TS is More than Tics: Understanding Behavioral Challenges & Related Symptoms

Behavioral Challenges Related to Tourette Syndrome

Tourette Syndrome (TS) and its related disorders can manifest as behaviors that often appear to be purposefully disruptive, attention seeking or manipulative. Therefore, it is not unusual to misinterpret these neurological symptoms of the disorder as behavioral problems.

The U.S. Department of Education (DOE) has included Tourette Syndrome under the Individuals with Disabilities Education Act (IDEA) definition of "other health impairment." The following statement addresses the common misperceptions of TS:

…we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.1

Students with TS may be punished for symptoms and behaviors that educators assume are disruptive and purposeful. Even an empathetic teacher, who recognizes the student as a child who has abilities may be frustrated because of the difficulties in understanding the cause of the behavior. Ross Greene, PhD, noted psychologist and author of The Explosive Child, writes that, "It is your explanation of the behavior that leads directly to how you respond to it." For example, a student with TS may appear to refuse to complete his assignment. One educator may perceive the student as being capable of this task but unwilling, and will, therefore, punish the student. Another educator, who sees this refusal as a sign of his symptoms of the neurological condition, will realize that the student's hesitance towards the assignment is due to his fear of failing, a skills deficit, processing delays, or obsessive compulsive difficulties, etc., and not an indication of defiance or laziness. Thus, the educator's response will be positive and proactive rather than negative and reactive.

Educators are more likely to punish a student who they see as being or causing the problem. If instead the educational team recognizes that the student is struggling due to an underlying problem, they will be more likely to provide unique and creative strategies for that student. When educators consider what they can do for the child and not what they can do to the child, strategies are more positive, proactive and effective.

TOURETTE SYNDROME: BEHAVIORAL CHALLENGES

DISINHIBITION

Inappropriate statements or behaviors can result from an inability to consistently apply "mental brakes" – the child cannot consistently stop himself from expressing thoughts or displaying actions that most students have the ability to control. **Examples of disinhibition might include excessive silliness, sassiness, uncensored and/or inappropriate comments, emotional outbursts, contextual swearing, explosive anger, or oppositional defiance.**

For a student who has trouble inhibiting, a sign saying "Don't Touch, Wet Paint" may serve as an invitation to touch the paint. Obeying the sign means inhibiting the very behavior suggested by the sign. Inhibiting behaviors is challenging for all children but can present a far greater challenge for students with TS due to their impulsivity and inconsistent ability to apply their mental brakes.

When a student says something inappropriate or acts impulsively, the teacher may not believe that every instance is out of the student's control. It is important to recognize that TS most often encompasses more than just the tics themselves. Many with TS, whether they have severe or mild physical and vocal tics, also have significant difficulty with invisible (but extremely disruptive) disinhibition. When a student is told that her turn on the computer is over and she makes an inappropriate remark, this student may actually be struggling with the inability to inhibit. In these instances, it is best to use 'planned ignoring' when possible, as well as to provide counseling support to help her understand why she has trouble applying the 'mental brakes'. Then, teach her strategies that allow a more appropriate response. Since her actions are due to a neurological disorder and are not purposeful, this may require extensive practice and patience.

OPPOSITIONAL BEHAVIORS

Approximately 26% of children with TS also have behavioral challenges such as Oppositional Defiant Disorder (ODD) or Conduct Disorder (CD). The support team should look for the underlying difficulties that may contribute to the oppositional behaviors, such as OCD, ADHD, tics, processing difficulties, written language deficits, and sensory issues. These related difficulties may prevent the child from expressing his or her needs or responding appropriately. For example, a student who becomes oppositional only during a task requiring writing may be communicating through his behavior that he is struggling with writing. If a student displays defiant behavior in a particular setting, this may indicate that he or she is somehow overwhelmed in this setting.

IMMATURITY

Children with TS frequently exhibit behavior that might be immature for their age, even though they may have more advanced academic abilities. Adults may perceive the age-

inappropriate behavior as being purposeful. However, these behaviors should be understood in the context of the disability.

OBSESSIVE COMPULSIVE DISORDER AND BEHAVIORS

Obsessive Compulsive Disorder (OCD) is characterized by recurrent, unwanted thoughts and images (obsessions), and/or repetitive behaviors (compulsions), which the person hopes will prevent the obsessive thoughts or make them stop. Performing the compulsions provides only temporary relief and not performing them significantly increases anxiety. OCD is a common co-occurring condition for people with TS.

Students may experience a wide array of difficulties due to OCD including, but not limited to, rigid thinking, perfection, difficulty with transitions, poor social skills, inability to respond in an appropriate manner, and beginning and/or completing work. They are often internally driven to complete the current task or stay in the current environment and not move on.

Some children with TS may not meet the full criteria for an OCD diagnosis, but may still experience obsessive compulsive behaviors, that may be misunderstood.

Unrecognized symptoms of OCD can often result in punishment. However, being punished can increase students' anxiety, inhibit academic performance, and lead to behaviors which are then interpreted as oppositional defiant, disrespectful, and/or lazy. Providing appropriate educational supports is significantly complicated for students with TS and OCD because it is often difficult to tell the difference between complex tics and obsessive-compulsive behaviors.

RAGE AND OUTBURSTS

A small number of children with TS have outbursts of uncontrollable anger, often referred to in the TS community as "rage". **Generally, this is displayed in the home setting more frequently than at school**. The child may yell, throw things, name-call, all in a manner that seems out of the ordinary. This characteristic is neither the fault of the child nor the parents. In many instances, professionals, and even friends and family members, tend to attribute these outbursts to the parenting skills or the situation at home. Even more, many parents tend to blame themselves. The causes for these outbursts may not be obvious but may be due to the neurological disorder. Teachers and families should examine why the outbursts happened and explore what led up to them.

Sometimes a change in routine or expectation of an event for a child may bring on these outbursts in a child who has difficulty with change. Inappropriate forms of intervention (including negative consequences) may also trigger or increase these rage episodes. It is critically important that adults in the child's life become aware of the factors that either intensify or lessen the explosive behaviors. In addition, children who are affected by neurologic rage need trusted adults who can provide care with flexibility and calmness.

EXTREME REACTIONS TO THE ENVIRONMENT

In general, students with TS have a heightened response to their environment that may cause them to become overwhelmed. This can escalate into a 'flight or fight' reaction. If this should happen, it is important that the student be placed with teachers who can remain calm in these situations and provide necessary supports.

DIFFICULTIES WITH TRANSITIONS

For the student with TS and additional anxiety, transition difficulties can be exacerbated. Transition strategies can be written into the IEP for teachers to follow. If a strategy has not been established, the current teacher may need to experiment with different ways of preparing the student for approaching transitions.

USE OF INAPPROPRIATE LANGUAGE (COPROLALIA)

Coprolalia is a symptom of TS characterized by unwelcome, unwanted and uncontrollable utterances of words or phrases that are inappropriate. Commonly, people come to know coprolalia as the "swearing tic". This symptom is often mocked in movies and other media, which contributes to misconceptions of TS. Many people believe that a person must have coprolalia in order to have a diagnosis of Tourette Syndrome. Only a minority of individuals with TS have this symptom. Ironically, while this is the most recognizable symptom, it is also misunderstood and often responsible for students being removed from class, receiving detention or suspension.

A common misunderstanding is that in order for 'inappropriate words or sounds' to be a symptom of TS, they must be said 'out of the blue' and must be repetitive in nature. This leads to the mistaken belief that if a student swears once and/or at an "appropriate" time, then it is not due to TS and therefore deserves punishment. However, it is important to keep in mind that TS symptoms, including coprolalia, are different for every individual, inconsistent, change periodically, wax and wane and are increased by stress. The inconsistency of a child with TS to inhibit the use of inappropriate behaviors and statements adds to the difficulty of understanding the symptoms of this disorder. The following is an example of coprolalia that may be misinterpreted as purposeful:

A student is being punished for what the teacher thought was said in a disrespectful manner. The teacher reported that every time she said that the class was going to have a test or homework, the girl would say "shut up".

While this is certainly inappropriate for the student to say this, it may be a symptom of TS. Indeed, many of the students may have been thinking the same thing, but they were able to inhibit these thoughts. The student with TS was not able to inhibit blurting out inappropriate statements that appeared to be purposeful. Perhaps the event of taking a test heightened her stress, contributed to her inability to inhibit, and made her tics worse. In these instances, punishments may not be an effective strategy to manage symptoms. The student may need to work with a professional to develop a better management approach.

REFUSING SUPPORTS AND ACCOMMODATIONS

A student may refuse supports and accommodations because he or she does not want to be singled out as being different. Guidance, support, and patience by parents and educators may help the child overcome his or her resistance for support. A positive and proactive plan should include discussions with the student emphasizing that "fair is not always equal, and equal is not always fair." If a child requires different supports, it's not "bad" or "weird", but simply "fair" for his or her situation.

BEHAVIORS THAT ARE DIFFERENT AT HOME AND SCHOOL

Students with TS generally do not have all the related issues discussed in this article. However, it is important for people to recognize that for the majority of students with TS, **TS is more than tics**. Managing the many and varied symptoms and difficulties, while attempting to complete schoolwork and have positive social interactions, can be exhausting and frustrating for the student. It is important that all school personnel be aware that regardless of how the students appear in school, the demands of the school day can result in a significant and distressing increase in symptoms when they arrive home. Adding to this is the stress of them needing to complete homework. It is often necessary, when possible, for the family to have an outside counselor involved. This professional can be instrumental in the process of developing supports and accommodations in the school setting which may assist in alleviating difficulties at home.

Consider a student with TS whose symptoms include rage manifested in the home, being expected to complete the same quantity of homework as other students in the class. The question that must be considered is, "At what cost is this to the family's and the student's physical and emotional wellbeing?" In some cases, the desired outcome of completed homework must be weighed carefully against the child's welfare and best interest. Is it possible to modify the workload in a manner that considers the impact of tics and numerous related disorders? It is sometimes critical to provide or designate a staff person who is capable of assisting with or managing the student's workload so that education is not compromised, while anxiety, stress and symptoms are reduced.

OTHER COMMON DIFFICULTIES FOR STUDENTS WITH TS

AUDITORY AND VISUAL DIFFICULTIES IN PROCESSING INFORMATION

Frequently, students with TS have difficulty processing information presented to them either verbally or visually. They may require more time to answer a question or respond to instruction. Some have learned to fill in the awkward silence by saying something. What they say can be negative, such as "this is dumb"; "I don't care about your stupid question"; "Shut up"; or "I don't have to do this."

One example of an effective support would be assisting the student to develop a different response when he or she requires more time to process. A positive strategy for a teacher

might be to ask the question, then tell the student that you'll come back to him in a minute for the answer. Any kind of stress reduction is helpful. Most importantly, teachers should understand that the reason for the delay in processing information is due to the child's neurological difficulties, and not deliberate misbehavior.

SENSORY INTEGRATION ISSUES

Difficulties processing sensory input is common in children diagnosed with TS. A student may become easily over-stimulated by minimal sensory input such as noise, bright lights, certain fabrics, particular tastes or smells, etc. Additionally, a student may exhibit a need for excessive sensory input, resulting in chewing, hitting, or hurting him or herself in some manner. Involving an occupational therapist who is qualified in sensory integration issues is essential. Developing a sensory plan, often referred to as a "sensory diet", can sometimes be beneficial for the child and everyone who works with him or her.

ATTENTIONAL DIFFICULTIES

Some students have trouble focusing for various reasons. For example, symptoms of ADHD, complex tics or obsessions can interfere with a student's ability to pay attention. The student may be focusing on suppressing her tics and is not able to attend to classroom activity. Other students may indeed be paying attention, even though it appears otherwise. For instance, many students with TS will doodle to help them concentrate on a lecture. Educators may periodically ask questions to determine the level of attention. Some students with TS are capable of paying attention even while experiencing a bout of complex tics, or while apparently directing their attention to doodling or other activities.

READING DIFFICULTIES

If a student is struggling with reading, there may be an underlying issue and many possible reasons should be considered. Any form of dyslexia needs to be considered and potentially ruled out. Even mild tics, such as eye blinking, can make reading difficult. Additionally, some students with TS and OCD have an obsession that compels them to count every word in a sentence and every sentence in the paragraph. This makes reading not only very arduous, but next to impossible. Professional help may be needed to discover the specific causes for the reading problem, and then to choose appropriate supports.

Sometimes, what might seem as a reading difficulty may actually be related to another underlying issue. For example, a student was given a reading comprehension test and performed poorly. It may seem that the student was struggling to read or comprehend the content. However, after further assessments were performed, it was determined that her reading comprehension was at the appropriate level, but she struggled with written language.

DIFFICULTIES WITH HANDWRITING

The majority of students with TS, especially those who also have ADHD, have written language deficits, causing difficulty in getting their thoughts into writing consistently, for a wide variety of reasons. Difficulties with writing, or dysgraphia, can include sloppiness; frequent erasing; time-consuming efforts towards perfectionism; reduced output; slow writing; refusal to write; and writing is poorly spaced or is difficult to read. Handwriting can become laborious, and a struggle for the child. The causes for written language deficits may include: hand, finger, wrist, arm, neck, shoulder, head and eye tics or hand cramping; lack of coordination or fine motor skills; an unexplained disconnection between ideas and the ability to express these ideas in writing. Some students, due to obsessive compulsive behaviors, become 'stuck' on writing perfectly, and it can take them an inordinate time to accomplish a task, leaving them frustrated, exhausted and unsatisfied with the results.

Parents and teachers frequently assume that the child is refusing to write because he or she does not like to do it. The reverse is very likely true. The child refuses to write because he or she is experiencing the symptoms described above. Writing can become extremely difficult and sometimes even painful. The resulting failure and subsequent refusal to write, are all part of the complex and confusing symptoms of TS.

Occupational therapy support for very young students is sometimes helpful. However, in most cases, practice, or specialized pens/pencils will not have a positive outcome. Extra practice or rewriting typically will not result in better penmanship. **Teaching the child keyboard skills is generally a better use of time and energy**. It is important to understand that a student's handwriting can be fine sometimes and messy at other times. Short assignments may be written neatly, but longer assignments may result in disintegration of writing and readability. Remember that all aspects of TS are inconsistent; symptoms wax and wane and are affected by stress and other environmental factors. OTs should evaluate a student at a time when tics are more interfering and obtain a lengthy writing sample.

Students with TS are often excellent auditory learners. For many, the concentration required to take notes can actually interfere with their learning. For this reason, providing pre-made notes for them to study can be beneficial.

A trial period to see if a specific support strategy improves grades, attitude, and performance is highly recommended. A student's frustration and embarrassment over sloppy, immature handwriting can often lead to more than academic difficulties, such as bullying. Support in this area can be critical to the overall success of the child.

EXECUTIVE FUNCTION DEFICITS

Executive function involves the skills necessary to succeed in school and in life; these may include time management and problem solving. A student with executive function

deficits can have extraordinary talents and abilities, but not possess the organizational capacities necessary to demonstrate these abilities in a useful and productive manner.

Many individuals with TS are chronically disorganized. They may have difficulty developing strategies and technique to overcome problems, as well as implementing those suggested to them. Despite their advanced abilities, they may not have the necessary skills to consistently demonstrate their full capabilities. These students may require support from a consultant teacher to help manage their workflow and learn strategies to help them succeed academically.

SOCIAL SKILLS DEFICITS

Many students with TS score above average on IQ tests, but may not act in a socially appropriate manner. Social deficits can cause an inability to understand acceptable social behaviors. For example, many students with TS talk continuously and/or tend to interpret things in a very literal fashion. This can create significant social difficulties. Speech therapists can teach pragmatic language skills.

While some students with TS struggle with social skills that may come more easily to other students, they are often motivated to learn these skills necessary to be successful. Therefore, it is important to include social skills training in an IEP or 504 Plan. The plan should designate a person in the school setting who is responsible for working with the student on these skills. Simply writing a goal stating that the child will act age appropriately is not sufficient for students to learn the techniques and skills that may be lacking.

INCONSISTENT PERFORMANCE

It is important to remember **that the only thing that is consistent about Tourette Syndrome is the inconsistency of symptoms and related issues**. Students may perform well one day and then perform poorly the next day. Often teachers assume this is done intentionally. The level of performance can change depending on the class or the time of day. This characteristic of TS adds to the difficulty of understanding this complex disorder.

ANXIETY AND FEAR OF RISK TAKING

Is the child reluctant to take risks? He or she may have anxiety surrounding specific tasks or situations. The child may be unable to articulate the reasons for his or her anxiety or may be embarrassed to do so. Refusing to attempt tasks may indicate that some underlying anxiety is preventing the child from being successful.

Strategies to help reduce anxiety need to be very specific and supported by everyone. Consistency is critical because this creates a sense of security. If a plan is in writing and everyone involved is on board, then the child will feel less anxious and more confident. Some strategies are relatively simple, e.g., being allowed to sit near the door with

permission to leave when necessary. Frequently this reduces anxiety to the extent that the student will no longer need to leave the classroom.

THE ROLE OF EDUCATORS

Educators should carefully examine a situation that is creating difficulty for the student and consider clues that may suggest an explanation. Often students with TS do not understand what triggers their behaviors. Typically, the best course of action is to:

- Ignore symptoms.
- Be alert to possible triggers.
- Provide accommodations and modifications.
- Acknowledge the student, separate from the symptoms.

Work with the student to develop and practice appropriate accommodations and supports. Recognizing, teaching and supporting the student with alternative strategies to manage inappropriate symptoms, instead of relying on punishments and negative consequences, are more likely to prove most effective. Remember to consider your reasoning for the behavior before you respond.

Asking a student what can be done to help him or her be successful, instead of asking why he or she is not successful often aids teachers in developing appropriate supports. This can also help establish an atmosphere of teamwork between the student and the educators; the student can take ownership of a positive and proactive intervention plan.

ACCENTUATING STRENGTHS

It may be helpful to ask the student about his or her interests and talents. Many students with TS have a great interest and/or talent in art, music, science, sports, creative writing, crafts or other hands-on activities. The importance of encouraging areas of talent cannot be overemphasized. Recognizing and supporting a student's strengths may be critical to his or her success.

This does not mean that the preferred activity should be taken away as a punishment according to a behavior plan. One disenchanted student said, "Don't ever let them know what you like because they will either take it away or make you earn it." However, depending on the student, being rewarded with extra time for a favored activity can sometimes work effectively as an incentive.

SELECTING TEACHERS APPROPRIATELY

Many students require a teacher, who is adept at creating a structured environment that also allows for flexibility and choice. This can reduce the students' stress and therefore lessen his or her symptoms. By providing options, the student may be less likely to behave in an inappropriate fashion – this is particularly true for students who tend to be inflexible or oppositional.

Some things to consider:

- A student who has difficulties with transitions may benefit from a teacher who provides a great deal of structure with consistent signals for transitioning. This may result in the student experiencing less anxiety related to unexpected changes and less opposition to transitions.
- A student who demonstrates difficulty being flexible will benefit from a teacher, who is willing to explore alternative and creative strategies.
- The best environment for learning will allow for the student to make mistakes.
- Having at least one teacher that the student can trust can be essential.

TRIAL AND ERROR

Working with the unique challenges of students with TS often becomes a matter of trial and error. Many times, a support will work for a while and then will need to be altered as situations, tasks, and people change. Maintaining a file describing strategies that have been successful or unsuccessful can be a valuable aid in this process.

HELPING THE STUDENT WITH TS SUCCEED

Students with TS are more likely to find success with a proactive and positive behavior plan. When teachers and students share in the positive feelings of success, confidence develops for both teacher and student, encouraging still more positive and proactive strategies.

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