Tourette's Syndrome

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Definition

Tourette's Syndrome (TS) is a neurological disorder characterized by tics -- involuntary, rapid, sudden movements that occur repeatedly in the same way. This syndrome is often associated with additional problems, such as attention deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and depression.

Introduction

Tourette syndrome is a chronic disorder that has both motor and vocal tics. These seem to be related to an abnormal transmission of messages from the brain. When they affect the muscles, they are referred to as motor tics. Examples would include eye blinking or eye rolling, facial grimaces, clapping, hair tossing, chewing or pulling on clothes, and lip smacking. More complex motor tics include squatting, skipping, walking backwards, walking on toes, twirling and jumping up. Vocal tics are also common and include throat clearing, grunting, sniffing, belching, spitting, snorting, humming, whistling, yelping, barking, and clicking. More complex vocal tics include repeating other's words (echolalia), repeating your own words (palilalia), muttering, animal sounds, stuttering, and using obscenities/socially taboo phrases (copraolalia). Can you imagine how frustrating this is to a child trying so hard to "fit in" at school?

Tourette syndrome is usually inherited, and most often starts between the ages of 6 and 10 years, although children can begin to show symptoms at younger or older ages. Because this is an inherited condition, the child's tics and associated problems are NOT the child's fault (nor are they the fault of his parents). While some persons with TS have limited control of their symptoms from seconds to hours at a time, suppressing them may merely postpone more severe outbursts. Tics increase as a result of stress, anxiety, excitement and fatigue.

Tourette syndrome is a chronic disorder that tends to progress and become more severe during puberty and then stabilize in adulthood. Because of associated behaviors, which a child truly cannot control, it is important to diagnose the problem as early as possible so that appropriate management -- and not punishment -- can be implemented at home and at school. It is also important to recognize associated learning disabilities, so that appropriate teaching techniques can be implemented in the classroom. Techniques specific to teaching a child with ADHD and OCD are frequently indicated, and should be incorporated as needed in the child's Individual Educational Plan (IEP) as required by law. Be sure you are as familiar with ADHD and OCD as you are with TS.

To allay common fears and misconceptions about TS, the Tourette Syndrome Association wants you to know:

- Persons with TS are not crazy.
- People with TS reflect the general population in terms of IQ and are slightly skewed toward the superior end of the spectrum.
- TS is not life threatening, or infectious.
- The child with TS is not responsible for his/her medical disorder, but must be helped to learn to take responsibility for its impact on others.
- TS symptoms vary widely, even hour to hour. Therefore all interventions must be highly flexible.
- Disorganization and impulsivity are associated symptoms and not willful behaviors.

Medications can help with some symptoms, but there is no magic pill to cure TS.

The fact that people can control the symptoms some of the time confuses and frustrates both the child and those working with him. Remember that symptoms wax and wane.

Diagnosis

At present, there are no specific tests for Tourette Syndrome. (Don't forget ADHD and OCD. There ARE neuropsychiatric tests to help you learn what your child's particular academic strengths and weaknesses, and learning styles are.) The following are the current criteria used to diagnose TS:

- Multiple motor and one or more vocal tics (not necessarily concurrently);
- Onset before age 18;
- Tics that occur many times a day, nearly every day or intermittently for more than a year, with symptom-free intervals not exceeding 3 months;
- Variations in anatomic location, number, frequency, complexity, and severity of the tics over time;
- Tics that are not related to intoxication with psychoactive substances or central nervous system disease, e.g. encephalitis; or if a diagnosis of ADHD is made without recognition of tics, and Ritalin is used to treat, sometimes tics will appear and/or worsen;
- Symptoms cause significant impairment of social, academic, and occupational functioning.

Treatment

As stated above, there is no magic pill to cure Tourette syndrome. Don't try to alleviate every symptom. Parents need to wisely consider which symptoms are most problematic and aim to decrease those. Learning everything you can about TS, ADHD, and OCD is essential. With support and understanding from your child's doctor and school, you will be able to institute both pharmacologic and nonpharmacologic treatment strategies.

Pharmacological treatment, because of potential side effects, should start with medications that can do the least harm. Are the tics causing the most difficulties or is the ADHD getting in the way or are your child's OCD symptoms the most distressing? Sometimes these need to be managed by a specialist, but sometimes your child's primary care physician can begin treatment and refer only if early interventions are not working.

To control tics some of the medications used include clonidine, guanfacine, benzodiazepines, or calcium channel blockers. Potent D2 antagonists are effective neuroleptics in suppressing tics. Resperidone and clozapine and olanzapine are also used. Botulinum toxin, opiate antagonists, and dopamine agonists are also options.

To control ADHD symptoms the psychostimulants are most effective although some may exacerbate tics. Antidepressants, clonidine, and selegiline may be used as alternative.

To control OCD symptoms the SSRI and tricyclic antidepressants are most effective. Lithium, buspirone or a dopamine antagonist with an antidepressant may also prove to be beneficial. Clonidine and opiate antagonists are also options to consider.

While this is a long list of promising options, remember to consider the pros and cons of the medication and any of the side effects that may create new problems. After thoughtful consideration give your choice time to work and monitor closely. Include the school's observations in your assessment and remain open-minded to new options.

Pharmacological treatment is most effective when prescribed in conjunction with other supportive interventions, not as the only means of therapy. Consider the following counseling and school interventions.

Behavioral and cognitive treatments are varied. The suggestions of your child's neuropsychologist following testing for strengths, weaknesses, and learning style are a good place to start. Consistency is important for many children, but especially those who have problems with attention and/or obsessions. Be sure your discipline is

consistent and make it consistent with the school's and your child's babysitter. Try to keep your daily schedule consistent, or at least have a consistent way of preparing your child for a change in scheduling. Information on working with children with these types of problems is increasing daily. Keep your eyes open and your school and babysitter informed.

Counseling and therapy include parent education and counseling to be knowledgeable advocates for their child and to have the tools and patience to survive the daily challenges.

Parent support groups are important to realizing you are not alone and to gain lots of good practical ideas. Family therapy helps the unit to survive and respond in more constructive ways to difficult behaviors. Group therapy does for your child what a parent support group can do for you. It will also provide a safe environment to practice age-appropriate social skills and to receive realistic feedback from peers. Individual and/or behavior therapy for your child may also be helpful.

School interventions include most importantly teacher/school personnel and peer education. Educational modifications must challenge the student's intellectual capacities, teach and practice age-appropriate social skills, and promote self-esteem while accommodating special needs. Approximately 25% of these students have co-existing learning disabilities, and individualized academic remediation is indicated. Because poor handwriting is frequently an issue, direct instruction in computer skills and word processing is a necessity. A home-school management program adds consistency to the child's life and makes it more secure and predictable.

Emergency Situations – What can go wrong?

Because this is a chronic disease that waxes and wanes, your days (and nights!) will be up and down, but true emergencies are usually secondary to impulsive behaviors. These are handled the same way as if your child jumped off a roof without having Tourette syndrome! It's not easy (for you or your child), but you will survive. Be sure to get all the support you need.

Conclusion

Tourette syndrome is a complex inherited disorder with abnormal transmission of messages from the brain. It is associated with multiple tics and is often accompanied by other conditions such as ADHD and OCD. The cornerstone of treatment is the education of the patient and family. Support from the physician and the school is critical to effective management.

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