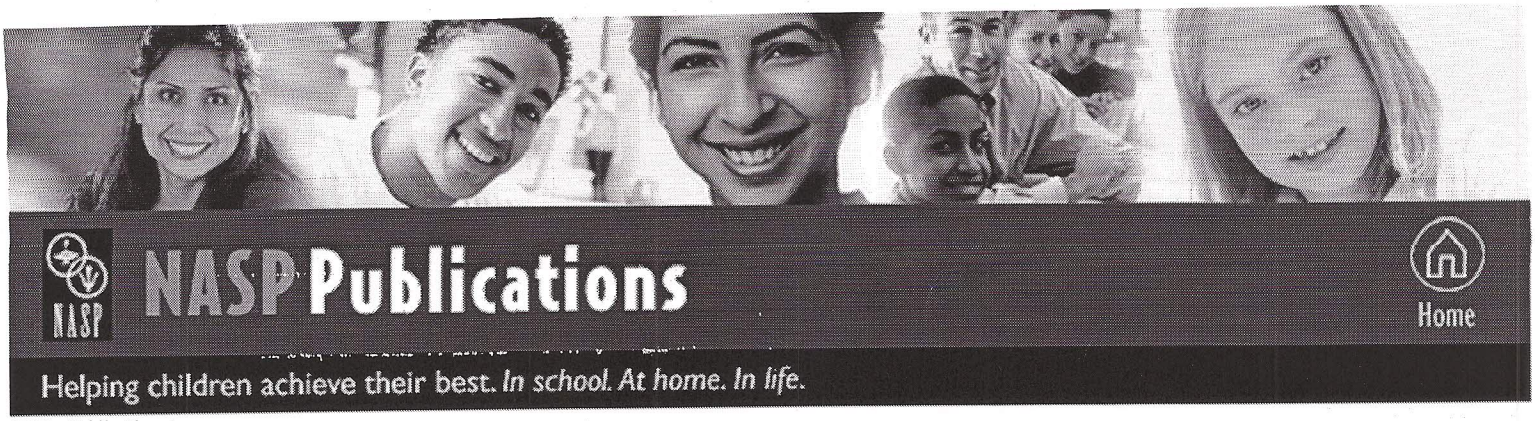

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Special Series: Tourette Syndrome

Tourette Syndrome: An Inside Perspective

By Susan A. Conners

Tourette Syndrome is one of the most misdiagnosed and misunderstood neurological disorders that impacts a child's educational performance and social/emotional well-being. It is my experience that most educators have now at least heard of Tourette Syndrome. This was certainly not the case when I began my work with children with TS some 18 years ago. It all started in 1984 when I was 36 years old and had been teaching French in a middle school in a suburb of Buffalo, NY for 15 years. I had the good fortune of watching an episode of "The Quincy Show" on television one Sunday night. The subject of that episode was Tourette Syndrome. It was the first time I had ever heard the word. It was also a night that changed my life forever. Three months after that episode I was diagnosed with TS. I had had my first symptoms at age 6. To this day, despite the significant media attention that Tourette Syndrome receives and the substantial contributions of the National Tourette Syndrome Association, it is still a disorder that most educators know very little about. And, what they do know is often inaccurate.

The Mystique of TS

There is a mystique about Tourette Syndrome, a perplexity that often aligns it with bad behavior. If it is treated as such in a classroom setting, no one wins, not the teacher, not the administration and, most importantly, not the child. The mystique of TS is easily explained if one simply looks at it as the medical condition that it is, not unlike other medical conditions that teachers deal with every day in their classrooms. One would never think of punishing a child who was exhibiting the confusion and out-of-sorts behavior associated with low blood sugar in diabetes. No teacher would ever think of reprimanding a child who is disrupting the class with an asthma attack. Yet, a student exhibiting the motor and vocal tics associated with TS is often disciplined to his or her extreme embarrassment for symptoms of a medical/neurological disorder. Why would this ever happen? It happens because people understand diabetes. People understand asthma. People misinterpret TS.

Diagnostic Criteria

Tourette Syndrome is a neurological disorder resulting from a chemical imbalance in the brain. There is currently no medical test that will clinically diagnose TS. It is therefore diagnosed by the presence of four very observable diagnostic criteria which I will list and expand upon in this article. These diagnostic criteria are as follows:

1. Multiple motor tics
2. Vocal tics
3. Waxing and waning of symptoms
4. Childhood onset of symptoms

Motor tics: Let's look more closely at all four criteria. A motor tic is a rapid, repetitive movement of any voluntary muscular group in your body. Simple motor tics could include rapid eye-blinking, head jerking, facial grimaces, arm flailing and/or finger tapping, to name a few. These tics can occur in bouts that can sometimes seem purposeful. Researchers have discovered that the brain chemical dopamine is affected in some way in the brain of persons with TS. Since dopamine has as one of its main functions the control of body movements, it is easy to understand the presence of such tics. Many people with TS also exhibit complex motor tics such as hopping, knee bending, whole body bending or a series of what look like simple motor tics. I, myself, have a complex motor tic where I must tap my finger on the table, touch my chin and then lick my shoulder always in that sequence. This must look quite ridiculous to someone who does not understand movement disorders.

A vocal tic can be defined as the repeated uttering of a sound, word or phrase. Vocal tics can be as simple as a constant sniffing or throat clearing. It could be a squeak, a snort, a howl, a bark or a word or phrase that is repeated over and over. A boy diagnosed with TS whom I currently teach makes a series of snorts and animal sounds. He also repeats phrases such as "chickens are fuzzy, chickens are fuzzy" and "I have a chicken in my pants." Unfortunately, anyone who knows anything about TS knows of the vocal tic that takes the form of inappropriate language. This is known as coprolalia. It does exist and can certainly be a part of Tourette, but is ***not*** necessary for a diagnosis. It actually occurs very infrequently with people with TS. It usually takes the form of curse words, but could be anything inappropriate such as ethnic slurs or comments on a person's appearance, such as "you're bald, you're fat." My student's "I have a chicken in my pants" could be classified as coprolalia. In my classroom where we all understand Tourette, it is simply ignored. In the real world, this certainly would not be the case.

The third criterion is ***waxing and waning***. This criterion has two implications. It first implies that the *tics change all the time*. You could be teaching a child who has a snorting tic and in a few weeks that could disappear and he could be shouting a word across your classroom. Tics change much more frequently in children than adults, which makes this particular criterion one of the most difficult for educators to get a handle on. You just get used to one set of symptoms and suddenly a new tic appears and replaces an old one.

Waxing and waning also means that tics *change in severity* depending on environmental circumstances. The most common of these are stress and anxiety, excitement and fatigue. Tics almost always worsen during times of stress and excitement in all persons with TS. Testing situations can be very stressful and this is also a time when the classroom is most quiet, which makes vocal tics especially difficult for a child with TS. Events such as family birthdays, vacations and field trips can be very exciting for a child, which could temporarily cause symptoms to worsen. Tics almost always tend to worsen at the end of the day because of the level of fatigue.

Childhood onset: This disorder must first manifest itself in childhood anywhere between the ages of 2 and 18. The most common age of onset of symptoms is 6 or 7.

Classroom Intervention

Understanding TS is the first step to dealing with it appropriately in a classroom setting. When I speak to educators about TS, my first word of advice to them is to be creative. There are many very important strategies to use for these children, but don't just stop at these suggestions. Be creative. Exhaust all possibilities.

If you are dealing with tics in the classroom, there are some very simple strategies that you can use. The number one thing that helps children is a ***quick break*** out of the classroom either to go to the bathroom, the drinking fountain or on a phony errand. These few minutes of privacy away from the other students allow the child with TS to release tics in a less embarrassing environment. Since stress and anxiety aggravate tics, it is also strongly suggested that children with TS ***take tests in a separate location with no time limits***. The worse thing an educator can do is to ask a child to stop ticking. First of all, that is not completely possible. The child may stop for a few minutes and do his/her best to hold in the tics, but the stress of being publicly humiliated and trying to suppress tics will only make tics worse. Attempting to hold in tics even for short periods of time also takes away from the child's ability to concentrate.

The key to demystyfying TS and solving the majority of the classroom issues around a child with TS is to ***educate the other children in the room***. Kids tease, fear and make fun of what they don't understand. Once they know about TS, the level of social acceptance of that child improves drastically. The Tourette Syndrome Association can provide you with a model peer inservice program, videos and books to assist you with this.

What I have just described is all that is really needed for a diagnosis of TS. However, what I also have just described is just the tip of the iceberg with TS. To reiterate, TS is a neurological disorder and as such it is almost always accompanied by other neurological disorders. The most common of these disorders are: 1) Attention Deficit Hyperactivity Disorder (ADHD); 2) Obsessive Compulsive Disorder (OCD); and 3) Learning Disabilities (LD). Any of these disorders can exist alone without the others, but it is extremely common to see combinations of these four, TS, ADHD, OCD and LD co-existing. I will discuss each of these in depth.

Co-Morbid Disorders: ADHD

ADHD can often be the precursor to TS. It appears from birth and the tics most often start nearer the age of 6. ADHD is characterized by several behaviors. Children with ADHD are very fidgety. They have a difficult time remaining seated for any length of time; they seem to be in constant motion. They also exhibit a very short attention span. These children can be very impulsive. They shout out answers before being called on. They interrupt and get in your face. They also have a difficult time initiating or finishing anything. They lack what we call executive function in the brain, which means that they are some of the most disorganized children you will ever encounter. These are the kids who always come to your class unprepared and with the wrong materials. They lose everything, pencils, pens, homework, etc. They can be some of the most frustrating children you will ever teach.

The 17-year-old son of a close friend of mine was recently involved in a very serious car accident. He sustained a traumatic brain injury to the frontal lobe of his brain. This once organized, high functioning honor student and athlete suddenly was having difficulty with the simplest of tasks. His attention span was very short; he could not retrieve words that he always knew; he had become very impulsive and seemed to lack the ability to plan, organize, sequence or understand the consequences of his actions. ADHD results from difficulties in the frontal lobe are of the brain. How easy it is now for me to understand the medical, neurological nature of this disorder.

Strategies for working with the TS/ADHD child are numerous. These are kids who should always be on an assignment sheet which is verified and initialed after each class by the teacher to assure accuracy. These are students who need all assignments broken down for them. They need to be seated in the front of the class, preferably on the side since tics may be more obvious to the rest of the class when the child is in the center front. They need constant help with organization-- a set of textbooks at home, color coordinated textbooks and folders to mention a few. The most difficult times for them in a school setting will be the cafeteria, the school bus, crowded hallways and the playground. Structure is lacking in all of these situations and kids with ADHD become very easily overstimulated in these environments.

When I entered my 20th year of teaching several years ago, I made the conscious decision not to "sweat the small stuff." I gave up worrying about kids who forget their pencils. I simply lend them one. I find that the majority of kids who always forget or lose their supplies are kids with ADHD. They are not doing it on purpose. They simply have a neurological disorder that prevents them from remembering. So why lose sleep over such a petty thing? We don't punish hearing impaired kids because they can't hear or visually impaired kids because they can't see, so why would we punish ADHD kids because they forget their pencil?

Co-Morbid Conditions: Obsessive Compulsive Disorder

OCD, I find, is the most closely related to the tics of TS. I have often referred to my obsessions and compulsions as *tics of the mind*. My body tics and my mind tics as it gets "stuck" on thoughts and ideas. An obsession is a thought that your mind gets stuck on which causes great anxiety. A compulsion is what you have to do to alleviate the anxiety of an obsession. For example, one of the most common obsessions that we hear about is a germ obsession. A person has a fear of germs and contamination, most often irrational. In order to alleviate this obsession, this person must wash. They may wash their hands over and over again, take very long, very frequent showers, clean their houses and belongings continually.

As a French teacher, I travel to Europe each summer with my students. On my most recent trip, I had with me a 13-year-old boy who suffers from OCD. He is obsessed with germs. One day, he had to go to the bathroom very badly, but just could not go because there was no soap in the public bathroom. The only way that I got him to use the facilities was to give him some moist towelettes that I had with me to disinfect his hands after he had used the bathroom.

Although germ obsessions are the ones we hear about the most, OCD can takes literally hundreds of other forms. A person can become obsessed with counting things over and over again. With OCD, there is always the doubt that you did something right the first time, so you must do it repeatedly, just to be sure. I once met a young girl who developed a counting obsession which took the form of counting every word in every line the she read or wrote. She was a sophomore in high school and was soon failing everything. The more anxious she became, the worse the compulsion was. Everything she attempted to read or write took hours and hours. Until the obsession subsided, it became necessary to provide her with a note taker and books on tape to allow her to be able to finish her work.

When I was 7 years old, I began a compulsion which caused me to read five words in my reader and then in my head count to 25 before I could go on to the next word. I was moved from the top reading group to several groups below because the teacher assumed that I simply did not know the next word. When I tell that story today, people inevitably ask me why I didn't simply tell the teacher what was going on in my head. There are two reasons why kids don't tell. First of all, you have nothing to compare it to. How did I know that other kids weren't doing the same thing in their head? Secondly, the biggest fear is that everyone will think that you're crazy. You feel crazy doing these ridiculous things over and over again.

An obsession could take the form of checking things over and over again. You're never quite sure that you did it right the first time. I would check the stove, the coffee pot, the iron, the thermostat, eight and nine times before I could get out of my house in the morning. Symmetry is a very common obsession. The blinds must be perfect, the bedspread without a wrinkle. Sometimes the silliest things can become an obsession. I became obsessed with the milk carton being perfectly straight on the refrigerator shelf. One morning I went back 8 times to straighten the milk carton. Feeling that I would never be able to get out of my house, I decided to take the milk to work with me. What is perceived as perfectionism is almost always a red flag for OCD-- kids who erase over and over again, kids who asked repeated questions. People with OCD don't transition well. They may appear to be stubborn, but may just be having a difficult time moving on to a new activity.

Whether you're dealing with tics, obsessions or symptoms of ADHD, I reiterate that the key word is creativity. First you must accept that this is not a child misbehaving or purposely trying to aggravate you, this is merely a neurological disorder over which the child has very little control. I once worked with a boy whose obsession was to always have a perfectly sharpened pencil. He would interrupt the class 16 or 17 times every class period to resharpen his pencil. The solution was quite simple. We gave him 20 sharpened pencils at the beginning of every class. Two weeks later, the boy himself came up with an even better solution. He bought a mechanical pencil. Of course, it's not always that easy, but as an educator you always be creative and keep an open mind.

Co-Morbid Disorders: Learning Disabilities

The last most commonly associated disorder with TS is Learning Disabilities. Once a diagnosis of TS has been made, I strongly urge that the child be tested by the school psychologist. Children with TS can have disabilities in many areas, but a very large number of children with TS are affected by nonverbal learning disabilities. These disabilities are usually in the area of auditory processing, fine motor and visual-motor impairment. It is therefore also strongly suggested that the child be evaluated by an Occupational Therapist and an outside Neuropsychologist. Fine motor impairment translates into very laborious and very messy and illegible handwriting. Visual-motor impairment makes it impossible for the child to copy accurately from the chalkboard, overhead projector or from the textbook to the paper. The child may copy the Math problem wrong and line up the columns incorrectly, which will surely result in an incorrect answer. Standardized tests pose particular difficulty for these students. They will know the correct answer, but transfer it incorrectly to the computer sheet. The simple answer to all of these issues is the use of a computer. A computer is the electric wheelchair to a child with nonverbal learning disabilities. They need it for survival.

Concluding Comments

TS is a very complicated medical condition. It is not the rare disorder that we once thought it to be. If I could conclude with a few bits of advice, it would be that you always remember the story of my friend's son who suffered the brain injury. When his mother approached the CSE (special education team) for services for him, no one batted an eyelash. He was provided with everything he needed and more. Kids with neurological disorders are not at all unlike this boy. The only difference is that his was a sustained injury and theirs is always there. The results are the same. Secondly, I urge you to not let this be the only article you ever read about TS. I encourage you contact the National Tourette Syndrome Association. They provide a wealth of information including pamphlets, videos and a curriculum which can be used to train educators how to understand and work with children with TS. And lastly, work very hard at looking beyond the tics and the obsessions and see that these are just kids like all other children you work with. They just happen to have Tourette Syndrome.

Reference

Leckman, J.F. & Cohen, D.J. (Eds.) (1999). *Tourette's Syndrome: Tics, obsessions, compulsions: Developmental psychopathology and clinical care*. New York: John Wiley.

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For more information, contact the National Tourette Syndrome Association at (718) 224-2999 or visit their website at www.tsa-usa.org. *See other articles on page 10 and the insert.*