

Tourette's Syndrome: A Primer for School Leaders

The symptoms of Tourette's syndrome affect students academically as well as socially.

By **Steven R. Shaw, Amelia H. Woo, and Shana Valo**

Marc is seated in the office waiting for the principal. He has been sent to the office for making disruptive noises and starting a fight his classroom. The referral notice from the teacher indicates that Marc made repeated barking noises and would not stop after being instructed to do so. He told the teacher that he could not help it. Other students became annoyed and an argument among the students ensued.

The principal looks into the waiting area and sees a young man pacing and looking agitated. He stretches his neck repeatedly, rolls his eyes, and grimaces. The principal also notices that the student clears his throat a lot. Suddenly, he makes a single sharp yipping noise that startles and angers the office staff.

When talking to Marc, the principal learns that he is a new student at the school and that this is not the first time

he has had problems in the classroom. He was suspended for disrupting class at his previous school and has moved between special and regular education throughout his school career. His records show that he has good academic skills but is too disruptive to attend most classes. Marc then explains that he has Tourette's syndrome (TS) and that he cannot help but be disruptive no matter how hard he tries. Marc reports that one of his biggest problems is the reaction of teachers and peers. His tics cause him great frustration and embarrassment.

The principal asks Marc's parents for help. They describe the nature of his tics and report a few triggers that seem to result in an increase in the frequency and severity of tics. Among these triggers are chocolate, cigarette smoke, and extreme levels of stress. They also express a strong desire that

Marc receive a regular education. To the greatest degree possible, they want Marc to be treated the same as other students in the school.

Marc's case raises questions of how to respond effectively to teachers' legitimate concerns for orderly classrooms while providing a free and appropriate education to a student with a medical condition.

Characteristics

Students with TS are a heterogeneous group. The symptoms of some students are mild and require few, if any, accommodations. The symptoms of other students can be extremely problematic for the students and disruptive for their teachers and peers.

TS has an estimated prevalence rate as high as 1% to 4% in a general high school population (Zhu, Leung, Liu, & Su, 2005) and affects males about three times more than females (Jankovic, 2006). Symptoms generally appear during the first decade of life and subside around young adulthood with periods of waxing and waning throughout. Attention deficit hyperactivity disorder (ADHD), poor impulse control, behavioral outbursts, and obsessive compulsive disorder (OCD) also co-occur with the syndrome, which further complicates the lives of those affected (Jankovic).

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TS is characterized by the presence of tics, both physical and vocal, over a period of at least one year. Tics are sudden, brief, stereotyped, and repetitive movements or sounds. Simple tics involve only one single muscle or group of muscles, such as eye blinking, coughing, or head or limb twitching. More complex types of tics include hitting, jumping, making lewd or obscene gestures, and imitating others (Jankovic, 2006). Motor tics, such as eye blinks, may begin as early as 3 years old, and vocal tics typically follow several years later (Leckman, 2002). Tic severity generally peaks in the early teenage years (Leckman), further complicating adolescent adjustment and peer acceptance during high school. Often, a dramatic decrease in tics is seen when the person is about 19 or 20 years old. It is not unusual for tics to come in bursts for a day or even over weeks.

Students with TS often report that they know a tic is coming when they experience sensations in a localized area or have a more general feeling of discomfort, anxiety, or other emotional symptoms. Many students try to control the tics by suppressing them when they experience these sensations, but they feel great discomfort and stress when doing so. Some students with TS have tics only when they are under stress or

when a specific trigger is present. Students with more severe TS may experience 30 to 100 tics per minute (Eldridge, Sweet, Lake, Ziegler, & Shapiro, 1997).

Behavioral Considerations

Students with TS face many behavioral and social difficulties, such as co-occurring disorders: 50% to 90% of children and adolescents affected by TS also have ADHD, oppositional defiant disorder, or conduct disorder (Sukhodolsky et al., 2003). In fact, the prevalence rate of ADHD was found to be 48.8% among students with TS compared to 4.2% among the general population, and those students also are less responsive to stimulant medication than other students with ADHD (Comings & Comings, 1987).

Even children and adolescents without co-occurring ADHD are more inattentive and have more impulse control problems than their unaffected peers (Schultz et al., 1998). Along with ADHD, many adolescents are also affected by OCD, which results in obsessive thoughts and compulsions that further divert their attention from tasks.

Finally, students with TS frequently struggle to suppress oncoming tics and overcome the sedative side effects of medications.

Often the social and emotional consequences of the behavior problems associated with TS are more impairing and disruptive than the tics themselves (Zhu et al., 2005). Tics have the greatest impact on children's social relationships and self-esteem between the ages of 7 and 12 (Leckman, 2002). Students with TS are at a greater risk for having poor peer relationships and becoming withdrawn and aggressive (Chang, Tu, & Wang, 2004). Moreover, high rates of ADHD and OCD associated with TS further complicate the social lives of affected adolescents. Conduct disorders lead to unpopularity among peers

and teachers, as well as peer rejection (Carter et al., 2000). Also, adolescents with TS and ADHD are more vulnerable to depression, drug abuse, and antisocial behavior (Leckman, 2002).

Impact on School Performance

The intelligence test scores of students with TS are generally normal, although performance (nonverbal) IQ often averages 2 to 11 points lower than verbal IQ. Yet many students with TS have significant impairment in their ability to learn, to read, and to retain information (Comings & Comings, 1987) and

require specialized education programs. Further, students with TS are often educated in classes for students with learning disabilities, severe emotional disturbances, and other health impairments.

For students with TS, the most noticeable behaviors are related to hyperactivity (Carter et al., 2000). Students with TS have greater difficulty staying seated and staying still. They are also more inattentive and impulsive. Specifically, they tend to have difficulty attending to teachers, are easily distracted, have difficulty concentrating, need extra supervision, and often act before thinking. In addition, students with TS

may have difficulty completing tasks, sticking with an activity, organizing their work, and waiting their turn, and they frequently call out in class.

But problems in school functioning are not solely due to these ADHD symptoms. Students with TS often have reading problems. The most significant problem is poor retention, which interferes with their ability to learn academic subjects and social skills. They have difficulties with reading speed and letter, number, or word reversal.

Phobias and panic attacks are additional problems for students with TS. Severe test anxiety is one of the most serious and common issues in school. The likelihood of anxiety and phobias increases with the severity of the behavioral manifestations of the student.

Many students with TS have speech problems, including stuttering and talking so rapidly that they are difficult to understand. These difficulties are not solely due to motor or vocal tics. In fact, it seems that stuttering is a primary result of the presence of the TS gene (Comings & Comings, 1987).

Finally, motor tics, especially if they are severe, cause three main types of problems in school: First, rapid eye-blinking, eye-gazing, and head-jerking tics may interfere with reading or writing because the student has difficulty keeping their eyes on the task. Second, tics may result in teasing, bullying, or ostracizing by the student's peers, especially when the student has leg tics that affect walking. Third, teachers may misinterpret the tics as deliberate misbehavior and discipline the students for actions that are uncontrollable.

Common Misunderstandings

People with TS can control the tics. To some small degree, this is true. Anxiety tends to worsen tics. Therefore, counseling to reduce anxiety appears to have a small effect. Fear of embarrassment, peer pressure, and concentration on a task can result in temporarily reduced tic activity. Systematic efforts to train tic reduction results in a 50% to 60% decrease in tics, but there is little evidence that tics can be entirely controlled for most people with TS.

If people with TS hold in their tics, there will be a buildup of pressure to the point where there is a rebound effect—an explosion of tics. To the degree that people can control tic behaviors, there does not appear to be any evidence of a rebound effect, but sometimes the intense effort required to hold in tics can produce anxiety.

People with TS use profanity. There are many types of tics. Most vocal tics are throat clearing or barking noises. A small percentage of people with TS have profanity tics. Many students with TS may use profanity more than their peers because of impulse control issues rather than tics.

People with TS are emotionally disabled or mentally ill. Many people with TS develop anxiety disorders, including obsessive compulsive disorder and attention deficit hyperactivity disorder. There are often adjustment and social problems because of the tic behaviors. Atypical antipsychotic medication is the treatment of choice for controlling tics although TS is not considered a psychotic disorder. People with TS are at risk for mental health problems, but many people with TS have no major mental health impairment.

People with TS will grow out of it. Although the symptoms of TS appear to change with age, most evidence suggests that TS is a lifelong problem.

Resources

Taking Action

Designing action plans for students with TS is a delicate balancing act. Although the needs of students with TS are diverse, there are some measures that can reduce tics, reduce the consequences of having tics, and help alleviate other symptoms of TS. The best approach is to individualize action plans to address the most problematic symptoms for each student.

Released times. For some students with TS, controlling tics is like holding in sneezes. Holding in tics all day is stressful and tiring. A private place and scheduled time to allow the student to have tics without embarrassment can be helpful.

Regularly scheduled exercise. Exercise can help students burn off high levels of energy and improve symptoms of anxiety.

The environment. Making changes to the school environment may reduce the triggers to tics. For example, new paint and carpet odors, florescent lights, and sugary treats may be triggers. The evidence does not clearly show that such factors trigger tics, but even if they do not, a placebo—the suggestion that removing the suspected triggers will help reduce tics—can have powerful and positive effects. When possible, work with parents and students to identify and eliminate triggers.

Social skills training. To a large degree, the most obvious symptoms of TS are much like those of ADHD. Social skill deficits are major factors in general adjustment and coping skill development. Social skills can include not only making friends and resolving conflicts but also talking with adults, following rules, taking tests, and studying.

Children With Tourette Syndrome: A Parent's Guide. T. Haerle. 2003. Bethesda, MD: Woodbine House.

Tourette's Syndrome: Finding Answers and Getting Help. M. Waltz. 2001. Sebastopol, CA: O'Reilly.

Straight Talk About Psychiatric Medications for Kids. T. E. Wilens. 2003. New York: Guilford.

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Individual or group counseling. Counseling can help students develop coping skills and appropriate emotional responses to the challenges of TS.

Medication. Knowing and reporting the effects of medications at school is an important part of treatment evaluation. The school should develop effective relationships with the parents and medical professionals.

Testing accommodations. Students who have special education or Section 504 plans should have specific testing accommodations. Some appropriate accommodations include taking tests alone, having extra time for tests, and performing relaxation exercises before taking tests.

Conclusion

If one or more of your students have TS, finding ways to help them manage their symptoms can alleviate their academic and social difficulties, reduce the distraction to their peers, and assist their teachers. **PL**

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