

Creating a Supportive Learning Environment for Students with Tourette Syndrome and Related Disorders

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Tourette Syndrome (TS; also known as Tourette's Disorder) is a complex disorder which begins in childhood. It is characterized by both sudden, rapid, repetitive movements (motor tics) and vocalizations (vocal tics). In order to meet criteria for TS, individuals must have experienced at least 2 motor tics and at least 1 vocal tic, not necessarily at the same time, over the course of at least one year.

TS is one of three neurobiologically-based conditions referred to as Tic Disorders. Other Tic Disorders include Persistent (Chronic) Motor or Vocal Tic Disorder (motor or vocal tics which persist for at least one year) and Provisional (formerly, Transient) Tic Disorder (motor and/or vocal tics which are present for less than one year). Tics are largely involuntary in nature, although they can sometimes be suppressed for a period of time. However, suppression typically requires a great deal of effort and is accompanied by increasing distress or sense of tension; this tension may be relieved by performing the tic. Tics are common in youth, occurring in as many as 1 in 5 school-aged children; approximately 1.2% of children meet the criteria for Tic Disorders, and 0.6% of children meet the criteria for TS. TS is more common in males than it is in females. It typically first appears at approximately 4 – 6 years of age, intensifying/peaking between 10 – 12 years of age, and typically diminishing to some degree by late adolescence/early adulthood.

Tics vary widely in appearance, frequency, intensity, and severity; they can be simple (involving one muscle group) or complex (involving multiple muscle groups). Some of the most common simple motor tics are eye blinking, mouth movements, shoulder shrugging, arm or neck movements, and hand or foot tapping. Some of the more complex motor tics include knuckle cracking, clapping, holding facial expressions, touching/tapping/hitting, echopraxia (echoing another's movements) and copropraxia (obscene gestures). Complex motor tics may also appear as multiple motor tics strung together, such as touching the tip of the nose, then touching the tongue, then copropraxia (obscene gestures). Complex motor tics may also appear as multiple motor tics strung together, such as touching the tip of the nose, then touching the tongue, then clenching the fist.

Examples of simple vocal tics include throat-clearing, coughing, sniffing, spitting, barking, yelling, grunting, and humming. Complex vocal tics may present as the repetition of specific words or phrases, changes in speech patterns (rhythm, tone, accent, or intensity), palilalia (repeating oneself), and echolalia (repeating others). Although less common,

occurring in approximately 10% of individuals with TS, coprolalia (inappropriate or socially taboo speech) may also occur.

TS is a complex disorder which often co-occurs with other neuropsychiatric disorders; in fact, approximately 86% of those diagnosed with TS have at least one co-occurring condition. Among the most common co-occurring difficulties are Attention Deficit/Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Learning Disorders, anxiety, behavioral struggles, sensory sensitivities, social skills deficits, and disturbed sleep.

As accompanied by the aforementioned challenges, some tics may be difficult to distinguish from these co-occurring struggles; thus, for example, tics can be mistaken for impulsive, compulsive, or oppositional behaviors. For this reason, careful assessment and analysis of the observed behavior is essential, if it is to be responded to in a helpful manner.

For example, calling out in class/speaking out of turn, running across a room, jumping in place, fidgeting hand movements or what appears to be an inability to remain in one's seat in the classroom may be indicative of hyperactivity and/or impulsivity, or these behaviors may be tics (vocal or motor).

Tapping, touching, or repeating a behavior may be related to obsessions and compulsions in the context of OCD, but in the absence of OCD, these behaviors may be more tic-like in nature. Hitting or touching another child, doing something immediately after being asked to stop a behavior or refrain from a behavior, making a sighing noise, rolling one's eyes, or obscene gestures all have the potential to be interpreted as intentionally oppositional in nature. Or, they may be tics.

Behavioral intervention planning might look very different in these scenarios, based upon the perception of the behavior. So the ability to be effective in behavioral intervention rests on the accurate understanding of the behavior and its function. This is often of particular significance in school or social settings, as not only may the symptoms impact the student, they may also be disruptive or have an otherwise significant impact on others.

Thus, it is vital for educators and school-based service providers to understand TS in order to provide a supportive learning environment in which these students may thrive. It is important that educators understand:

- Tics can be exhausting, uncomfortable, or even painful.

- The suppression of tics can require a great deal of mental effort and can significantly detract from a student's availability to attend to learning.
- Tic suppression is not always possible, as tension can build and become unbearable.
- In some cases, students may not be aware of the occurrence of a tic.
- Tics are not intentional and are not "nervous habits."
- The occurrence of tics can be modulated by emotions or physiological states (e.g., excitement, anxiety, fatigue, hunger, illness).
- Difficulty inhibiting thoughts and behaviors (applying the "mental breaks") is very common, resulting in what may appear to be impulsive or intentionally defiant behaviors.
- Commonly co-occurring difficulties, such as handwriting and learning difficulties may result in anger, frustration, rage, or oppositional behaviors in the classroom.
- Immature behaviors and social deficits are not uncommon; those with TS are vulnerable to being taunted or bullied by peers.
- Cognitive rigidity, psychological inflexibility, perfectionism, difficulty initiating and/or completing schoolwork, and with transitions are not uncommon in students with TS.

Education is critical to creating a supportive learning environment for students with TS. Teaching the educational team to accurately identify, understand, and appropriately respond to tics and related symptoms is vital to a student's success in the classroom. For example, if a student has an eye-rolling tic, sighing tic, or echolalia, an educator may misperceive these behaviors as rude or disrespectful and may, in turn, respond by reprimanding, disciplining, or sending the student out of the classroom. This may negatively impact the student psychologically and socially. Moreover, drawing attention to the tics and the tension this may create, has the potential to increase the tics and other related behaviors. If the educator perceives the student as problematic, rather than as having a neurobiological disorder with which he or she struggles, the educator is more likely to unintentionally perpetuate the difficulties in the classroom. Essentially, it is important to understand that the student is not giving the educator a hard time, the student is having a hard time. When the student is not misperceived as intentionally causing a problem, educators are more likely to consider what they can do for a student, rather than to a student, paving the way for supportive, empathic, proactive, and creative strategies which more effectively address the behaviors in the classroom.

Strategies to successfully create a supportive learning environment should be individualized and flexible. Strategies can be varied and many. In addition to accommodations or strategies which may be used to support a student with the commonly co-occurring struggles, a few of the most common and useful strategies specifically targeting tics, include:

- Create a “tic-neutral environment.” That is, ignore tics, whenever possible, and avoid drawing attention to or criticizing the student for tic behavior.
- Educate other students about TS and tics so that they better understand the behaviors and how to most appropriately respond to them.
- Arrange an in-service for educators or a peer presentation on TS via the New Jersey Center for Tourette Syndrome and Associated Disorders.
- Provide access to a space wherein students with TS can calm themselves and release tics, but use caution to avoid sending them to an office that may be perceived as a punishment.
- Give the student a set of passes to use for the day (3-4 minutes per pass, with restrictions) so that he or she may less disruptively engage in bouts of tics.
- Test in a separate location with time limits waived/extended.
- Seat the student with TS in an area where tics will be less noticeable, disruptive, and/or embarrassing.
- Whenever possible, reduce stressful situations.
- Consider conducting a functional analysis of the behavior (or request consultation from the school’s behavior analyst) to generate a targeted plan for a specific problematic tic. Then use this to plan specific behavioral strategies for intervention.

Based on an analysis of the behavior, generating stimulus control strategies (manipulating the environmental cues) and competing response strategies (engaging in alternative behaviors that are incompatible with, or cannot be carried out at the same time as the tic) may be very effective means of decreasing tics. For example, a student who hums during tests and other periods of quiet work may benefit from sitting in the front row where he may be less distracting to other students. Or the student may experience a decreased urge to hum during quiet work, if given the opportunity to chew gum during these times. Or teaching the student to focus on a slow, rhythmic breath, with his lips slightly parted during these quiet periods, may result in a decrease in humming behavior.

Evidence-based treatment for TS includes medication management and behavior therapy. Psychopharmacological agents most often prescribed for tics include atypical antipsychotics or antihypertensives. Cognitive behavioral intervention for tics (CBIT) is a structured therapy based on functional analysis. Utilizing the information gathered in the assessment, clinicians help individuals to increase their awareness of tics and urges to tic, develop and implement specific competing responses when an urge to tic is noticed, and make changes to daily routines and activities which may be helpful in reducing tics. To learn more about CBIT and training opportunities to learn CBIT, visit Tourette.org on the web.

Quality resources for schools, families, and communities to raise awareness and provide comprehensive and reliable information about TS and related disorders is fundamental.

The New Jersey Center for Tourette Syndrome and Associated Disorders (NJCTS) (njcts.org), a not-for-profit organization dedicated to the advocacy of children, adolescents, adults and families affected by Tourette Syndrome and its associated disorders, is such a resource. NJCTS provides programs and services to support families, public outreach and awareness campaigns, education for schools and healthcare professionals, and referrals for specialized treatment providers across the state of New Jersey. Additional programming, such as educational webinars, virtual support groups, youth advocacy programs, the NJCTS Tim Howard Leadership Academy, the NJCTS Family Retreat Weekend, and research collaborations also provide impactful means of supporting the TS community. To learn more about TS and resources in New Jersey, visit njcts.org. Additional information about TS and related disorders may be found at Tourette Association of America (Tourette.org).

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