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## Do Maternal/Paternal Child Relationships Have a Similar Pattern When the Child Has Tourette's Syndrome? A Case Study

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RELATIONSHIPS WHEN CHILD HAS TOURETTE'S SYNDROME

Do Maternal/Paternal Child Relationships Have a Similar Pattern

When the Child has Tourette's Syndrome? A Case Study.

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Abstract

Although I did not realize it at the time, my first experiences in parenting evolved around a child who was diagnosed with onset pervasive developmental disorder by age five. Due to his hyperactivity, he was prescribed Ritalin. Within two weeks after being given this medication, he developed motor and vocal tics and was diagnosed with Tourette's syndrome (TS) by the time he reached nine years of age. Subsequently, I began a teaching career in special education. During this time, I had guidance by a psychologist and two physicians who taught me a great deal about Tourette's syndrome (TS). In the years that followed, I continued to research TS and met individuals through my job, at meetings, and at conferences. I discovered that there were different characteristics among individuals who have a child diagnosed with TS. Through review of recent research I discovered there remains controversy in the symptoms and characteristics of an individual with TS and related disorders. I remain interested in this field and continue to be captivated by the evolving history and research in the area of Tourette's syndrome.

## PURPOSE AND METHODOLOGY

The purpose of this study is “to compare the perceptions of those involved in maternal/paternal child relationships of children with Tourette’s syndrome (TS) to their perceptions of siblings without TS.” A review of the literature revealed there is no anecdotal evidence that TS is an issue in families. Further, there is no study that systematically examines family relationships. This led me to ask the question: “Are there differences and similarities in sibling relationships with their mother/father? If so, are these differences or similarities influenced by the child who has Tourette’s syndrome? How?”

The participants in this study included one family in Minnesota who has a child with TS. This family has three boys who are ages 16, 13, and 10. His mother as being very “gifted” describes the eldest boy. The middle son has been diagnosed with Attention Deficit Disorder (ADD). He also has difficulty learning, but is not in a special education program. The youngest child has been diagnosed with Tourette’s syndrome and has been diagnosed with an anxiety disorder. Both of these diagnoses were made within the last year. However, the mother indicated that the symptoms of her youngest son have progressed since age six. Both father and mother work outside the home and have been married for 20 years.

I met and interviewed this family and corresponded with them through e-mail and through phone conversations. This study continued over a two-month period using qualitative research methods to study the perceptions of the relationships between family members affected with TS and family members who were not diagnosed with TS. Methods included visits and interviews, follow-up interviews, and the reading of published material.

The raw data obtained from interviews and observations were then translated into codes, which Maxwell (1996) describes as the main categorizing strategy in qualitative research. This process helped me to break apart data and rearrange it into theme categories. This would facilitate the comparison of data between categories, creating possible concepts. Although I was not aware of what the theme

categories were until I had analyzed all the data, there were coding patterns that were emerging throughout the study. Themes and assertions developed throughout the study are:

1. Families who have members who have been diagnosed with TS want to be considered no different than other families.
2. The relationships between mother/father and children with and without TS may have differences and similarities.
3. Through experience, the families who live with TS on a daily basis deal with “tic” symptoms differently during intervals throughout the life of the child.

#### CHARACTERISTICS OF Tourette’s syndrome

Many controversies remain concerning TS and its range of clinical expression. Bruun, Cohen, and Leckman (1990) stated a principal area of controversy concerns “associated” features of TS, which have been recognized since Tourette’s first report (obsessive compulsions, attention difficulties, impulsivity, and personality problems).

#### *Associated Features*

Questions are present concerning whether or not “associated” features are secondary to an individual’s tic problems, or if they reflect the same underlying patho-biological process or are independent. The Diagnostic Statistical Manual (DSM-IV) (American Psychiatric Association, 1994) places emphasis on defining motor and phonic tics and identifies the following five criteria:

1. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently. (A tic is a sudden non-rhythmic, stereotyped motor movement or vocalization.)
2. The tics occur many times a day (usually in bouts), nearly every day, or intermittently throughout a period of more than a year, and during this period there was never a tic-free period of more than three consecutive months.

3. The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning.
4. Onset is before age 18.
5. The disturbance is not due to the direct physiological effects of substance (e.g., stimulants) or a general medical condition.

### *Summary of Characteristics*

Researchers report clinical observations of Tourette's syndrome (TS) characteristics as far back as the late 19<sup>th</sup> century. The DSM-IV (American Psychiatric Association, 1994) clarifies the syndrome with diagnostic criteria. Research shows that in TS something is wrong with the way in which the brain produces or uses important substances called neurotransmitters, which control how signals are sent along the nerve cells. The neurotransmitters dopamine and serotonin have been implicated in TS; noradrenaline is thought to be the most important stimulant (Cramer, 1999).

### HISTORICAL BACKGROUND

Tourette's syndrome (TS) was diagnosed as an affliction over a hundred years ago. The syndrome was first seen as a possession of the devil (Garelik, 1989). Subsequent to Garelik's theory, it was described as a psychiatric disease and later as a disease with organic cause. From the early 1920s through the 1960s, TS was described as a disease with psychiatric symptoms. From the 1970s until the 1990s it was described as a disease with a chemical cause.

In much of today's literature TS is described as an inherited tic disorder (Merck, 2001; Murray, 1997; National Institute of Neurological Disorders and Stroke [NINDS], 2000; Willis, 1993). However, other recent literature indicates that only 50% to 70% of the diagnosed cases are hereditary (Meyers, 1984). Research suggests the remainder of the cases (acquired Tourette's syndrome, or Tourettism) might be related to other causes including the environment, infectious, and psychosocial factors (Zinner, 2000). Stell, Thickbroom, and Masteglia (1995, p. 729) related Tourettism to "inflammatory, toxic

metabolic and structural lesions of the central gray matter of the brainstem.” Meyers (1984) reports “a growing number of children have been identified with stimulant induced TS. That is, stimulant medications commonly prescribed to hyperactive children (e.g. Ritalin, Cylert, Dexedrin, etc.) can precipitate TS in predisposed children, according to the Food and Drug Administration. This condition is neither degenerative nor terminal” (p. 4).

Gilles de la Tourette, a French neurologist, identified Tourette’s syndrome (TS) in 1885. De la Tourette described the condition as characterized by multiple muscle tics, vocal noises, and compulsive swearing (McGruther, 1996; Goetz, Tanner, & Wilson, 1987). He clinically documented nine patients with similar symptoms. He also reviewed a case where Dr. Itard, in 1825, described a French noble woman who displayed, since age seven, involuntary muscle tics that were later accompanied by coprolalia, which is an involuntary utterance of swear words. His research and documentation gave the disorder his name (Price, Kidd, Cohen, Pausl, & Leckman, 1985).

Gilles de la Tourette described a tendency in patients to imitate the speech of others, labeled echolalia. A second tendency was called palilalia, the repeating of one’s own words. Thirdly, echopraxia was observed, the mimicking of other people’s actions. The final description recognized coprolalia, which is the involuntary utterance of swear words. This was not recognized in every patient, but usually appeared at the beginning of the illness and could not be regulated with disciplinary interventions (Comings, 1990).

Tourette’s syndrome (TS) has a variety of behavioral symptoms, particularly those associated with attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). It is believed these disorders can co-exist and can interfere more than tics do with overall functioning and performance. In addition this co-existence of symptoms can lead to social and emotional maladjustment. Although only three to six percent of school age children have ADHD (Abwender et al., 1998), a majority of patients with TS have symptoms of ADHD, OCD, or both at some time during the

course of their illness (Tulen, Azzilina, Groeneveld, Passchier, & Van De Watering, 1999). For individuals with TS, the inability to pay attention is the result not only of coexisting ADHD, but also of uncontrollable intrusions of thoughts, or obsessive fixation of attention on irrelevant objects, or topics of the mental concentration that are excited in an effort to suppress tics and premonitory urges.

### *Scientific Attention*

Tourette's Syndrome (TS) had little scientific attention until the 1960s (Mehren, 1980). By 1971, the Tourette's Syndrome Association was founded when a New York family had spent over \$50,000 in a fruitless search for the cause of their son's problem and then wrote a letter to a local newspaper: "We have exhausted out the resources in this lonely battle," they said. "Would the parents of patients with this syndrome please contact us?" (Belson, 1977). After reading this newspaper article, Shapiro began to study the syndrome. His extensive research on Tourette's syndrome led to the book, *Gilles de la Tourette syndrome* (Shapiro, Shapiro, Bruun, & Sweet, 1978). The book stimulated interest in the syndrome by other researchers.

Great strides were made in the late 1970s and early 1980s in understanding the syndrome (Bruun, 1984). More cases were diagnosed and more effective methods of diagnosing were developed. The cumbersome name of Gilles de la Tourette's syndrome gradually changed to Tourette's syndrome or simply the initials TS.

The broad clinical picture of Tourette's syndrome has changed little since its first description a century ago. Many controversies remain concerning the disorder as noted by Bruun (1984). A principal controversy concerns the "associated" features of TS, which have been recognized since the first report of TS (obsessions, compulsions, attention difficulties, impulsivities, and personality problems).

Questions have developed concerning whether or not the "associated" features are secondary to the patient's tic problems, if they reflect the same underlying patho-biological process, or if the two are independent.

Jankovic (2001) describes the diagnosis of TS being based on a history of observation of tics which were often supported by the presence of existing behavioral disorders, particularly attention deficit hyperactivity disorder (ADHD) and obsessive compulsive disorder (OCD), and a family history of similar symptoms. Tics, the clinical hallmark of TS, are sudden, brief, intermittent, involuntary, or semi voluntary movements (motor tics) or sounds (phonic or vocal tics).

### *Genetic Investigators*

Cohen (1984) suggested that ADHD, involving a short attention span, daydreaming, poor concentration, hyperactivity, or obsessive compulsions, might be associated with TS. These associated features have similar underlying genetic factors. Eight years later, Kurlan (1992) suggested that in recent genetic research, obsessions (recurrent persistent ideas, thoughts, images, impulses) and compulsions (repetitive behaviors performing as rituals or in stereotyped fashion) might be clinical manifestations of TS. Golden (1990) stated that these conditions might be two manifestations of the same gene. Alsobrook (2002) described evidence for a TS spectrum of symptoms that included chronic tics and obsessive-compulsive disorder. Systematic genome linkage studies of TS are progressing. To date, however, no significant linkages exist, although the search has included many relevant studies that suggest that patterns of TS and chronic tics are consistent among families.

Genetic studies of TS and other tic disorders have revealed how genes have been transmitted over several generations. Cohen, Leckman, and Tow pin (1989) reported that TS is clearly a genetic disorder, meaning that individuals are vulnerable to the tic disorder due to genetics. The precise type of disorder or severity may be different from one generation to another. This vulnerability is transmitted by either mothers or fathers and can be passed on to either sons or daughters. If one of the parents is a carrier or has TS, it appears that there is about a fifty-fifty chance that an individual will receive the genetic vulnerability from that parent.

The unusual genetic characteristic is that not everyone who inherits the genetic vulnerability will express any of the symptoms of TS. Males will have a 99% chance of showing some clinical expression of the gene. This degree of expression is described as penetrance. Females will have a 70% chance of expressing any of the symptoms of TS. Males are more likely to have some form of expression of the genetic vulnerability due to the higher penetrance (Bruun, 1989). The severity of TS is also highly variable. Most individuals will not need to seek medical attention due to the TS genetic vulnerability and wide range of forms of TS, which include full-blown TS, chronic multiple tics, ADHD, and COD (Comings, 1990).

Due to the variety of symptoms that may be associated with the syndrome, several views are presented that have evolved over an extensive period. A large number of the studies associated with TS deal with tic disorders, attention deficit disorder, and obsessive-compulsive disorders with specific information undefined due to the known similarities and inability to separate completed symptoms. Genetic interrelationships between psychiatric disorders will be determined by precise genetic markers (Alsobrook, 2002).

#### TREATMENT

One primary goal of physicians is effective treatment of Tourette's syndrome (TS). It is important to start patients on a small dose of medication for monitoring side effects and to diminish symptoms. Also, the duration of the medication trial is important for effective symptom control, with importance given to the medication side effects and possible withdrawal symptoms if discontinued.

#### *Effective Medication*

Three medications have been effective in controlling tics: Haloperidol, Clonidine, and Pimozide. Kugler (2000) states these medications may have serious side effects; researchers are now looking at caciufen and botulinum toxin used together, as well as ondansetron, paroxetine, antibiotics, and marijuana. Halperidol (Haldol) has been the mainstay treatment of TS. High doses were given initially,

but more effective treatment was determined by a smaller dose. Initially the high doses benefited 80% of the patients dramatically. However, long-term follow-up studies suggest 20% to 30% of the individuals continue on halperidol for an extended period and suffer side effects from the medication. Emergence of side effects include fatigue, weight gain, dysphoria, parkinsonian symptoms, intellectual dulling, memory problems, personality changes, feeling like a "zombie," akathisia, school or social problems, loss of libido, and sexual dysfunctions. Chronic uses over a long time may also produce tardive dyskinesia, which are involuntary movements of the mouth, lips, tongue, trunk, or limbs. The usual starting dose is .05 to 0.25mg at bedtime. Doses may increase up to 0.25 mg per day every five to seven days if needed, to a maximum dose of 10 mg per day.

Woods (2000) refers to Clonidine (catapress) as another of the major drugs of choice to treat TS. It does not however; appear to be as effective as halperidol. Patients show improvement in attention problems and obsessive-compulsive behaviors. Clonidine is rapidly eliminated from the body, making three to four doses per day necessary. Beneficial effects of the drug occur slowly and three to four months are often necessary to evaluate its full effectiveness. The most common side effect is sedated feelings. The sedated feelings, however, decrease over time. Medication is started at a low dose of 0.5 mg a day and slowly increased over several weeks up to 0.15-0.30 mg per day. Perhaps the greatest benefit of clonidine is that it does not have the potential of causing tardive dyskinesia. In most successful cases, attention, behavioral, and complex phenomena seem more responsive than simpler tics to medical treatment. When there is a positive response to the medication, improvement may progressively appear over many months and up to a year or more later.

Pemozide (orap) is a newer drug that is proving to be effective in reducing tics. It can be given once daily due to its half-life, but in a significant number of patients it may cause electrocardiogram change including T-wave aversion that results in calcium blocking effects. Therefore doses over 20 mg need to be monitored closely due to the calcium blocking effects that cause heart attacks (Bruun &

Rody, 1989; Cohen, 1984; Comings & Comings, 1984; Comings, 1990). Pimozide should be used only if other drugs are not effective. Doses are initiated at 1.0 mg a day and dosage is gradually increased on clinical need to a maximum of 6.0-10.0 mg a day for children and 20.0 mg a day for adults. Doses greater than 0.2 mg/kg or 10 mg/day are not recommended.

#### *Pharmacological Management*

The goal for treatment is symptom reduction and not elimination of tic symptoms. A reduction of 60% to 80% of tics may be achievable through pharmacological management. Kerbashian, Burd, Fisher, Martsof, and Wilkenheiser (1985) state pharmacological management is helpful in 70% to 80% of the patients with TS. However, tic symptoms of TS fluctuate, making treatment difficult. Symptoms of TS also decrease in late adolescence and adulthood. This causes a tendency for symptoms to improve. Hearle (1992) states no matter how severe tics were in childhood, there is usually some improvement in adulthood.

Researchers currently believe tics associated with TS are due to the over sensitivity to the brain chemical called Dopamine. Dopamine is a chemical that ordinarily helps transmit signal-involving control of motor movement from one nerve cell in the brain to the next. Therefore, the treatment of tics relies on neuroleptics with dopamine receptor blocking activity (Golden, 1990). In rare instances, it may be necessary to combine a psycho stimulant and a neuroleptic for attention deficit hyperactivity disorder (ADHD) and/or compulsive symptoms with TS. Clearly tics are involuntary and need continued monitoring by physicians to prevent additional problems.

The majority of individuals with TS who are old enough to describe their own emotional climate will speak of "inner tension" (Bruun, 1989). Many people do not feel they have been successfully treated until the "inner tension" has been alleviated by medication. Emotion is not attached to the performance of tic acts with the exception of frustration from the inconvenience they cause. Bruun (1989) stated 5% of his study group has had remission of TS for one year or more. However, individuals

with TS are known to have periods of violent and angry behavior. The symptoms are controllable and uncontrollable for short periods. This makes treatment and potential improvement difficult. Due to this, medications and clinical responses have created phenomena in need of further understanding by physicians and patients. Each case should be given a clinical trial to reduce the side effects (Alsobrook, 2002).

#### EDUCATIONAL IMPLICATIONS

The educational implications of students with Tourette's syndrome (TS) may involve special education, tutoring, a self-contained classroom, a special school, residential placement, or no special services at all. The need depends on the severity of behavioral problems associated with TS (Bruun et al., 1990; Burd, 1992). Burd's research stated about 40% of children with TS have learning disabilities (LD) while Bruun and researchers (1999) found 60% show some sign of LD. In addition, they also may have motor and vocal tics. For about 60% of children with TS, educational difficulties peak between 11 and 13 years of age and then gradually decrease.

Many students have academic difficulty, not because they cannot work, but because they cannot complete the work (Hearle, 1992). This is often due to increased stress, which causes behavior problems and therefore affects their performance. These behaviors may be directly related to TS. Behaviors included are: sustaining attention, restlessness, impulsivity, hyperactivity, obsessive thinking, and compulsive behavior leading to rituals such as tapping and touching.

#### *Educational Needs*

Perhaps the primary task in education is to educate teachers about TS. Teachers observe students daily and may assist with the diagnosis, treatment, and service needs of the individual. Colligan (1989) addresses motor, phonic, and the complex symptoms of TS and has developed a teacher's checklist used as a screening tool for students with TS. Once possible identification is made, a referral may be made but does not constitute a diagnosis. Screening is, however, a very important part of the

diagnosis and treatment. A broad view of the disorder may help parents and physicians provide appropriate treatment which otherwise would not be available.

The most useful approach a teacher can use for a child with a special problem like TS is to assist students in fostering feelings of self-worth and self-esteem (Colligan, 1989; Wertheim, 2003). In addition, communication is useful in building self-esteem. Listening to individual hurts and talking with children about their embarrassments associated with this disorder is another positive approach that can be taken to support these children. Words reflect what we think, judge, feel, value, honor, love, hate, fear, desire, hope for, believe in, and commit to. Therefore, the classroom setting is established by the teacher and should encourage feelings of human kindness, tolerance, and compassion. An older student with TS stated at the national TS conference (1991), "All I ever wanted was for my teacher to understand and accept me. Underneath my tics and noises, I'm a person just like anyone else."

#### *Summary of Educational Needs*

Strokes, Brawden, Camfield, Backman, and Dooley (1988) state individuals with Tourette's syndrome (TS) may be handicapped by their inability to mobilize their social coping skills effectively. The reason for this could be due to lack of social skills or as a direct result of the disorder. Students with TS may achieve success depending upon their interest, level of difficulty or challenge, purpose, opportunity for practice of mastery, and reading level of textbooks. Providing structure, consistency, and routine are important when combined with school and medical programs. Anxiety increases when daily life is unstructured, causing increased symptoms (Hearle, 1992). Therefore, providing a multimodal approach including home, school, and medical assistance is necessary. Providing this assistance to all caregivers and agencies involved with the individual's programming is important for success.

#### FAMILIES

Tourette's syndrome (TS) causes a strain on families and each individual with TS (Bruun, 1984; Fulton, 1988). This strain requires support for families dealing with this disorder. Behind the usual

movements of the individual with TS is someone who desperately wants to be normal and who needs to be understood as a person.

### *Coping Strategies*

Hughes (1990), in the book, "*Ryan*," addressed the criticism and harsh judgments often placed on the parent(s) of the individual with TS. This is particularly due to the behaviors encountered by a public that does not understand the neurological basis for the misconduct. People are quick to judge, criticize, and blame parents who cope daily with the impact of the disability on their family life. Parents and other family members need to educate themselves on Tourette's syndrome to assist the individual with TS in managing the disorder. It is often difficult for family members to understand behaviors, which are beyond the control of the individual with TS and in their view, should be controlled (Bruun, 1984). However, most people accept this disorder when they begin to understand it.

Tics may be suppressed for a short time. Doing this causes additional strain on families because individuals suppressing their tics until returning home allow their full expression in the home environment. In these cases, it is helpful for some individuals with TS to be allowed a release (space) to discharge their tics in privacy. This may be done at work, home, and school. This will help to prevent severe family problems with the individual.

Another difficulty families living with TS exhibit is being less flexible. TS changes the structure within the family and an individual with TS often requires more direct time by family members. Much energy and time are required to provide for the individual with TS needs. For other children in the same family, the attention given the child with TS may leave the others feeling unloved.

### RESULTS OF THE STUDY

Erickson (1998) identifies the review of literature as a generation of key linkages among various items of data. The key to a linkage is to connect many items of raw data to analogous instances of the same phenomenon. In this case, the difference between a family with one child and a family with more

than one child may have a distinct effect on how children and parents deal with Tourette's syndrome (TS). Examples from interviews and observations conducted during this study showed a link in the relationship between interactions of child and parent.

General patterns for key linkages were completed at the end of my study. Since this research took place within the dynamics of one family in Minnesota, I have made an internal generalization, which has produced valid conclusions. "The descriptive interpretive and theoretical validity of the conclusion all depended on the internal generalization to the case research as a whole." Although I interviewed and observed each family member individually, I wanted to include a description of the entire family and not selectively focus on only one member. This allowed me not to jeopardize my research.

#### *Themes or Patterns*

*Theme number one.* The family sentiments provided a family environment of support and compassion. This has enabled the 10-year-old child with TS to be surrounded by a home environment that is accepting of him. Each family member expressed verbal acceptance of his or her 10-year-old son/brother with T).

- > His 14-year-old brother stated, "I feel bad for my brother who has to deal with it every day." And "I wrote a book and dedicated it to my brother because he has to live with TS."
- > His 16-year-old brother stated, "I don't really notice it, but on occasion you can hear it, you get use to it." and "If you ignore it, it goes away."
- > His father stated, "TS has not been a problem." "He does not really have needs and is quiet compared to his 14-year-old brother." Lastly he stated, "TS is not a disability. I think I did things like him when I was younger."

- > His mother stated, "We have no concerns with his learning." "TS is not a disability for him." "If he cannot sleep, I give him things to play with (like a baseball computer game in bed) to help him relax."
- > The 10-year-old with TS said, "My mother is easy to talk to." and "My dad does not treat me any different. It's my brother (14-year-old) who is always in trouble for something. It does not affect me." and finally, "I would not like to 'be' any of my brothers."

It is apparent that the family was able to provide a setting for the children which supported all of them despite any specific needs. The family did not recognize TS as a disability or as a "difference" that has caused undue hardships to the family interactions. This family does not see themselves any differently than other families. The family members all had a sense of humor and appeared to enjoy my visits. I felt their acceptance of me was an asset to this research.

*Theme number two.* There is a pattern suggesting there are similarities and differences between the relationship of the 10-year-old child with TS to his father and to his mother. While interviewing, it was apparent the parents' perceptions of the child were very different. This was shown through their interactions with the TS child. However, the interactions between the other children without TS and their parents were similar.

*Similarities:*

- > His father stated during an interview, "TS has not been a problem" and "He does pretty well in school and he loves sports, especially baseball." and lastly, "My middle son is our challenge."
- > His mother stated during an interview, "We do not see his diagnosis with TS as a disability, and he does very well in school." and "We have not had problems with him. It is our middle son with attention deficit disorder, which has caused me problems; it seems like he is always in trouble."

- > The oldest son stated during an interview, “We all talk to each other, but I probably talk to my parents more because I am the oldest.”
- > The middle son stated during an interview, “People with TS make faces and noises. They can’t help it. They are nice people.” and “I play baseball with my brother a lot. He is good at it.”
- > The 10-year-old with TS said, “My mother is easy to talk to” and “My dad does not treat me any different.”

*Differences:*

- > The mother stated during an interview that “His (10-year-old) father and I do not always agree on discipline for him.” and “I think his father is too hard on him when he can’t stop. When he cannot sleep, he raises his voice and tells him it will go away. I help him when he hears voices and is frightened by giving him a game to play in bed under the covers.”
- > His mother also stated, “I have seen a progression in my youngest son’s needs since he was six years old. He and I wanted to find out *why* he was doing some of the things he was. He would grasp his crutch and not quit. I feel like crying when he does that, and I can’t get him to stop.”
- > His father stated during an interview, “My youngest son does not have any problems. He blinks his eyes once in a while and plays with his belt or elastic when playing basketball; otherwise his only problem is his allergies, but he takes medicine for them.”
- > The middle son stated during an interview, “I fight with him sometimes. When I ask him to stop it, he gets worse and that bothers me.” He also stated, “Tourette’s is a disability because it can make me embarrassed.”

There are interactions that present differences and similarities within the family. The research reveals no distinguishing differences that indicate a difference between children and parents due to the

Tourette's syndrome. There appears to be a difference of opinion on what is a concern and what is not a concern regarding the child with TS. While the mother is aware of specific needs the child with TS has, the father does not "feel" any needs are apparent. Therefore, it would seem possible for the interaction between the child with TS and the mother and father to be quite different.

In contrast, the child with attention deficit disorder appears to cause concern for the parents. They both agree that he has caused problems within the family due to his behaviors. The parents agree he is the one that is always in trouble, but from the kind of "trouble" the child has experienced, it is apparent the problems have been mutually understood.

*Theme number three.* The family reported the "tics" displayed by their son and brother is not a current problem. They have reported no differences in the way they perceive him before or after he was diagnosed with Tourette's syndrome. Since his diagnosis was made, there have been no differences in how they interact with him. The family appears to support differences and puts their interests into sports activities.

- > The father stated, "All the boys play ball and they are pretty good at it. The oldest plays football, the middle son plays baseball and basketball, and the youngest plays soccer, basketball, and baseball."
- > The mother stated, "We keep very busy with sports. We all play some sort of ball. I often drive the bus to sporting events. This is an opportunity for me to see the boys play."
- > The oldest boy stated, "I would change the stereotype society has of TS. My brother is good at sports and he only wanted to know what was wrong with himself."
- > The middle son stated, "I didn't know anything about TS until my brother had it. He is good at all the sports. I play only baseball and basketball. I want to tell everyone that he is a nice person even if he blinks his eyes a lot."

- > The 10-year-old with TS stated, "I love baseball and I am good at it, too. Tourette's syndrome does not affect me."

The pattern displayed by the family is that of acceptance and love. The family is very busy between school, work, and sports. These activities assist the family in accepting each member for who they are. The apparent "tics" do not affect the family's interaction with the 10-year-old, nor do they affect how he is perceived as part of their family while involved in sports activities. Although his mother describes bedtime as a problem for him, it has not changed how the family unit interacts with him.

#### RELATIONSHIPS AND CONCLUSIONS

The conclusions from this study are defined in the relationships of the themes presented in the research. Because this research lasted only over a period of two months, it is possible this study has inadequate information to support further study. However, it has created the opportunity for understanding the interactions among family members when a child has been diagnosed with Tourette's syndrome (TS). From this experience parents can begin to understand how and why interactions between family members can deviate from usual patterns due to behaviors that are not easily understood.

Three themes were produced in this study. They are as follows:

1. The family sentiments provided a family environment of support and compassion.
2. There is a pattern suggesting there are similarities and differences between the relationship of the 10-year-old child with TS to his father and to his mother.
3. The family reported the "tics" displayed by their son and brothers are not a current problem. They have reported no differences in the way they perceived him before or in the way they have perceived him since he was diagnosed with TS.

By providing a family environment of support and compassion, one might make the inference those parents and family members can impact the success of an individual who has TS. Although the

family members reported feelings of compassion towards the member of the family who has TS, their actions did not portray sympathetic actions, but rather those of understanding and acceptance. When the family participated in sports events, he was an essential part of the activity. As a family unit, they expressed hope that he could stop what he was doing when he did something repeatedly, but they still did not accept his behavior as “bad” or troublesome.

Although his parents shared mutual respect for their child, there were some apparent similarities and differences in their relationship to their child with TS. Both parents agreed he had less behavioral concerns than his older 14-year-old brother did.

The main difference in the parents’ relationship to the child dealt with the method of disciplining him. When the child would go to bed and could not sleep, the father was said to be “too hard” on him. When the child could not stop doing what he was doing, the father also raised his voice at him. The father also stated during an interview that he (the 10-year-old) did not have any problems with TS. The only problems his son had were with allergies, and he took medication for them.

The mother felt more empathy when the child could not sleep because of nightmares; she would provide an activity for him to keep occupied with in an effort to help him fall asleep. His mother also stated he would grasp his crutch and not quit. She felt like crying when he did that and she could not get him to stop.

Although these different behavior management styles have not apparently mired the 10-year-old’s interactions with his parents, he does display a higher comfort with his mother when he describes her willingness to talk to him. Even though she also expressed frustration with his inability to stop a behavior he had started, the family’s ability to talk about the situation will provide ongoing support during family interactions. The evidence is not suggesting one parent has stronger interactions with the child, but rather the interaction of listening may be more helpful when meeting the child’s needs while displaying symptoms of TS.

It is apparent that this study cannot be generalized to other families with children who have TS. Rather, it brings to our attention the need for continued interaction between parents and family members regarding the management of behaviors related to TS. The consistency of interaction between child and parent and the modeling of appropriate behavior is essential to the success of the individual with TS. This modeling of acceptable behavior and consistency during intervention will allow the child and family to grow and support one another through their experiences with Tourette's syndrome.

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