

Tourette Syndrome: A Review of Literature on What Educators Know and How to Better
Help Students with the Disorder

by

Holly Hazen

A Research Paper
Submitted in Partial Fulfillment of the
Requirements for the
Master of Science Degree
in

School Counseling

Approved: 2 Semester Credits


Dr. Denise Zirkle Brouillard

The Graduate School

University of Wisconsin-Stout

May, 2009

**The Graduate School
University of Wisconsin-Stout
Menomonie, WI**

Author: Hazen, Holly A.
Title: *Tourette Syndrome: A Review of Literature on What Educators Know and How to Better Help Students with the Disorder*
Graduate Degree/ Major: MS School Counseling
Research Adviser: Denise Zirkle Brouillard, Ph.D.
Month/Year: May, 2009
Number of Pages: 33
Style Manual Used: American Psychological Association, 5th edition

ABSTRACT

Tourette syndrome is a debilitating disorder that affects school aged children. The purpose of this study was to assess what research is available as well as interventions regarding children with Tourette syndrome and the school system. Acquiring knowledge on this disorder can only benefit those affected. Educators who are aware of Tourette syndrome and its symptoms are better equipped to help students and implement the proper interventions to help students succeed academically and personally.

The research discusses the history of the disorder, symptoms, and treatment options. Research highlights the educator's role as it pertains to the student affected by Tourette syndrome as well as provides options for different modes of effective programming. Review of interventions currently in use lead to the proposal of newer programs and more education in the area of educators.

The Graduate School
University of Wisconsin Stout
Menomonie, WI

Acknowledgments

I would like to thank Linda, Gary, and Spencer for living full and meaningful lives as well as enduring this disorder. They provide inspiration and support to many around them. I would also sincerely like to thank Christopher for being my thesaurus, idea generator, and for always listening. He has always been there and I know the support and hugs will continue through the years.

TABLE OF CONTENTS

	Page
.....	
ABSTRACT.....	ii
Chapter I: Introduction.....	1
<i>Statement of the Problem</i>	2
<i>Definition of Terms</i>	3
Chapter II: Literature Review	4
<i>Introduction</i>	4
<i>What is Tourette Syndrome?</i>	4
<i>Prevalence</i>	6
<i>Diagnosis</i>	6
<i>Tics</i>	7
<i>Comorbidities</i>	9
<i>Treatment</i>	10
<i>Educator's Role</i>	14
Chapter III: Summary, Critical Analysis, and Recommendations.....	19
<i>Summary</i>	19
<i>Critical Analysis</i>	21
<i>School Based Interventions</i>	24
<i>Recommendations</i>	25
References.....	27

Chapter I: Introduction

Spencer is a seven year old second grader who has been referred by his teacher to the school counselor. For the past nine months Spencer has been disruptive in class and his grades have been slipping. He is being referred because his teacher knows he is a good student and his grades used to be above average. Within the past nine months Spencer has had periods that were disruptive free, but the disruptive behavior is detrimental to both Spencer and his classmates' learning. Spencer appears distracted throughout the day. His schoolwork is rarely done on time and when there is in class work time, Spencer seems to have trouble with writing. Spencer's handwriting needs to be "perfect" in his eyes and because the first attempt is not always done right, he erases until there is a hole in the paper causing him to have to start completely over. This takes time and is the main reason Spencer has not been turning in any work on time. For the first three months of school Spencer had a loud cough and the teacher made a point to talk to the parent's about this. Spencer's parents took him to the doctor who told them it was a cold and would go away in time. The cough persisted for three months, faded away, and is now back. Spencer also has a tendency to smell things. He sniffs a lot which the teacher also attributed to a cold at first, but that came after the cough started the first time and is now gone. When Spencer gets frustrated in class, he talks to himself and is sometimes heard repeating what the teacher has just said but this also seems to come and go. The teacher has noticed that when Spencer seems agitated, these symptoms seem to be worse and during lunch and recess there appear to be no symptoms at all.

After being referred to the school counselor, Spencer was then passed on to the school psychologist who had Spencer take an assessment test for obsessive compulsive

disorder (OCD). The findings were conclusive and Spencer was diagnosed with OCD. After taking this assessment to his medical doctor, Spencer was prescribed medication to help with his OCD, but his symptoms persisted. Spencer's symptoms persisted because he did not only have OCD. Spencer has Tourette Syndrome (TS). TS is a neurological disorder that starts in childhood before the age of eighteen (Kenney, Kuo, & Jumenez-Shahed, 2008). Spencer should be diagnosed with TS and having a comorbidity of OCD because his symptoms wax and wane. His teacher said that his coughing persisted for about three months, went away for awhile and then came back. During the time the cough was gone, a new tic presented itself in place of the cough. The most common cause of both motor and phonic tics is TS (Kenney, Kuo, & Jumenez-Shahed 2008). *Tourette's Syndrome: What It Is and How It's Treated* described tics as "sudden, brief movements (like muscle spasms) or sounds (like words or grunts) that a person repeats over and over" (American Family Physician, 2008, p. 1). For these reasons, Spencer's symptoms would be diagnosed as tics and he would be found to have Tourette syndrome.

Statement Problem

The purpose of this literature review is to identify pertinent information on Tourette syndrome and what educators can do to help those children affected by the disorder.

Definition of Terms

There are several terms that need to be clarified to better understand this disorder. These terms are as cited from the National Tourette Syndrome Association website.

Attention deficit hyperactivity disorder (ADHD) – A neurobiological disorder causing distractibility, hyperactivity/impulsive behaviors and a general inability to focus attention.

Co-morbid condition/comorbidity - Medical term used when one condition or disorder occurs along with another. However, one condition does not directly cause the other.

Coprolalia – Involuntary utterances of obscene or inappropriate statements or words.

Obsessive-Compulsive Disorder (OCD) - When a person has uncontrollable thoughts and compulsive behaviors to the extent that they impair functioning.

Tic - An involuntary movement (motor tic) or involuntary vocalization (vocal tic).

Tourette Syndrome (TS) - Defined as multiple motor and vocal tics, lasting for more than one year, with onset before the age of eighteen.

Waxing and waning – A naturally occurring increase and decrease in severity and frequency of TS symptoms.

Chapter II: Literature Review

Introduction

This chapter will explain what Tourette syndrome (TS) is and the related symptoms associated with this disorder. Within this chapter the presentation of TS will be discussed, specifically the severity and prevalence and course of TS. That will be accompanied by discussion of diagnosis and tics. In addition, treatment and the educator's role will also be discussed.

What is Tourette Syndrome?

Gilles de Tourette is known as the father of Tourette syndrome (TS) because he documented nine cases of the syndrome in 1885. People who had what we now know as Tourette syndrome were once thought to be possessed by demons or evil spirits, often exhibiting strange or inappropriate behaviors (Waltz, 2001). Today TS is more accurately known as a neurological condition. The condition was named after Gilles de Tourette because he was the one to document the most characteristics about the disorder, although he was not the first person to document cases of this disorder. His cases were more interesting than previous ones and as his cases pointed out new evidence that spoke of specifics regarding TS (Waltz, 2001). However, not all of Tourette's beliefs turned out to be true. He thought that TS always got worse over time and that the tic coprolalia was unavoidable. Gilles de Tourette is the one considered to be the person who discovered the disorder but he was not the only one who was interested in it. Others had thoughts and ideas about the disorder which proved to be more accurate. "Some early researchers suspected that it was caused by brain infection, but they lacked the means to explore this theory. Others noted that the disorder appeared to run in families" (Waltz,

2001, p. 3). Around the time of Sigmund Freud these notions held true. Freud replaced these with ideas of his own. His theories consisted of unique ideas such as tics were evidence of the urge to masturbate or of a compulsive masturbator. Freud blamed the patient's families for the tics and symptoms of Tourette's (Waltz, 2001). Today, we know these findings to be untrue; bad parenting does not cause tics, nor does it cause Tourette syndrome (Waltz, 2001). Treatments for Freud's theories included psychological analysis. His theories were disproved when psychiatric medications were established around 1959. Since then much has been found out about TS.

"Tourette's syndrome is an inherited, developmental disorder of synaptic neurotransmitter reuptake in the corticostriatalthalamic circuitry of the brain" (Rindner, 2007). In more understandable terms, Tourette syndrome, (TS), is a tic disorder, one of the most common in society today (Kenney, Kuo, & Jumenez-Shahed, 2008). It is also an inherited disorder. "...genetic factors are implicated in vertical transmission in families with a vulnerability to Tourette's syndrome and related disorders" (Leckman, 2002, p. 1578). The brain of a person with TS looks the same as a person without TS. For people with Tourette's "it's how the brain works that's different" (Waltz, 2001, p. 10). Doctors have been able to observe circuits misfiring in the brain of patients with Tourette's (Waltz, 2001). The part of the brain that sends the tic signal is the basal ganglia. Through this research doctors are now able to medically establish that TS is a neurological disorder and not a psychological problem or the result of bad parenting (Waltz, 2001). The important thing now is for doctors and educators to become aware of how Tourette syndrome is presented, and what to do when presented with it.

Prevalence

Before Gilles de Tourette's time, TS was an unnamed syndrome with few people being diagnosed (Robertson, & Baron-Cohen, 1998). Since that time more has been found about the syndrome. Even though there is still a lot to learn and find out about TS, the knowledge today is better than that of even five years ago.

Tourette syndrome was "once thought to be a rare disorder, the prevalence of Tourette's syndrome is presently estimated to be between 31 and 157 cases per 1,000 in children aged 13-14 years" (Leckman, 2002, p. 1578). The true number of people with TS is hard to determine due to misdiagnosis, under diagnosis, and people not being tested. Within the United States, it is estimated that up to 100,000 people have TS and are undiagnosed (Shimberg, 1984). Like many other disorders, TS occurs more frequently in boys than girls (Rindner, 2007).

Diagnosis

Diagnosing Tourette's syndrome (TS) is challenging because TS is a clinical diagnosis. There are no blood tests or medical tests available to make the diagnosis (Waltz, 2001). The way that Tourette's is diagnosed is through observation and evaluation of the tics. The doctor looks at the severity of the tics and uses a rating scale such as the Yale Global Tic Severity Scale (Rindner, 2007). Since TS is not the only tic disorder there are important things to consider and watch for when diagnosing TS. "...the criteria for Tourette's disorder include the onset of motor and vocal tics before age 18 and multiple motor and vocal tics that occur throughout the day for at least 1 year (with no tic-free periods of more than 3 consecutive months)" (Rindner, 2007, p. 19). "Diagnostic criteria for Tourette's syndrome highlight the presence of multiple tic types,

the total duration of symptoms, and age of onset before 18 years” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 652). The tics cannot be associated with any physiological effect. That means that the tics cannot come from stimulants or another disorder such as Huntington’s disease (American Psychiatric Association, 2000). When diagnosing TS there are four feature characteristics doctors should look for: 1. involuntary multiple motor tics, 2. vocal tics, 3. symptoms wax and wane, and 4. symptoms change over time (Bronheim, 1991). It is important to note that people with TS can have other symptoms not relating to TS and most do.

Tics

As previously mentioned, one of the main criteria for being diagnosed with Tourette syndrome (TS) is the onset of tics. “Tics are involuntary or semi-voluntary sudden, brief, intermittent, repetitive movements (motor) or sounds (phonic) that are classified as simple or complex” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 651). Tics in general come in two categories, motor and phonic/vocal. Motor involves the movement usually of limbs, body parts, or facial tics such as the blinking of one’s eyes. Phonic is audio or sounds. An example of a phonic tic would be the coughing that Spencer experienced. For most patients, the first symptom usually consists of a facial tic, such as an eye blink. The facial tic is most often replaced by a tic of the neck (Shimberg, 1984). In order to understand TS better, it is important to understand that waxing and waning in frequency of tics occurs. For some with TS tics can become more prevalent with anxiety, stress, excitement, or even physical exertion. Tics may sometimes even appear to have a mind of their own (O’Quinn & Thompson, 1980). Tics are involuntary, which means that people with Tourette’s do not intend to do these actions or make the

noises that they do. Although tics are involuntary, for some people certain things can set off tics such as a handshake for someone with a tic of the hand (Leckman, 2002). Tics cannot be stopped or controlled, however, “all patients develop some ability to inhibit symptoms when the situation demands. Some can inhibit symptoms for hours, some only for a minute. However, each must release these symptoms. Inhibiting increases strain” (Sewell, n.d., n.p.). So although patients with TS cannot control their tics, they may be able to hold them in for awhile. Eventually though, the tics must come out. Often times holding in the tics will cause for a greater urge to tic. Holding in the tics only causes more ticking later, it does not stop the tics, nor do they go away because they were held in (Kenney, Kuo, & Jumenez-Shahed, 2008). Most doctors do not believe that tics can be suppressed. Doctors tend to believe that suppressing the tics only makes things worse (Skipp & Campo-Flores, 2007). One thing that is for certain is that nobody tics on purpose (Waltz, 2001).

Right before a tic occurs most people with Tourette syndrome (TS) get the urge to tic. Depending on the situation and setting, people may try to control the urge or suppress it. The urge to tic and the struggle within someone to try and control the tics is often as incapacitating as the tics themselves (Leckman, 2002). For some, the symptoms of TS tend to decrease when involved in something enjoyable (Shimberg, 1984). For example, if someone really enjoys playing video games, the urge to tic may be less frequent while playing. Stress and anxiety bring on tics. During stressful situations such as school, tics may come out more often and more fervently. Sometimes, children will work to suppress the tics when at school making the tics appear worse at home (Shimberg, 1984).

Examples of simple motor tics include: eye blinking, shoulder rotation, and nose twitching. These are movements that involve only one muscle group (Connors, 2002). Most commonly simple motor tics appear in the face or head. Complex motor tics may consist of hopping, whole body bending, knee bending or a series of simple motor tics (Connors, 2002). The other set of tics is defined as phonic or vocal. Vocal tics are the “repeated uttering of a sound, word or phrase” (Connors, 2002, p. 1). These types of tics can be simple or complex just like motor tics. A simple vocal tic could be anything from a sniff or throat clear to a snort or a howl. Some of the more complex vocal tics are the making of animal sounds or echolalia which is the echoing of what others say (Kenney, Kuo, & Jumenez-Shahed, 2008). People with TS tend to have a variety of tics, some more common than others. There are many people diagnosed with TS that have very unique tics (Waltz, 2001). “Less than 15% of patients exhibit coprolalia, which includes the involuntary blurting of socially inappropriate words or phrases” (Munson, 2005, p. 29). Most people who do have coprolalia only have that specific tic for a short while (Waltz, 2001). Because tics wax and wane, people with Tourette syndrome may only experience a certain type of tic for a very short period of time and may never experience that tic again (Waltz, 2001). Tics get replaced by new ones or new tics get added to current tics (Shimberg, 1984).

Comorbidities

Additional symptoms beyond Tourette’s may constitute a whole new disorder known as a co-morbid condition or comorbidity. Common among people with Tourette syndrome (TS) are Attention Deficit Hyperactivity disorder (ADHD) and Obsessive Compulsive Disorder (OCD). “ More than 50 percent of children with Tourette’s

syndrome experience a psychiatric comorbidity, commonly ADHD by age four and OCD by age seven” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 652). In 2002 a study was done by Wilkinson, Newman, Shytle, Silver, Sanberg, and Sheehan. They found “50-83% of children with TS have Attention Deficit/Hyperactivity disorder (ADHD)” and “28-90% have Obsessive Compulsive Disorder (OCD)” (p. 478). The symptoms of these comorbidities often overpower the symptoms of TS causing a misdiagnosis much like the one Spencer received. People with TS and OCD or ADHD have both disorders. In order to receive the right treatment, both diagnoses have to be made. Although the diagnosis of one disorder may explain all or most symptoms, the symptoms of these disorders are different and need to be treated as such. For people who have Tourette’s ticking is physical whereas OCD consists of rituals and is associated with the mind. (Waltz, 2001). OCD goals are usually associated with the tasks that are carried out, and this is not the case with TS. The tics associated with TS appear more automatic and out of reflex versus the clear intent of an OCD ritual (Elliot & Smith, 2009). While ADHD and OCD are more commonly associated with TS, an excessively high number diagnosed with TS are also diagnosed with a learning disability (Bronheim, 1991).

Treatment

There are several different forms of treatment for TS. The most common type of treatment is medication, however, most people with TS do not require medication as their symptoms do not considerably hinder them (Munson, 2005).

The most important thing to remember when seeking treatment for TS is that each case of Tourette’s is unique. If a doctor recommends a certain medication because it worked with other patients, it may not work for another patient. According to Kenney,

Kuo, and Jumenez-Shahed (2008), there are three types of therapies that are options for treating TS: nonpharmacologic, pharmacologic, and other. Nonpharmacologic includes behavior therapy, modifications in daily life, and identifying the triggers of tics (Kenney, Kuo, & Jumenez-Shahed, 2008). This form of treatment can help people with TS better understand the syndrome and manage it. Some of the more common forms of treatment include cognitive behavior therapy, awareness training, relaxation therapy, habit reversal therapy, and assertiveness training (Kenney, Kuo, & Jumenez-Shahed, 2008).

Cognitive behavioral therapy focuses less on the tics themselves and more on the anxiety accompanied by those tics. This form of therapy cannot stop the ticking but helps with the anxiety which most people feel is more debilitating than the tics themselves. Cognitive behavioral therapy helps one with TS change their behavior which ultimately changes the way they feel and think. This form of therapy usually works quickly and effectively.

The most common form of cognitive behavioral therapy is exposure and response prevention. Someone with TS may have anxiety about ticking in school for fear of being made fun of and feeling embarrassment (Waltz, 2001). Exposure and response prevention mean that this person would expose themselves to the possibility of being made fun of and embarrassment. The person would tic in school. By exposing oneself to the fear and anxiety, they will then be able to deal with the experience. This forces the person with TS to focus solely on the experience and not the anxiety. This process helps your brain recognize when the error messages are being sent out and how to respond in more functional ways (Waltz, 2001). It is not very functional to have a panic attack

simply because you ticked at school; cognitive behavioral therapy helps people with TS live more functional lives.

The premise behind habit reversal therapy is simple; instead of ticking, people with TS will do something else. For instance, a nine year old boy with a tic of squatting after every step now locks his knees and counts to ten before proceeding (Skipp & Campo-Flores, 2007). This form of therapy does not prevent or stop the tics; it simply replaces them with something else.

According to Waltz, (2001) there are four basic factors involved with habit reversal therapy; awareness training, competing response training, social support, and motivational strategies. The first step is to become aware of what happens before a tic. For most children this will be hard considering they are not as in tune with their bodies as adults. An adult such as a parent or teacher may want to help with this step (Waltz, 2001). The next step is to come up with something else to do instead of the tic. These can include something less painful such as the little stopping and counting versus squatting or something as simple as a breathing technique. One of the more important factors when dealing with any form of treatment especially habit reversal is the social support. In order for therapy to work one must have a strong support group. Habit reversal therapy is much more effective with people who have a strong support group such as family and friends, even teachers (Waltz, 2001). The role of the support group is to encourage. When the person with TS successfully avoids a tic, praise is warranted and beneficial. Lastly, motivational strategies need to be implemented in order for habit reversal therapy to work. The object of habit reversal is to change the habit of ticking. In order for this to work, the person with TS needs motivation from him/herself. “Using

self-chosen rewards as a motivating factor to encourage using competing responses” can be the defining factor as to whether or not this form of therapy works (Waltz, 2001, pg. 200).

Pharmacologic therapy is the second treatment option presented by Kenney, Kuo, and Jumenez-Shahed. Of the medications used to treat Tourette syndrome, “dopamine-receptor-blocking drugs remain the most effective pharmacologic treatment for tics” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 656). Haloperidol and Pimozide are the names of this type of medication that have been approved by the Federal Food and Drug Administration (Kenney, Kuo, & Jumenez-Shahed, 2008). Besides dopamine-receptor-blocking drugs, there are also noradrenergic drugs that include Catapres and Tenex. There are also dopamine-depleting drugs such as Tetrabenazine, but this particular drug is still in the investigational stages (Kenney, Kuo, & Jumenez-Shahed, 2008). Even with all the research and science surrounding TS, a magic pill has yet to be found that will make the symptoms disappear without causing side effects (Bronheim, 2001).

With any medication there are risks of side effects. Among the medication used for TS the side effects most often associated are drowsiness, weight gain, and slow thinking (Bronheim, 2001). If the child with TS is already suffering from low self-esteem or having trouble in school, these side effects may do more harm than what the medication would improve. It is important to remember when treating Tourette syndrome that the “goal of treatment should be to improve social functioning, self-esteem, and quality of life” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 654-655).

In regards to the learning environment, there are some forms of treatment that may be available through the student’s school. For most students with Tourette

syndrome (TS) learning disabilities accompany the disorder. Along with accommodations made by the teachers and staff, an occupational therapist may be helpful for students with TS (Giordano, n.d.). An occupational therapist can assist the student in learning ways to better accomplish academic tasks. Many students with TS have problems with handwriting and copying notes. An occupational therapist may be able to help the student learn new ways to assist them in their handwriting and note taking skills. “Children can become withdrawn and socially isolated, and may have poor self-esteem because of their symptoms and teasing by peers” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 653). Children who have TS may also benefit from counseling. Counseling could help the child cope with both the social and physical impact of their disorder (Bronheim, 1991).

Educator's Role

A disturbingly large number of children with Tourette syndrome (TS) have some form of a learning disability (Connors, 2002). Non-verbal learning disabilities are the more common form among children with TS. These types of learning disabilities present themselves within the fine motor, visual motor impairments, and auditory processing (Connors, 2002). There are numerous modifications that teachers, counselors, and staff can do to make learning easier. “The treatment of this complex, perplexing neurological movement disorder requires a strong team approach. The parents, child, medical professionals and especially the teacher, all working together, can effectively ensure that children with this disorder can live up to their fullest potential as individuals” (Bronheim, 1991, p. 17). Students with TS will most often only show signs of TS in the classroom through ticking. It is the response of the school staff that will determine the reactions of

others including the child's peers, and that is what will make or break the child with Tourette syndrome's educational experience. For most children, educators are the people who see them the most. A student with TS can benefit from educators who are both educated and involved. It is the educators who hold the power to help the child adjust (Bronheim, 1991). A crucial part to both the physical and emotional well-being and adjustment of a child with TS is an informed teacher (Bronheim, 1991).

The most important concept for educators to understand is that the child with TS is not misbehaving or acting in defiance but rather is affected by a neurological disorder. One in which the child affected has virtually no control over. Children with TS should not be punished for their disorder just as someone with diabetes would not be punished for displaying signs of low blood sugar (Connors, 2002). "Acceptance of the fact that the symptoms and behaviors are not in the child's control and not purposely done to be "naughty" is sometimes enough to allow the child to function comfortably at home and at school" (Bronheim, 1991, p. 18). Educators play a crucial part in children's lives and the more knowledge an educator has regarding this disorder the better chances the child has of succeeding.

When it comes to learning disabilities and Tourette syndrome, the areas most affected are fine and visual motor impairment. These impairments affect the student's handwriting, note taking, and test taking abilities. Fine motor impairment can cause students handwriting to be messy and illegible (Connors, 2002). Visual motor impairment usually causes students' inability to correctly copy down a problem from the board into their homework assignment or to fill in the correct bubble on a standardized test score sheet. Students with TS may also lack the ability to transfer the data correctly

from one item to another (Connors, 2002). “The vast majority of students with TS have dysgraphia. Dysgraphia can be defined as the inability to get thoughts from the brain to the paper for a wide variety of reasons” (Giordano, n. d.). This is what causes most TS students to have trouble with their handwriting and copying abilities. The best way to help students with these disabilities is to get creative. There are very simple modifications that can be made to help the student learn better. For example, the easiest and usually most effective modification is to allow the student to leave the classroom for a short period of time. Have the student run an errand for the teacher or allow him or her to get a drink of water. This will allow the student the time away from others and away from the social embarrassment to tic which in turn may allow them to pay better attention and get back to the task at hand (Connors, 2002).

Tics are triggered more by stress and anxiety. This being said, there are simple ways to help alleviate stress and anxiety for the student, such as allowing the student to take tests in a separate room away from others. This will allow the student ease in concentrating and the embarrassment free room of ticking (Connors, 2002). Some easy accommodations to help students are:

- Use of computer for taking notes, writing essays and long answers
- Allow printing in place of cursive if this is easier for the child
- Extended time for tests, quizzes, projects, etc. (Giordano, n.d.)
- Seat student in area free from distractions, allowing ample space for motor tics
- Have an agreed upon cue for student to leave classroom
- Provide a quiet place for student when tics are severe (Ottinger, 1999)

There are two very important things to remember when working with a student that has TS. The first is to never ask them to stop ticking because that is nearly impossible and that will only cause more stress which in turn will cause more tics. The second is to help educate others about the disorder, especially classmates. “Education of family, teachers, classmates, and other school personnel helps create an accepting environment for a child with Tourette’s syndrome who may otherwise be teased, ridiculed, disciplined, or simply told to “stop it”” (Kenney, Kuo, & Jumenez-Shahed, 2008, p. 655). If possible, include the student with TS to help. It will show the other students that TS is not something to be afraid of and the child with TS will feel included (HBO & TSA, 2005). The school atmosphere will be easier for all students if they are aware of the disorder.

Another problem educators may have to deal with is the student with TS not wanting to be singled out. This can cause problems because it may mean the student will refuse want accommodations so that the other students will not find out about the disorder (Giordano, n. d.). In cases like this it is most important for teachers, counselors, and staff to make accommodations and provide support as seamless as possible for the student. The point of the accommodations is to help the student and not to hinder them socially or academically. “Guidance, support and patience on the part of all the educators working with that child may be helpful in overcoming this. It will require consistent support and discussions with the student and student’s peers regarding “fair is not always equal and equal is not always fair”” (Giordano, n.d.).

Research shows that “children with TS who can feel comfortable with their teachers and peers blossom in school and grow to become individuals who can develop

their talents and make a positive contribution in life” (Bronheim, 1991, p. 20). Children with TS have the same capabilities as other students without the disorder. Research also shows that teachers who demonstrate knowledge on TS can be a great asset to a student’s personal adjustment and positive self-image (Shimberg, 1984). Children spend a majority of their time in a school setting. Educators play a crucial role in helping the child with TS adjust to life both in and outside of school. It is important to note that teachers who understand the disorder are in a better position to help the student than those teachers who know little or nothing at all (Bronheim, 1991). Educators can also be a crucial part of the diagnosing process. If educators are aware of this perplexing disorder then children’s lives will hopefully be made easier. The more people made aware of TS the more understanding a child with the disorder has. “...teachers, school nurses, counselors, physical education instructors, etc. They need to understand Tourette because if they don’t, their mistaken perceptions of [the child] will alter the way they feel about him [or her], and how they interact” (Shimberg, 1984, p. 15). The educator who is able to look beyond the disorder and see the child is incredibly important to the well being and development of the child with TS (Bronheim, 1991).

Chapter III: Summary, Critical Analysis, and Recommendations

This chapter will summarize the findings from the literature reviewed. In conclusion, the chapter will provide further recommendations for research in the area of Tourette syndrome.

Summary

Tourette syndrome (TS) is a neurological disorder that affects people of all races, ethnicities, and ages. Tics must be present prior to age eighteen. Children who present with symptoms of TS will need a trained medical professional to make a proper diagnosis as TS can also present itself much like obsessive compulsive disorder or attention deficit/hyperactivity disorder. These may be comorbidities of TS but diagnosis and treatment need to be addressed differently as each disorder affects everyone differently.

Tourette syndrome (TS) is a debilitating disorder that affects children. The majority of a child's time is spent in school between the ages of five and eighteen years old. Educators not only play a crucial role in a child's educational development but also in their social development. For children with TS, it is even more important to have an understanding teacher. Teachers and educators alike are important to all children's lives. For those children with a disability such as Tourette's, it is even more important the school personal know what the child is going through and are able to teach the children compassion and acceptance. Because of hate crimes, tolerance throughout the United States is low for people being discriminated against or bullied because of being different. Children with TS could potentially qualify for special education or 504 plans under the Individuals with Disabilities Education Improvement Act (IDEIA). Educators need to be aware of that fact or they could potentially be in trouble legally. Although there are

many things that educators can do to help a child with TS live a more fulfilling life and function well in school, the most important thing for educators to realize is that children with TS cannot help their tics, they cannot control them and most of all these children do not want to tic anymore than those around want to witness it.

When looking for interventions to help children dealing with Tourette syndrome (TS), it is essential to first foster an environment that can support these students. This can be done by helping other students understand the condition. Educators need to help change how students interact with those who are different (Waltz, 2001). Most schools already have a no bullying policy and this is a good start. However, in order for any interventions to be effective the policy has to be in effect and also enforced and adhered to. Children are not the only people that will need to be supportive of their peers, adults involved in the child with Tourette syndrome's life are also very important. If adults do not know about or understand the disorder then how are the kids supposed to learn? The adults that are involved need to know compassion and be able to teach that to the children in the school. Compassion is an easy tool that can go a long way in an intervention for a child with TS. Holly-not sure if previous sentences on adult cooperation is necessary-we could assume that teacher sand other school personnel

For the kids who are dealing with TS certain skills might be helpful for them to better function in a school setting. TS is a debilitating disorder that can be very hard for a young child to cope with and accept. Children with TS may have anger issues, lack social skills, and have low self-esteem (Waltz, 2001). Teaching kids with TS anger management and social skills would greatly help improve their time at school and their life in general. These kids may have low self-esteem because of their tics and other kids

picking on them. Along with a no bullying policy, it is important to educate children about bullying and its effects. Bullying curriculum is available and is able to help address the issues of disability and difference (Waltz, 2001). Another great resource for schools is the Tourette syndrome association website. There are links to support groups for children and adults. The website is filled with great information on the disorder that educators and students can use to their advantage. These resources can help educate others about TS and hopefully help make the lives of children with TS better.

Critical Analysis

Educators need to be knowledgeable in regards to Tourette syndrome (TS). For most students with TS school can be a terrifying place. Children with this disorder can experience tics at anytime whether that be in front of peers, family, or teachers (Rindner, 2007). Teachers and staff who are aware of this disorder and what it entails can make all the difference for children dealing with TS. The more people who are aware of TS the better it is for everyone.

Even though there are special education laws and practices in place within the school systems, not all children with TS will qualify for these services. This being said, those who do not qualify may need extra care within the regular education classroom. There are simple things that can be done to help those with TS both educationally and socially. Teachers and staff who know of these accommodations truly make a difference in the lives of those children who have this incapacitating disorder.

Although there is research on Tourette syndrome, it is not necessarily available to all who need it or would benefit from it. The education of Tourette syndrome needs to be implemented more firmly in educator training programs. There are a wide range of

disorders including TS that are briefly discussed in classes for educators but more needs to be done. Disorders such as Tourette's are on the rise and this affects the schools (Leckman, 2002). Children with TS can only benefit from their peers and the adults in their lives knowing and understanding what it is they deal with on a daily basis.

A critical analysis of the treatment that is in place for children with TS includes medication and different forms of therapy. There are numerous varieties of medication that are available for help with treating TS; some are more experimental than others. For each individual with TS, the treatment plan needs to be different. Critical analysis of the various therapies shows that much like, it is a case to case basis. Tourette syndrome varies in each person that has the disorder. No two people will have the same tics at the same time. Some tics may be more extreme in others. The different kinds of therapy that have been most effective are habit reversal and cognitive therapy. Therapy unlike medication does not have side effects, although it can take longer to see any type of effect.

Habit reversal includes awareness training which involves the patient becoming aware of the sensation that precedes the tic (Waltz, 2001). This is harder for young children because they are less aware of their bodies. Habit reversal can help improve a person with Tourette syndrome's social life; however, it takes a lot of work and focus. This form of therapy is still relatively new and research has shown that this type of therapy can in some people make ticking worse (Waltz, 2001). Habit reversal therapy, much like medication, should be used on a trial basis with TS patients. It may or may not work and the effort put into the therapy may be more than the patient gets out of the therapy. It used to be thought that habit reversal therapy was more of a substitution

therapy. In other words, if a tic was alleviated something else would be done in its place thus causing substitution rather than helping the problem of ticking. However, this is not the case. Some have also argued that being made aware of tics and when they are going to happen would force those behaviors to increase. Studies have also shown that this is not the case either. In fact, studies have shown that for some people with TS, an increased awareness actually helps reduce the symptoms (Elliot & Smith, 2009).

Cognitive behavioral therapy involves attentiveness to the here and now. The person with TS changes behavior which in turn helps change the way they feel and think (Waltz, 2001). This is the more practical type of therapy. It helps patients deal with the symptoms; it does not stop ticking but rather makes it more bearable. Cognitive therapy tends to work better for those with TS. This type of therapy works fast and works well for most. For younger children cognitive therapy is a much better option than habit reversal. This is because cognitive therapy does not use insight but rather uses action (Waltz, 2001). Children with TS would benefit from cognitive therapy because they are told to focus on the action of ticking, what happens to their body. Cognitive therapy helps those with TS notice the action that goes along with a tic, both before and during. This way, the patient can focus on what happens and change it, thus lessening tics or the urge to tic. This form of therapy tends to have the most success among children. No form of therapy stops tics completely but cognitive behavioral therapy helps people with TS live more functional lives. The tics associated with TS can be severely debilitating. Cognitive behavioral therapy's focus is to help those with TS be able to live life, go to school and perform well.

School Based Interventions

Children spend the majority of their time within a school setting. This is where they learn personal/social skills as well as academic. School based interventions are important in helping these children learn their skills. Interventions are needed when children with TS are not making adequate progress. When tics are interfering with the child's learning, school interventions are necessary (Findley, 2002). School personnel should be made aware of certain things regarding a child with TS, such as the age the TS symptoms started (Bagheri, Kerbeshian, & Burd, 1999). With this information, the school will be better equipped to help determine the correct interventions for the child.

A regular school day is anywhere from seven to eight hours long. For a child with Tourette's this time can be especially excoriating. The interventions a school uses can be simple or more complex. Simple interventions most often would not require any sort of special education plan. These types of interventions are things that teachers can do on their own. Educators do need to get creative though because each child is different and each child's symptoms are different. Some of the simple interventions can include things such as allowing the child to sit near the door and allowing the child to take a break if needed in the hall when tics get bad. They can also include social skills training or having the child partake in a friendship group in order to strengthen social skills (Palmquist, 2004). More complex interventions can involve 504 plans or even individualized education plans (IEP). Whichever interventions are used, educators need to be looking at the child in his/her entirety and not just the symptoms (Connors, 2005).

Recommendations

The most important recommendation would be to educate those involved in the school system on Tourette syndrome. Within teacher, counselor, and principal training programs there needs to be more emphasis on the disorders that affect children, specifically Tourette's. Aside from family, educators spend the most time with children and therefore they are in a good position to help the child with Tourette syndrome.

Programs within schools should be implemented to assist with children who have TS. Another component of helping those with TS is to educate not only the teachers and staff, but students as well. As stated in the *I Have Tourette's but Tourette's Doesn't Have Me* DVD, children with TS are encouraged to be a part of the education process for their peers. It is the children with the disorder who have the most information on what they are dealing with and going through. To have the other children see the child with TS talk openly about it helps teach understanding and acceptance among peers.

To better help all students understand a variety of disorders including TS; a school based program would be beneficial. The recommendation of a curriculum that includes educating students on the disorders that affect their classmates and may even be affecting them. This could be part of a health class or even science class. Taking the time to enlighten students of even the most basic symptoms and information on disorders would go a long way for understanding and acceptance. Unless students are affected with a disorder, most know little to nothing about any and even those who are affected may not have all the facts. The best way to help students who are affected is to inform everyone. Knowledge can only empower not inhibit.

Along with the above mentioned recommendations, more research needs to be done. This disorder is not going away anytime soon and the more that is found out the closer a cure becomes. Living with this disorder is not easy. In a sense you are trapped in your own body. Although there is no cure at this point, treatment and interventions are available. The learning process needs to never cease and those that do know need to share the information.

References

- American Family Physician. (2008). *Tourette's syndrome: What it is and how it's treated*. Retrieved March 22, 2008, from: EBSCO host database.
- American Psychiatric Association. (2000). *Desk reference to the diagnostic criteria from DSM-IV-TR*. Arlington, VA
- Bagheri, M., Kerbeshian, J., & Burd, L. (1999). Recognition and management of Tourette's syndrome and tic disorders. *American Family Physician*, 59, 2263-2272, 2274. Retrieved February 28, 2009. from: EBSCO host database.
- Bronheim, S. (1991, January). An educator's guide to Tourette syndrome. *Journal of Learning Disabilities*, 24(1), 17-22.
- Connors, S. (2005). *Catalog of accommodations for students with Tourette syndrome, attention deficit hyperactivity disorder and obsessive compulsive disorder*. Bayside, NY: Tourette Syndrome Association, Inc.
- Connors, S. (2002). Tourette syndrome: An inside perspective. *Communiqué*, 31(2), 8-9.
- Elliot, C., & Smith, L. (2009). *Obsessive-compulsive disorder for dummies*. Hoboken, NJ: Wiley Publishing
- Findley, D. (2002). Tourette syndrome: information for educators. *Communiqué*, 31, 195-198.
- Giordano, K.J. (n.d.). *TS is more than tics*. Bayside, NY: Tourette Syndrome Association, Inc.
- HBO and the Tourette Syndrome Association (Producers). (2005). *I have Tourette's but Tourette's doesn't have me*. [DVD]. (Available: Tourette Syndrome Association Website) <http://www.tsa-usa.org/>

- Kenney, C., Kuo, S., & Jumenez-Shahed, J. (2008). Tourette's syndrome. *American Family Physician*, 77, 651-658. Retrieved March 22, 2008, from: EBSCO host database.
- Leckman, J. (2002). Tourette's syndrome. *The Lancet*, 360, 1577-1586. Retrieved August 5, 2008, from: EBSCO host database.
- Munson, B. (2005, August). ...About Tourette's syndrome. *Nursing*, 35, 29. Retrieved September 15, 2008, from: Academic Search Elite database.
- O'Quinn, A., & Thompson, R.J. (1980). Tourette's syndrome: An expanded view. *Pediatrics*, 66, 420-423. Retrieved August, 5, 2008, from: EBSCO host database.
- Ottinger, B. (1999). *Modifications for students with Tourette syndrome, attention-deficit disorder and obsessive-compulsive disorder*. Retrieved September 27, 1999, from: www.vh.org/Patients/IHB/Psych?Tourette/Modifications.html
- Palmquist, R. (2004). *Tourette syndrome: a guide for parents*. Bethesda, MD: National Association of School Psychologists.
- Rindner, E. (2007, August). Living with Tourette's syndrome. *Journal of Psychosocial Nursing & Mental Health Services*, 45(8), 19-23. Retrieved November 14, 2007, from: CINAHL Plus database.
- Robertson, M., & Baron-Cohen, S. (1998). *Tourette syndrome: The facts* (2nd edition). Oxford, England: Oxford University Press.
- Sewell, J. (n.d.). *Information about Tourette syndrome for teachers*. (Available: 404 Cheyenne Drive, Waukesha, W 53188)
- Shimberg, E.F. (1984, May). *Coping with Tourette syndrome: A parent's viewpoint*. Milford, OH: Tourette Syndrome Association of Ohio, Inc.

Skipp, C., & Campo-Flores, A. (2007, September 3). Taking on Tourette's. *Newsweek*, 150, 53. Retrieved November 14, 2007, from Business Source Elite database.

Waltz, M. (2001). *Tourette's syndrome: Finding answers and getting help*. Sebastopol, CA: O'Reilly & Associates, Inc.

Wilkinson, B., Newman, M., Shytle, R., Silver, A., Sanberg, P., & Sheehan, D. (2002, December). Family impact of Tourette's syndrome. *Journal of Child & Family Studies*, 10(4), 477-483. Retrieved September 15, 2008, from: MasterFILE Premier database.