing these facts to the public” (TSA, 2007).

While acknowledging the well-researched episode, the TSA expressed concern over the consequences it could cause for children with TS:

“No doubt this South Park episode did generate increased national awareness about TS. Nevertheless, we are very concerned that school children with TS will be mocked and even bullied by insensitive peers who may have seen the program” (TSA, 2007).

Despite the efforts of the creators of South Park to have a more informed comedy, the majority of participants in this study have experienced more of the misinformation about TS and stress associated with it that the TSA expressed concerned over. Thus, it is not surprising that nearly all of the participants in this study expressed a desire for more understanding about TS.

Increased Understanding

Despite each participant’s unique experience with TS, there was a universal desire among them for an increased understanding of the disorder by the public. At the heart of this appeal for more understanding was the desire for both the facts about TS and

individual experiences that accompany it to be recognized. With respect to facts, some participants insisted on the public needing to recognize the involuntary nature of tics: “I want them to know it’s really hard not to do a lot of things.” Other facts the participants wanted clarified included the natural ebb and flow of tics, with one participant likening it to “a rollercoaster,” as it has “been good sometimes and really hard to deal with others.” Another participant urged for a better understanding of the fact that comorbid disorders often accompany a TS diagnosis, as some “people with TS always have that temptation to do their tics and OCD rituals.” Along these lines, there was also a clamor for more understanding of how difficult it can be to live with TS. One participant wanted other people to know “how hard it can be” to live with TS. Another humble participant corroborated this point:

“I’d like them to know maybe like how hard it is for some people. It’s not hard for me, so I really wouldn’t like them to be in my footsteps cause they won’t really get an idea of what it’s like.”

This strong desire for the dissemination of facts and acknowledgement of the difficulty of living with TS by the public seemed to be at the core of this group’s wishes. They sought to have their actual experiences validated rather than overlooked for the sensationalized stereotypes portrayed in the media.

Supportive Families with Stress

While the participants clamored for more understanding about their TS from the public, there was no shortage of understanding by their families. Every participant in the study agreed that their family understands their TS. This understanding has been cultivated by families working with the doctors that diagnosed and treated their child’s

symptoms and conducting individual research to further educate themselves on TS. In fact, all of the participants' parents attended a TS support group either through the TSP or through another organization, and most were involved in weekly outpatient therapy. It should be acknowledged that these parents had their children in treatment at the TSP prior to voluntarily enrolling them in this study and were supportive of their treatment. Thus, their level of understanding of TS and commitment to its treatment may not be reflective of a treatment-naïve or treatment-avoidant parent. It is important to note that the participants were never in treatment with the PI and their treatment at the TSP was completely independent of their participation in the study. This understanding of their child's TS and pursuing treatment to mitigate its impact is essential when considering the literature which demonstrates that parents of children with TS have been shown to have more marital conflict, substance abuse and poorer quality interactions with their child (Storch et al., 2007). The stress uniquely associated with TS has also been shown to have more of a negative impact on families than those with a child that has diabetes or asthma (Bawden et al., 1998; Cooper et al., 2003). The adverse impact of the TS-related stress on parents is also felt by the child.

The majority of participants were sensitive to the perceived stress they believed their TS had caused their parents. Some participants highlighted examples of parental stress as having to be taken to therapy, the cost of paying for therapy and the medication that helps to reduce their tics. At the same time, others believed their parents to be stressed because of the academic struggles they endured due to the interference of tics. This experience of stress led to half of the participants reporting that their parents became frustrated and disciplined them for exhibiting a tic that they believed to be a behavior

done on purpose. Several participants described incidents in which parents would get “mad” or “yell” at the expression of tics and implore them to “stop,” while others experienced embarrassment in public places. The parents of one participant thought he was intentionally humming in church and bringing unwelcome attention upon them, despite telling his parents, “I can’t stop.”

Participants were candid with their feelings citing both “guilt” and “anger” as a consequence of feeling that in some way their TS had burdened their parents. Exploring these negative emotions in therapy could be helpful in teaching adolescents the distinction between appropriate and inappropriate guilt and validating their anger at having TS. Similarly for the parents, therapy might be helpful in normalizing their frustration with their child’s tics and provide them with a contained and appropriate place to vent their anger. In doing so, both the adolescent and their parent might reduce their overall level of stress, reduce the strain on their relationship and escape the foreboding fate of the research findings.

While all participants identified their immediate and extended family members as supportive and understanding of their TS, half of these participants reported having TS-related conflicts with their siblings. Interestingly, participants all gave examples in which they teased their siblings first, and in turn, their siblings teased them back, focusing on their tics. An illuminating example of how conspicuous a target TS can be for teasing was given by a 17-year-old participant who began teasing his younger brother about the way in which he ate his hamburger. His brother replied curtly, “Why don’t you go to your psychiatrist?” Clearly there is no relationship between eating a hamburger and psychiatry, yet the younger brother was able to quickly identify a button that he could

successfully push to tease his instigating older brother. Research has demonstrated that siblings have been found to tease to express affection, promote playful interactions, and as a means of building or maintaining group membership (Voss, 1997). Thus, this button-pushing strategy often employed by siblings in teasing each other is not unique to the TS population.

Academic Challenges

For the majority of participants, the academic experience was made more difficult by having TS. Each participant that endorsed having these difficulties cited having difficulty “concentrating” in the classroom and studying at home, resulting in lower grades for some. Participants stated, “It would be harder for me to concentrate because it was a pretty loud vocal tic;” “I don’t study because of my tics, I’m always doing them and I just can’t pay attention in class;” and “I would do the tic and wouldn’t catch what the teacher said. Also it took me a long time to do my homework.” Taken as a whole, these statements capture the core of the daily struggles participants endured inside and outside of the classroom with TS.

It is important to highlight the wording of the question posed to the participants, which asked specifically if having TS had affected their ability to learn. This is crucial because even though research has demonstrated that TS interferes with one’s ability to learn effectively (Comings et al., 1990; Ferrari et al., 1984; Hagin & Kugler, 1988), there is also ample research that suggests that the intellectual and academic problems of children with TS and ADHD is due to ADHD symptoms (Dykens et al., 1990; Sattler, 1988; Shaprio et al., 1988). This deliberate wording of the question was designed to have

the participants in the study with a comorbid ADHD diagnosis (n=2) answer it with respect to TS only. Both did so successfully.

As most of the participants acknowledged significant academic struggles in connection with TS, nearly all of these participants reported receiving classroom accommodations to facilitate learning. These accommodations include testing modifications, using the Resource Room, having a classroom aid, Occupational Therapy and social skills training. These facts support the research suggesting that TS alone is impairing in the classroom, making accommodations an essential educational intervention. It is important to give credit to each parent that has pursued these necessary supplemental services for their child's education, as getting approval from the school board can be a challenging endeavor, especially taking into consideration that many school districts are confronted by budget cuts.

Active Suppression of Tics

A less visible challenge to the student with TS is choosing whether or not to actively suppress their tics in the classroom. Again, tic suppression is the temporary and willful suppression of tics (Himle & Woods, 2005). The majority of participants reported actively suppressing their tics in school and highlighted the various consequences of doing so. One participant described having to choose between attending to class material and controlling his tic, as he could not do both: "If I'm doing the tic, I can do the tic and pay attention (in class). But when I want to control it (the tic), then I have to focus on one thing." One can easily imagine the stress associated with having to repeatedly choose between suppressing a tic and attending to class material throughout the day and the

strain it places on effective learning. This difficult choice makes it even more understandable why classroom accommodations are necessary.

An additional consequence of tic suppression is the physical discomfort associated with it: “I usually get a tingling feeling and sometimes when I try resisting, some part of me, some part of my body starts hurting, like cramping a little bit.” For those children who are socially conscious of their tics (“Yeah, I kept on feeling like they were watching me.”), this presents another difficult choice: either endure physical discomfort via suppression or deal with the anxiety of expressing your tic in a classroom or public setting.

A final consequence of tic suppression is the fear that it will cause a rebound effect, a paradoxical increase in tics after efforts to suppress them cease. While this rebound effect is debated by researchers (Marcks, et al., 2004), there is no doubt that it is experienced by adolescents with TS. One participant echoed this fear, “Well, if I prevent myself from doing the tics it will probably get saved on for later and then when I do it later it’s gonna be worse.” This final consequence adds another wrinkle to the tic suppression dilemma, namely that its temporary benefits may exacerbate tic expression later on. When taken as a whole, these adolescents report that tic suppression has made learning in the classroom more challenging, has caused physical discomfort and has led to rebound effects resulting in more tics.

Complex Peer Interactions

For all of the participants, social interactions with their peers have been made more complex by having TS. Peer reactions to their TS have been mixed. The majority of peers showed curiosity, “Some of them don’t know it so they just ask why I do it” and

others demonstrated understanding, “They were really nice about it. They didn’t talk to me about it and didn’t act like I was different from them.” Yet, the majority of participants also experienced peers teasing and intentionally mocking their tics. Reactions to this teasing ranged from irritation, “Yeah, it bothered me. That’s all.” to intense anger, “I got really angry... I wanted to punch the kid. I wouldn’t have done it because I would have gotten in trouble at school”. These same reactions to bullying have been supported in the literature. Cutler et al. (2009) captured one child with TS reacting to bullying, “I just end up kicking them or something, as I just get really angry... And I end up falling out with them.” One participant succinctly encapsulated this complex peer experience, “Some do it (mimic his tics) on purpose, some understand. The ones that aren’t my friends will do it on purpose.”

While some parts of the social experience with their peers are complex, other parts are more straightforward. Specifically, there is little social benefit from having TS. Participants answered questions in this domain quickly and with assurance. The vast majority reported that having TS did not ever help them to make friends and further, they believe there are no positive social aspects to having the disorder. This social difficulty is well documented in the literature as children with TS have been shown to be at high risk for poor peer relationships than children with other chronic diseases and having more difficulty with socialization compared to other areas of adaptive functioning (Bawden et al., 1998; Carter et al., 2000; Dykens et al., 1990). One area of research that may help improve these difficult peer interactions is preventative disclosure. This strategy has been shown to help prevent the stigma that people with TS face in social situations by disclosing information about their condition before others can form a negative impression

(Marcks et al., 2007). Such an intervention may help peers empathize with the TS experience and reduce the unnecessary and harmful social aggression that the majority of participants have experienced.

Positive Self-Concept

Despite the many challenges that confronted these participants, all of them were able to easily identify positive self-attributes that contribute to their overall self-concept. Parker (2010) describes self-concept as the total picture of how an individual perceives or understands him or herself, his or her attributes and how an individual perceives others' perceptions of him or her. Half of the participants described themselves using the adjectives "nice" and "friendly" ("I feel that like I'm nice to people... I'm friendly;" "I'm a nice person I guess... I don't know, I have a good heart"). Several other participants described themselves as possessing a hard work ethic ("I work hard as much as I can. Like I do push myself for academics, sports"), while other participants used "creative" and "athletic" to describe their abilities. These positive attributes serve as part of the subcategories of a healthy global self-concept (Shavelson & Bolus, 1982), a foundation that bolsters a positive view of the self.

When the participants were asked if there was anything they wish they could change about themselves, a minority of participants expressed their desire to get rid of their TS. Reasons for this included the stress of tics and a wish to feel more comfortable in social settings around new people, "I'd be more comfortable... I avoid... I feel funny talking to people." However, the majority of participants did not wish to rid themselves of TS, with one participant offering, "It doesn't matter if I have TS or I don't. I wouldn't get rid of it or anything. It's not bothering me. So if it's not broken, then why fix it?"

That's kind of my mentality.” This mentality the participant speaks of views TS as merely a part of their self-concept and not the defining feature. Further, it allows for other healthy attributes (as mentioned above) to flesh out the skeleton of the emerging self-concept, allowing for an identity that goes beyond the confines of TS. Parents, teachers and peers are instrumental in shaping an adolescent's self-concept through their feedback, and in supporting their positive attributes, they also diminish the influence of TS on self-concept (Harter, 1999).

Consistent with not wanting to get rid of their TS, the majority of participants stated that having TS did not impact their view of themselves in any way. In fact, two participants reported TS impacted them in a positive way, with one feeling “unique” and “creative” and the other feeling more resilient:

“It's just kind of made me a stronger person I guess, like having to go through... like it used to be really bad. And I don't know, like conquering that and like it not being so bad anymore, like having the tics bad anymore... I don't know. I feel like I can over come it. “

In building on the ways in which the disorder has made them more unique, creative and resilient, these participants enhanced their self-concept. As the literature demonstrates, individuals with a high self-concept have lower incidences of behavior problems, inattention, depression, a history of negative life events and report higher attachments to their parents (Parish & Parish, 1991). Collectively, these adolescents with TS have persevered in the face of daunting obstacles and constructed resilient self-concepts that propel them toward a brighter future.

Optimistic Outlook on the Future

Built on a foundation of resilient self-concepts, the majority of participants were optimistic about their future. In fact, every participant had plans for their future, with some in the immediate and others in the distant future. These plans varied with half of the participants identifying the goal of attending college, “I really want to go to Harvard University. I really want to become a heart doctor;” “go to college and learn a science of something... that will probably be like a better decision in the future where I’ll kind of know what I want to do.” One participant that is planning on attending college has additional long-term goals of trying, “to do well in school, be nice to people and have a lot of friends.” Other participants that did not plan on attending college had a clear path toward the future. Specifically, a 17-year-old participant reported wanting to own a small business and is actively working toward it:

“I would like to own my own business for like a landscaping business and do like landscaping architecture. We actually have 15 houses... right now; we mow the lawn weekly and clean up the houses. We’ve done a couple of jobs, mulching and rocks.”

The optimism displayed by the majority of participants has solid roots in the literature. Kumpfer’s (1999) findings that dispositional optimism is essential to positive adjustment, especially in the contexts of stress and adversity relates well to the travails successfully overcome by these participants with TS. In viewing TS as part of their lives but not the defining feature, these participants have constructed individual paths toward their future goals of leading satisfying lives. For instance, half of the participants are seeking professional futures in graphic design. They reported a palpable passion for computer

graphic and video game design that is now a vibrant industry and a plausible career path. This passion is critical as higher levels of satisfaction in youth are positively related to interpersonal relations, positive relationships with parents and hope, and negatively related to depressive symptoms and anxiety (Gilman & Huebner, 2003). The findings of Ey et al. (2005) that show how optimism longitudinally predicts lower levels of depression and externalizing problems resonate for some of these participants who successfully use an optimistic outlook to shape the narrative of their future. The aspiring Harvard cardiologist has watched, “movies where doctors have Tourettes and they perform surgery. So everybody has something.” This use of an inspirational role model that has defied the odds can be instrumental in helping this 13-year-old participant realize his future with TS. While role models guide some participants, others seek to become role models themselves. This is the case for the 17-year-old participant with serious aspirations for a future in graphic design, “I mean if I ever become famous or something, I’ll be known as that person with Tourettes, I guess.” By constructing resilient self-concepts as result of the challenges posed by TS and embracing an optimistic worldview, these inspirational adolescents have forged individual paths toward bright futures.

Limitations of the Study

This study has several limitations that require attention when interpreting its findings. First, the study used a small sample (n=8), which requires discerning readers to caution themselves from generalizing these findings to the broader population. Along with the small sample size, having only adolescent male participants does not capture the entire TS experience for adolescents, limiting its generalizability. The lack of female participants in the study was not related to the study’s design or skewed recruiting on the

investigator's part. The lack of females with TS in the clinical population is consistent with the research that shows how males are diagnosed three to five times more than females in clinical settings (DSM-IV-TR, 2000). In addition to the small and exclusively male sample, the participants were composed of an entirely clinical sample, with the majority of participants being treated through the Tourette Syndrome Program (TSP) and a minority of participations having involvement with the New Jersey Center for Tourette Syndrome (NJCTS). Participants in clinical samples tend to have more impairing symptoms than do those in community samples and thus, are more likely to seek out treatment. It is possible that the experiences of TS reported in this study are reflective of more impairing cases and may not be truly reflective of the general population.

Investigator bias is another limitation of this study that warrants attention. The PI designed the semi-structured interview based on the existing research findings and clinical experiences in working with children and adolescents with TS, along with their families. In addition to designing the interview, the PI conducted all of the interviews, completed the data analysis and interpreted the data. Due to the considerable amount of time and involvement devoted by the PI to creating and implementing the study and interpreting its data, the study's findings should be interpreted with caution and considerate of the influence of investigator bias.

Implications for Future Research

From the outset, the aim of this investigation has been to develop a deeper understanding and appreciation of the unique subjective experiences of adolescents with TS. By allowing room for these experiences in this critical developmental period to go beyond tics and their management, this investigation attempted to understand how these

daily experiences with the disorder impact critical experiences with their family, peers, school, self-concept and view of the future. The paramount goal of this investigation has been an appeal to the scientific community researching TS to recognize the importance of qualitative research in understanding what it means to live with TS and designing experiments that broaden this part of the literature. For instance, such research could investigate more thoroughly the critical factors that help contribute to a positive self-concept and an optimistic view of the future that was evidenced by participants in this study, despite the stress and adversity caused by TS across psychosocial domains. Once identified, these critical factors can be used as a vital component of treating TS and augmenting the existing, excellent research findings on the etiology of TS, medication for its symptom reduction and behavioral therapies to manage the expression and impact of tics. By increasing the qualitative research on TS, the true experiences of adolescents and others with the disorder will be more thoroughly understood and appreciated and treatment will become more holistic.

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Are you an Adolescent with TS?

Do you want to participate in a new study about your experiences with TS?

Males and females with TS, ages 12-17, are being recruited for a doctoral dissertation study at the Graduate School of Applied and Professional Psychology (GSAPP) of Rutgers University. Participants will be interviewed about their experiences with their family, peers, school, self-concept and view of the future. If you are interested, please notify your clinician and they will contact the study's Principal Investigator, Rob Happich, Psy.M.

Participants with developmental disabilities or a serious psychiatric disorder (e.g. bipolar disorder, psychosis) will not be included in the study. Interviews will last approximately 90 minutes and will be audio taped. Confidentiality will be ensured. There is no compensation for participating in this study.

Study on Adolescents with TS
Rob Happich, Psy.M.
Graduate School of Applied and Professional Psychology
Rutgers University
Piscataway, NJ 08854
(732) 445-6111 ext. 918

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Males and females with TS, ages 12-17, are being recruited for a doctoral dissertation study at the Graduate School of Applied and Professional Psychology (GSAPP) of Rutgers University. Participants will be interviewed about their experiences with their family, peers, school, self-concept and view of the future. If you are interested, please contact the New Jersey Center for Tourette Syndrome (NJCTS) at 908.575.7350 or by email at info@njcts.org.

Participants with developmental disabilities or a serious psychiatric disorder (e.g. bipolar disorder, psychosis) will not be included in the study. Interviews will last approximately 90 minutes and will be audio taped. Confidentiality will be ensured. There is no compensation for participating in this study.

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Rob Happich, Psy.M.
Graduate School of Applied and Professional Psychology
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APPENDIX C

BASIC INFORMATION

Participant's Name: _____ Date: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Contact- Home Phone: _____ Cell Phone: _____

Work Phone: _____ Email: _____

Sex: M F Date of Birth: _____ Age: _____

Person completing this form: _____

Relationship to participant: _____

Race: _____

Living Situation: _____

- 1 = White
- 2 = African American
- 3 = Hispanic
- 4 = Asian
- 5 = Native American
- 6 = Pacific Islander
- 7 = Other

- 1 = White
- 2 = African American
- 3 = Hispanic
- 4 = Asian
- 5 = Native American
- 6 = Pacific Islander
- 7 = Other

What is the participant's current grade in school? _____

Has the participant ever been asked or required to repeat a grade? ___ Yes ___ No

If so, please explain: _____

Is the participant currently: ___ Mainstreamed ___ 504 Classification ___ Special Education

What services does the child currently receive in school? Please check all that apply:
___ Speech Therapy ___ Occupational Therapy ___ Physical Therapy ___ Social Skills
___ Resource Room ___ Testing Modifications ___ Classroom Aid ___ Vocational Training
___ Pre-vocational Training ___ Other

What services does the child currently receive at home or outside of school? Please check all that apply:

Speech Therapy Occupational Therapy Physical Therapy
 Family Therapy Individual Psychotherapy Tutoring (specify) _____

List all current medications that the participant is taking:

Medication	Target Symptom	Dose	Date Started

APPENDIX D

Interviewer instructions to be read aloud to subject: “Please answer the following questions as honestly as you are willing to and take your time in thinking about your response.”

1. What is it like to have TS?
2. Have you ever experienced stress from having tics? How do you define stress?
3. What are the positive aspects of having TS?
4. At what age were you diagnosed and what were your initial tics?

In what way does TS impact this adolescent in their school setting?

5. Has TS affected your ability to learn in class, to study or your grades?
6. Are there any accommodations that have been made to help you learn?
7. Has there ever been a complaint about your tics from a classmate?
8. Do you think that your tics bother your classmates? If so, how did that make you feel?
9. Do you try to suppress your tics while at school? What happens when you do this (any consequences)?
10. What do your teachers and school staff members know about your TS? Who educated them?

How does TS impact this adolescent in their family?

11. When did your family learn of your having TS?
12. Did your parents ever discipline you thinking that your tic was a behavior done on purpose?
13. Do you believe that your tics cause your parents stress? How does that make you feel?
14. Has your family had to change in any way because of your tics? If so, how?
15. Does having TS cause any problems in your family that wouldn't be caused for a person without it?
16. Does your family understand your TS and if so how did they learn about it? Did you teach them? Did they learn from a doctor?
17. Has your TS caused any conflicts with your siblings/extended family?

In what ways does TS impact this adolescent with their peers and social situations?

18. Do the kids at school and in your social circle know that you have TS?
19. How do they react to you? What do they say/do?
20. Have you ever been teased?
21. Do you think having TS caused you to be treated differently by your peers? How so?
22. Do you think having TS has ever helped you make friends?
23. Have there been any positive social aspects to having TS?
24. Has it prevented you from doing things that you feel like you could do if you didn't have TS? (making new friends, try out for sports or clubs, apply for a job or anything else)

What has been the impact of TS on this adolescent's self-concept?

25. What do you like about yourself?
26. Is there anything you wish you could change about yourself?
27. Does having TS impact your view of yourself in any way? How?

How has having TS impacted the adolescent's plans for their future?

28. What are your plans for the future?
29. Has TS impacted your plans for the future in any ways, positive or negative?

Final Questions

30. What are some misconceptions about TS that you would like to see cleared up?
31. What, if anything, would you like people to know about what it is like for a person with TS?
32. Have you ever been diagnosed with another disorder? Rank them in order based on associated distress.

APPENDIX E

Yale Global Tic Severity Scale (YGTSS)

PATIENT ID #:	TODAY'S DATE :	/	/
RATER:			

MOTOR TIC SYMPTOM CHECKLIST

Description of Motor Tic Symptoms. Motor tics usually begin in childhood and are characterized by sudden jerks or movements, such as forceful eye blinking or a rapid head jerk to one side or the other. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and/or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Although any part of the body may be affected, the face, head, neck, and shoulders are the most common areas involved. Over periods of weeks to months, motor tics wax and wane and old tics may be replaced by totally new ones.

Simple motor tics can be described as a sudden, brief, "meaningless" movement that recurs in bouts (such as excessive eye blinking or squinting). Complex motor tics are sudden, stereotyped (i.e., always done in the same manner) semi-purposeful (i.e., the movement may resemble a meaningful act, but is usually involuntary and not related to what is occurring at the time) movements that involve more than one muscle group. There may often be a constellation of movements such as facial grimacing together with body movements. Some complex tics may be misunderstood by other people (i.e., as if you were shrugging to say "I don't know"). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., "I have hay fever that has persisted" even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older sibling, or a relative, as you answer the following questions.

- Age of **first** motor tics? _____ years old
- Describe **first** motor tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** motor tics? _____ years old

Motor Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
- 2) is **CURRENTLY** experiencing (during the past week)

State **AGE OF ONSET** (in years) if patient has had that behavior.

Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).

[In Years]			The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
Ever	Cur- rent	Age of onset		
-eye movements.				
			eye blinking, squinting, a quick turning of the eyes, rolling of the eyes to one side, or opening eyes wide very briefly.	
			eye gestures such as looking surprised or quizzical, or looking to one side for a brief period of time, as if s/he heard a noise.	
-nose, mouth, tongue movements, or facial grimacing.				
			nose twitching, biting the tongue, chewing on the lip or licking the lip, lip pouting, teeth baring, or teeth grinding.	
			broadening the nostrils as if smelling something, smiling, or other gestures involving the mouth, holding funny expressions, or sticking out the tongue.	
-head jerks/movements.				
			touching the shoulder with the chin or lifting the chin up.	
			throwing the head back, as if to get hair out of the eyes.	
-shoulder jerks/movements.				
			jerking a shoulder.	
			shrugging the shoulder as if to say "I don't know."	
-arm or hand movements.				
			quickly flexing the arms or extending them, nail biting, poking with fingers, or popping knuckles.	
			passing hand through the hair in a combing like fashion, or touching objects or others, pinching, or counting with fingers for no purpose, or writing tics, such as writing over and over the same letter or word, or pulling back on the pencil while writing.	
-leg, foot or toe movements.				
			kicking, skipping, knee-bending, flexing or extension of the ankles; shaking, stomping or tapping the foot.	

			taking a step forward and two steps backward, squatting, or deep knee-bending.	
--	--	--	--	--

Ever	Current	Age of onset	The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
------	---------	--------------	---	-----

-abdominal/trunk/pelvis movements.

			tensing the abdomen, tensing the buttocks.	
--	--	--	--	--

-other simple motor tics.

			Please write example(s): _____	
--	--	--	-----------------------------------	--

-other complex motor tics.

			touching	
			tapping	
			picking	
			evening-up	
			reckless behaviors	
			stimulus-dependent tics (a tic which follows, for example, hearing a particular word or phrase, seeing a specific object, smelling a particular odor). Please write example(s): _____	
			rude/obscene gestures; obscene finger/hand gestures.	
			unusual postures.	
			bending or gyrating, such as bending over.	
			rotating or spinning on one foot.	
			copying the action of another (echopraxia)	
			sudden tic-like impulsive behaviors. Please describe: _____	
			tic-like behaviors that could injure/mutilate others. Please describe: _____	
			self-injurious tic-like behavior(s). Please describe: _____	

-other involuntary and apparently purposeless motor tics (that do not fit in any previous categories).

		Please describe any other patterns or sequences of motor tic behaviors: <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	
--	--	--	--

Phonic (Vocal) Tics

Description of Phonic (or Vocal) Tic Symptoms Phonic tics usually begin in childhood, typically after motor tics have already started, but they can be the first tic symptoms. They are characterized by a sudden utterance of sounds such as throat clearing or sniffing. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and/or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Over periods of weeks to months, phonic tics wax and wane and old tics may be replaced by totally new ones. Simple phonic tics are utterances of fast, meaningless sounds whereas complex phonic tics are involuntary, repetitive, purposeless utterances of words, phrases or statements that are out of context, such as uttering obscenities (i.e., coprolalia), or repeating over and over again what other people have said (i.e., echolalia). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., “I have hay fever that has persisted” even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older brother or sister, or older relative, as you answer the following questions.

- Age of **first** vocal tics? _____ years old.
- Describe **first** vocal tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** vocal tics? _____ years old.

Phonic Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
 2) is **CURRENTLY** experiencing (during the past week)

*State **AGE OF ONSET** (in years) if patient has had that behavior.*

*Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).*

Ever	Cur- rent	Age of onset	The patient has experienced, or others have noticed, bouts of involuntary and apparently purposeless utterance of:	Ver
			-coughing.	
			-throat clearing.	
			-sniffing.	
			-whistling.	
			-animal or bird noises.	
			-Other simple phonic tics. Please list: _____	
			-syllables. Please list: _____	
			-words. Please list: _____	
			-rude or obscene words or phrases. Please list: _____	
			-repeating what someone else said, either sounds, single words or sentences. Perhaps repeating what's said on TV (echolalia).	
			-repeating something the patient said over and over again (palilalia).	
			-other tic-like speech problems, such as sudden changes in volume or pitch. Please describe: _____ _____	
			Describe any other patterns or sequences of phonic tic behaviors: _____ _____ _____	

SEVERITY RATINGS

NUMBER	Motor	Phonic	
None	⑥	⑥	0
Single tic	⑥	⑥	1
Multiple discrete tics (2-5)	⑥	⑥	2
Multiple discrete tics (>5)	⑥	⑥	3
Multiple discrete tics plus as least one orchestrated pattern of multiple simultaneous or sequential tics where it is difficult to distinguish discrete tics	⑥	⑥	4
Multiple discrete tics plus several (>2) orchestrated paroxysms of multiple simultaneous or sequential tics that where it is difficult to distinguish discrete tics	⑥	⑥	5

FREQUENCY	Motor	Phonic	
NONE No evidence of specific tic behaviors	⑥	⑥	0
RARELY Specific tic behaviors have been present during previous week. These behaviors occur infrequently, often not on a daily basis. If bouts of tics occur, they are brief and uncommon.	⑥	⑥	1
OCCASIONALLY Specific tic behaviors are usually present on a daily basis, but there are long tic-free intervals during the day. Bouts of tics may occur on occasion and are not sustained for more than a few minutes at a time.	⑥	⑥	2
FREQUENTLY Specific tic behaviors are present on a daily basis. tic free intervals as long as 3 hours are not uncommon. Bouts of tics occur regularly but may be limited to a single setting.	⑥	⑥	3
ALMOST ALWAYS Specific tic behaviors are present virtually every waking hour of every day, and periods of sustained tic behaviors occur regularly. Bouts of tics are common and are not limited to a single setting.	⑥	⑥	4
ALWAYS Specific tic behaviors are present virtually all the time. Tic free intervals are difficult to identify and do not last more than 5 to 10 minutes at most.	⑥	⑥	5

INTENSITY	Motor	Phonic	
ABSENT	⑥	⑥	0
MINIMAL INTENSITY Tics not visible or audible (based solely on patient's private experience) or tics are less forceful than comparable voluntary actions and are typically not noticed because of their intensity.	⑥	⑥	1
MILD INTENSITY Tics are not more forceful than comparable voluntary actions or utterances and are typically not noticed because of their intensity.	⑥	⑥	2
MODERATE INTENSITY Tics are more forceful than comparable voluntary actions but are not outside the range of normal expression for comparable voluntary actions or utterances. They may call attention to the individual because of their forceful character.	⑥	⑥	3
MARKED INTENSITY Tics are more forceful than comparable voluntary actions or utterances and typically have an "exaggerated" character. Such tics frequently call attention to the individual because of their forceful and exaggerated character.	⑥	⑥	4

SEVERE INTENSITY Tics are extremely forceful and exaggerated in expression. These tics call attention to the individual and may result in risk of physical injury (accidental, provoked, or self-inflicted) because of their forceful expression.	⑥	⑥	5
--	---	---	----------

COMPLEXITY	Motor	Phonic	
NONE If present, all tics are clearly "simple" (sudden, brief, purposeless) in character.	⑥	⑥	0
BORDERLINE Some tics are not clearly "simple" in character.	⑥	⑥	1
MILD Some tics are clearly "complex" (purposive in appearance) and mimic brief "automatic" behaviors, such as grooming, syllables, or brief meaningful utterances such as "ah huh," "hi" that could be readily camouflaged.	⑥	⑥	2
MODERATE Some tics are more "complex" (more purposive and sustained in appearance) and may occur in orchestrated bouts that would be difficult to camouflage but could be rationalized or "explained" as normal behavior or speech (picking, tapping, saying "you bet" or "honey", brief echolalia).	⑥	⑥	3
MARKED Some tics are very "complex" in character and tend to occur in sustained orchestrated bouts that would be difficult to camouflage and could not be easily rationalized as normal behavior or speech because of their duration and/or their unusual, inappropriate, bizarre or obscene character (a lengthy facial contortion, touching genitals, echolalia, speech atypicalities, longer bouts of saying "what do you mean" repeatedly, or saying "fu" or "sh").	⑥	⑥	4
SEVERE Some tics involve lengthy bouts of orchestrated behavior or speech that would be impossible to camouflage or successfully rationalize as normal because of their duration and/or extremely unusual, inappropriate, bizarre or obscene character (lengthy displays or utterances often involving copropraxia, self-abusive behavior, or coprolalia).	⑥	⑥	5

INTERFERENCE	Motor	Phonic	
NONE	⑥	⑥	0
MINIMAL When tics are present, they do not interrupt the flow of behavior or speech.	⑥	⑥	1
MILD When tics are present, they occasionally interrupt the flow of behavior or speech.	⑥	⑥	2
MODERATE When tics are present, they frequently interrupt the flow of behavior or speech.	⑥	⑥	3
MARKED When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.	⑥	⑥	4
SEVERE When tics are present, they frequently disrupt intended action or communication.	⑥	⑥	5

IMPAIRMENT

NONE	⑥	0
MINIMAL Tics associated with subtle difficulties in self-esteem, family life, social acceptance, or school or job functioning (infrequent upset or concern about tics vis a vis the future, periodic, slight increase in family tensions because of tics, friends or acquaintances may occasionally notice or comment about tics in an upsetting way).	⑥	10
MILD Tics associated with minor difficulties in self-esteem, family life, social acceptance, or school or job functioning.	⑥	20
MODERATE Tics associated with some clear problems in self-esteem family life, social acceptance, or school or job functioning (episodes of dysphoria, periodic distress and upheaval in the family, frequent teasing by peers or episodic social avoidance, periodic interference in school or job performance because of tics).	⑥	30
MARKED Tics associated with major difficulties in self-esteem, family life, social acceptance, or school or job functioning.	⑥	40
SEVERE Tics associated with extreme difficulties in self-esteem, family life, social acceptance, or school or job functioning (severe depression with suicidal ideation, disruption of the family (separation/divorce, residential placement), disruption of social ties - severely restricted life because of social stigma and social avoidance, removal from school or loss of job).	⑥	50

SCORING

	Number (0-5)	Frequency (0-5)	Intensity (0-5)	Complexity (0-5)	Interference (0-5)	Total (0-25)
Motor Tic Severity						
Vocal Tic Severity						

<i>Total Tic Severity Score = Motor Tic Severity + Vocal Tic Severity (0-50)</i>	
<i>Total Yale Global Tic Severity Scale Score (Total Tic Severity Score + Impairment) (0-100)</i>	

APPENIDIX F

Informed Consent Agreement

Tourette Syndrome in Adolescence: How the Disorder Impacts an Adolescent's Experiences of their Family, Peers, School, Self-Concept and View of the Future

You are invited to participate in a research study. Before you agree to participate in this study, you should know enough about it to make an informed decision. If you have any questions, ask the investigator. You should be satisfied with the answers before you agree to be in the study.

Purpose of the Study

This study will examine the experiences of adolescents, ages 12-17 with Tourette Syndrome. Specifically, the study seeks to understand how having TS has impacted adolescents' experiences with their family, peers, at school, on the their self-concept and their view of the future. Ultimately, this study seeks to find if there are common experiences for adolescents with TS and if so, what these experiences are. I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University and am conducting this study to fulfill my dissertation and doctoral requirements. It is anticipated that 5-10 individuals will participate in this study. If you or your child wish to be provided with the general results of this study, please notify me, and this information will be shared with you at the completion of the study.

Study Procedures: Your child will be interviewed by the Principal Investigator about how his/her having TS impacts their experiences of their family, peers, school, self-concept and view of the future. The interview will take roughly one to one and a half hours.

Interviews will be audio taped to ensure the authenticity of the study. Interviews will be transcribed and tapes will be destroyed after transcription. I will maintain any tape recordings, transcripts of interviews, or other data collected from you in confidence in a locked filing cabinet. These materials will be destroyed after three years.

Risks: The interview focuses on how your child's having TS impacts their experiences of their family, peers, at school, on the their self-concept and their view of the future. It is my hope that the interview will be a positive experience for your child. However, recalling some unpleasant memories and discussing matters of a personal nature may cause discomfort for your child. If your child experiences distress related to the study, please let me know and discuss this with me, so that I can assist you and help provide you with referrals to local counseling services for your child as necessary. Please note that the study will not pay for such services – you would assume financial responsibility for such services.

Benefits: Your child's experience and knowledge have tremendous value to understanding the issues affecting adolescents with TS. The information your child shares has the potential to help other children and adolescents with TS, as well as their parents, in preparing them for life experiences that lie ahead. Additionally, the opportunity for your child to share their experiences and knowledge about TS may be of value to them. There is no compensation for participating in this study.

Subject's Initials _____

Confidentiality: All records will be stored in locked files and will be kept **confidential** to the extent permitted by law. The data about your interview will be stored on a password protected electronic data file in my personal computer in order to keep it confidential.

The data will be available only to the principal investigator and no identifying information will be disclosed. Audiotapes and other paper work will be assigned a case number. Your responses will be grouped with other participants' responses and analyzed collectively. All common identifying information will be disguised to protect your confidentiality. This will include changing your name and other demographic information (i.e. age, occupation).

Research Standards and Rights of Participants: Your child's participation in this research is **voluntary**. If your child decides not to participate, or if decides later to stop participating, your child will not lose any benefits to which they are otherwise entitled. Also, if you or your child refer other individuals for participation in this study, your child's name may be used as the referral source only with your permission.

I understand that I may contact the investigator or the investigator's dissertation chairperson at any time at the addresses, telephone numbers or emails listed below if I have any questions, concerns or comments regarding my participation in this study.

Rob Happich, Psy..M. (Principal Investigator)
Rutgers University
GSAPP
152 Frelinghuysen Rd
Piscataway, NJ 08854-8085
Telephone: 732.445.6111 ext. 918
Email: happich_r@hotmail.com

Lew Gantwerk, Psy.D. (Chairperson)
Rutgers University
GSAPP
152 Frelinghuysen Rd
Piscataway, NJ 08854-8085
Telephone: 732.445.7793
Email: gantwerk@rci.rutgers.edu

If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at:
Rutgers University, the State University of New Jersey
Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: 732-932-0150 ext. 2104
Email: humansubjects@orsp.rutgers.edu

Signature of Research Subject

I hereby give my consent for me and my child to participate in this research study and agree that my personal health information can be collected, used, and shared confidentially by the researchers and staff for the research study described in this form. I will receive a signed copy of this consent form.

Parent/Guardian's Signature: _____ Date: _____

Parent/Guardian's Name: _____

Signature of Study Staff Witness: _____ Date: _____

Study Staff Witness' Name: _____

Child's Name: _____

Child is a minor; age _____

You have already agreed to participate in a research study entitled *Tourette Syndrome in Adolescence: How the Disorder Impacts an Adolescent's Experiences of their Family, Peers, School, Self-Concept and View of the Future* by Rob Happich. I am asking for your permission to allow me to audiotape (make a sound recording) as part of this research study. You do not have to agree to be recorded in order to participate in the main part of the study.

The recording(s) will be used for analysis by Mr. Happich.

The recording(s) will be distinguished from one another by an identifying case number - not your name.

The recording(s) will be stored in a locked file cabinet by identifying number not by name or other information that might disclose your identity. The tapes will be retained until the project is completed and the dissertation has been successfully defended. It is expected that the tape will be destroyed within four years after your interview.

Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Parent/Guardian's Signature: _____ Date: _____

Parent/Guardian's Name: _____

Signature of Study Staff Witness: _____ Date: _____

Study Staff Witness' Name: _____

Child's Name: _____

Child is a minor; age _____

APPENDIX G

CHILD ASSENT TO PARTICIPATE IN A STUDY

1. We are asking you to be a part of this study because we are trying to learn more about what it is like for you having TS and what your experiences are like with your family, peers, at school, on your self-concept and view of the future.
2. If you agree to be in the study, today, we will ask you to spend about 1 – 1 ½ hours talking to an interviewer about your experiences with TS with your family, peers, at school, on your self-concept and view of the future.
3. There may be some benefits to being in this study. For example, your answers about your experience with TS may help researchers find better ways to help other kids who have TS.
4. There may also be some things you don't like about participating. During the interview, you may find some of the questions hard to answer, or they may remind you of things you do not like to think about. You do not have to answer questions that you would rather not answer. And remember, everything you say will be private, unless we hear something that makes us worry about your safety or the safety of others.
5. We will not tell anyone what you tell us without your permission unless there is something that could be dangerous to you or someone else. If you tell us that someone is or has been hurting you we have to tell that to people who are responsible for protecting children so they can make sure you are safe.
6. You may talk with your parents before you decide whether or not to participate. We also ask your parents for their permission for you to talk with us. **Even if they say “yes”, you can still decide not to be in the study.**
7. If you don't want to be in this study, you don't have to participate. **Remember, being in this study is up to you**, and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.
8. If you have a question about the study, you can contact Lew Gantwerk at 732.445.7793. If you have questions about your rights as a research subject, you may contact the IRB administrator at Rutgers University at:

Rutgers University, The State University of New Jersey
Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick NJ 08901-8559

Tel: 732-932-0150 ext. 2104

Email: humansubjects@orsp.rutgers.edu

9. Signing your name at the bottom of this paper means that you agree to be in the study.
You and your parents will be given a copy of this form.

Your signature: _____ Today's date: _____

Your name: _____ Age: _____