

Tourette Syndrome and The School Nurse

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Patrick

Patrick, a 9-year-old fourth grader, was brought into the school nurse's (Mary Jones) office to wash an abrasion on his face. He had been in a fight with another boy during recess. As Ms. Jones cleaned Patrick's face, she inquired about the fight. "Johnny called me a weirdo," Patrick said. "Why did he call you that?" Ms. Jones asked. "Because of my habits; I make faces, I blink my eyes, sometimes I jerk my arms. Johnny says I tried to hit him—I didn't."

As Patrick talked, Ms. Jones observed some of these movements. She noticed eye blinking, facial grimacing, shoulder jerks and tensing of his abdominal muscles. Patrick also sniffed and cleared his throat frequently. She wondered if he had a cold, if he had been crying, or perhaps these noises were tics as well. Ms. Jones sent Patrick back to class and decided to review his medical record. She also scheduled a meeting with Patrick's teacher.

The 4th grade teacher reported to Ms. Jones that she too had noticed Patrick's facial grimaces, arm movements and noises. In fact, she had moved him to the back of the room because he was unable to sit still and be quiet. At least in the back of the room, he would be less noticed by his classmates. He was falling behind in his assignments, and the teacher had just sent a note to Patrick's mother requesting a conference. She also recalled that Patrick had recently received a detention for fighting on the bus.

Tics and Tourette Syndrome

Tics are repetitive, involuntary movements (motor tics) or utterances (phonic tics) that may be simple or complex. Simple motor tics involve brief, rapid movements such as eye blinking, facial grimacing and head jerking. Examples of simple phonic tics include throat clearing, grunting and snorting. Children may also exhibit more complex motor tics such as hopping, spinning or repetitive touching. Complex vocalizations may include repetitive phrases such as "wow," "honey" or "oh boy." Sometimes tics occur in orchestrated bouts in which various tics happen in close succession.

Tic disorders are classified by the age of onset, duration of symptoms, and whether both motor and phonic tics are present. The available evidence suggests that tic disorders reside on a continuum from mild to severe, though additional research is needed to confirm this impression.

Transient tic disorder is characterized by one or more motor tics or phonic tics (but not both) that are present for a period of weeks to months and then disappear. The most common motor tics are eye blinking or other facial tics. Phonic tics may include throat clearing or snorting. Transient tics are common in school age children and are usually mild with minimal interference in school performance or peer relationships.

Chronic tic disorder is differentiated from transient tics by duration in that either motor or phonic tics, but not both, are present for more than a year. Chronic motor tics are probably more common than chronic vocal tics. The presence of chronic motor or phonic tics does not necessarily herald the onset of Tourette Syndrome. Nonetheless, chronic tic disorders may be severe in their own right and require treatment. Furthermore, a chronic tic disorder may be a manifestation of the same underlying vulnerability.

Tourette Syndrome (TS), which was first described by the French neurologist, Georges Gilles de la Tourette, is a more severe tic disorder characterized by the presence of chronic motor and phonic tics. The essential diagnostic criteria for TS include:

- Age of onset before the age of 18;
- Both multiple motor and one or more vocal tics present at some time during the illness, not necessarily concurrently;
- Tics occur on a daily basis, persist for at least one year with no tic-free periods of more than 3 consecutive months;

— *Diagnostic & Statistical Manual - Fourth Edition, TR*
American Psychiatric Association, 2000.

Although TS is often regarded as the most severe of the tic disorders, symptoms range from quite mild to severe. The number and frequency of tics not only vary among children with TS, they also vary within a given child over time. Tics may be inhibited in school or at a neighbor's house only to become very frequent as soon as the child arrives in the safe environment of home. Tics may be worsened by life stress, fatigue and excitement. Curiously, focused activity usually results in a reduction of tics, but relaxing activities such as watching television may be accompanied by more tics. The average age of onset is about seven years old with eye blinking, facial movements, head jerks, throat clearing or grunting being the most common early symptoms. In its most severe forms, TS may present with near constant, forceful motor and phonic tics that occur in bouts. A small percentage of children with TS may utter obscene vocalizations or gestures and, very rarely, a few might manifest self-injurious behavior. In most cases, the tics of TS decline in severity by young adulthood.

Tics are defined as involuntary. However, many children and adults describe an urge or a feeling of localized tension that precedes their tics. Children with TS often report that if they do not make a certain movement or sound, they will feel “weird,” “uncomfortable,” or as if they will “explode.” Some children develop elaborate means to camouflage their tics such as brushing hair from the face to mask a head jerking tic, dancing movements to hide spinning around, or hitting themselves while performing a socially unacceptable act such as “giving the finger.” Differentiating between complex tics, behavior intended to camouflage tics and impulsive behavior can be a challenge requiring careful discussion and clinical experience.

Epidemiology

Estimates of prevalence for transient tics, chronic tic disorder and Tourette Syndrome vary due to differences in the definition of TS, as well as different methods of data collection and community sampling. Transient tics appear to be relatively common in school-age children and may be as high as 10 to 15 percent. Estimates for chronic motor or vocal tics are in the range of 1 to 4% depending on the population studied. By contrast, the prevalence of TS has been estimated to be approximately 1-10 cases per 1,000. The largest study to date was carried out in Israel with sixteen and seventeen year-old army recruits. This study observed a prevalence of 1 per 2000. A more recent study in Sweden identified 6 cases per 1000 in school-age children, suggesting a higher prevalence in this age group. Boys are more commonly affected than girls. TS occurs in all social groups and across all racial and ethnic lines.

Associated Behaviors

Obsessive-compulsive symptoms

In addition to motor and phonic tics, as many as 50% of children and adults with TS have recurring thoughts (obsessions) and/or repetitive habits (compulsions). In some cases, though certainly not all, these clinical features emerge after the onset of the tics and they can be quite distressing. Common compulsions include the need to arrange objects in rows or patterns, repeatedly turning light switches on and off, tying and retying shoes and performing cleaning rituals. Children may report the need to repeat a behavior until it feels or looks “just right.” These compulsive behaviors may be as disruptive as the tics and may impair school performance. For example, a child might write and rewrite sentences in class, or go over the same letter so many times that assignments are not completed. In some cases, children become stuck in their repetitive behavior and are unable to move on to the next activity until they get it “just right.”

Obsessions can also be distressing for children with TS, and they may find it difficult to talk about their recurring thoughts. Some repetitive thoughts, such as the frequent intrusion of a certain song, a phrase or number sequence, can be a distracting nuisance to young people. More distressing are recurring thoughts of harm in the form of illness or injury coming to one's self or family members. Less common, though equally distressing, are recurring thoughts about committing harmful acts. These thoughts are distressing because the child may struggle with an urge to do something aggressive

while knowing that he (she) does not want to commit such an act. If the obsessive-compulsive symptoms take up time on a daily basis, cause distress and interfere with ordinary routines, a formal diagnosis of obsessive-compulsive disorder (OCD) may be appropriate.

Hyperactivity, inattention and disruptive behavior

Other common behavioral problems associated with TS in childhood involve the regulation of attention and activity. In clinic samples, 50% or more of the children with TS have difficulty concentrating, are distractible, impulsive and over-active. These familiar symptoms of Attention Deficit Hyperactivity Disorder (ADHD) often precede the onset of tics and may manifest in different combinations such that some children are primarily inattentive, while other children may be predominantly hyperactive or impulsive. ADHD is often associated with disruptive and defiant behavior. Several studies have shown that children with TS and ADHD have greater impairment in school, home and with peers than those with TS alone. Thus, when they occur, these behavior difficulties often overshadow tic problems.

Learning disabilities

Most children with TS have average intelligence. Nevertheless, some may have specific learning disabilities. Children with learning problems should be carefully assessed in order to identify the specific disability and design an appropriate educational program. Moreover, because learning disabilities may coexist with ADHD, some children with TS and a learning disability may also exhibit disruptive behavior. As with other children with ADHD, these children may require additional structure in the classroom to ensure academic success. Also, they will need specific remediation for their learning problems. The extent to which these problems of learning and disruptive behavior are part of TS or merely additional problems is unclear and is a matter of ongoing research.

In summary, although many children with TS do quite well in a mainstream educational program, others may require special education services. Having TS can interfere with educational progress in several ways: direct interference from tics, intrusive thoughts and repetitive behaviors, symptoms of ADHD, and/or specific learning disabilities. Special educational services may consist of modest accommodations in the mainstream classroom, assignment of a teacher's aide, resource room assistance, placement in a special classroom setting, or, in rare cases, day hospital programs or placement in a residential facility.

Psychosocial Consequences

Children with TS often worry about the reactions of others to their symptoms, and some may become the object of teasing. Moreover, results from recent studies suggest that some children with TS may also be predisposed to anxiety disorders. OCD symptoms may also be a source of anxiety and distraction. Children with ADHD may have additional social impairment due to their impulsiveness and disruptive behavior. Given the potential for these negative social consequences, it is not surprising that some children and adolescents with TS may become anxious, tense and discouraged. Despite efforts to suppress them, the inevitable recurrence of tics may add to this discouragement. Academic failure may further erode the child's self confidence. Thus, as with other chronic conditions, the secondary problems of TS and the individual child's response to having this distressing disorder may be as important as having the disorder itself. Education of the child, family and school personnel is essential to promote optimal development.

Etiology: Genetic and Epigenetic Factors

The cause of TS is unknown, but it appears to be due to a genetically transmitted vulnerability. TS is considerably more common in families with an affected member than in the general population. Secondly, twin studies have shown that identical twins, who have all of their genes in common, are far more likely to be mutually affected by TS than fraternal twins (who share half of their genes on average). Finally, careful analysis of the inheritance of TS suggests that it is transmitted in families, though it may not be caused by a single gene. Accumulated evidence from various studies suggests that the presumed inherited vulnerability results in a dysregulation in brain circuits that connect the frontal cortex and the basal ganglia. These brain circuits are known to be involved in the planning and execution of movement, and are also known to play a role in other movement disorders.

Although there is considerable evidence that TS is genetically transmitted, the disorder demonstrates a wide range of expression. Indeed, the severity of TS varies greatly from one individual to another within the same family. This variability is also true among mutually affected identical twin pairs. Thus, it is clear that environmental factors also play a role in TS severity. These factors may include adverse perinatal events, exposure to stimulant medications and perhaps stressful life events as well. Recent research has also raised the possibility that group A beta hemolytic streptococcal infections may induce an exacerbation in tics. This

intriguing hypothesis is in the early stages of scientific inquiry. Accordingly, conclusions about the role of immunologic processes in tic disorders must await further investigation. Currently, there are no specific treatment recommendations based on the strep theory.

Twin and family genetic studies also provide information regarding the relationship of TS, OCD and ADHD. Genetic research has supported the clinical impression that TS and OCD are related conditions.

Not only is there an increased frequency of OCD in relatives of individuals with TS, but OCD appears to follow the predicted pattern of genetic transmission. The genetic connection between TS and ADHD is less clear. Although ADHD does occur at higher than expected rates in the families of children with TS, that disorder does not appear to follow a simple genetic transmission pattern. Additional research may help to unravel the relationship of TS and ADHD.

Ms. Jones reviewed Patrick's school record which indicated that he was of average intelligence. Although there had been some concern about his academic performance in kindergarten, he was promoted to the first grade and had remained in mainstream classes since. His second grade teacher had reported excessive eye blinking and facial movements, but they were dismissed as "nervous mannerisms." Patrick occasionally received unsatisfactory reports for distractibility, inattention and disruptive behavior throughout his school years, but he had not demonstrated any serious conduct problems.

Patrick's medical record revealed that he was healthy with no history of major illness, serious injuries or hospitalizations. He had occasional bouts of otitis media which apparently responded to antibiotic treatment. His frequent eye blinking prompted a referral for an eye examination which was negative.

Ms. Jones contacted Patrick's mother to inform her of Patrick's abrasion and scuffle in the playground. She asked Patrick's mother whether she had noticed his movements and sounds at home. At that point Patrick's mother started to cry. She didn't know what was happening to her son—he was making all these noises and movements, fighting with everyone at home and on the bus, and she had recently received a note to confer with Patrick's teacher. Ms. Jones arranged a meeting with Patrick's parents on the same day as their meeting with his teacher.

Ms. Jones listened to the description of Patrick's symptoms and suggested that these "nervous mannerisms" and behavioral difficulties could be part of a neurological disorder called Tourette Syndrome. She advised Patrick's parents to consult with their primary care practitioner who very likely would make a referral to a pediatric neurologist, child psychiatrist or developmental pediatrician. She also gave the family the address of the Tourette Syndrome Association to obtain additional free information.

The School Nurse as Clinician

The school nurse or nurse practitioner in a school-based clinic can play an important role in the identification of children with tic disorders. A child who is sent to the nurse's office for medication, or to a school-based clinic for assessment may provide the opportunity to identify a previously undetected tic disorder. For children who have already been diagnosed with TS, the school nurse can be an important resource for information about tic disorders and the medications used in the treatment of tics and related problems.

Children with TS may wonder why they have tics, if they are to blame for their tics, and whether the tics will ever go away. The nurse can provide reassurance that,

in most cases, tics do get milder as the person matures into adulthood. Although it is difficult to predict which children will go on to have severe tic symptoms as they develop into adulthood, tic disorders are generally not progressive conditions. Even for children with severe TS in childhood, tics tend to change in number and frequency over time. One movement or vocalization will be replaced with others and previous tic symptoms may return. Although involuntary, tics can be voluntarily suppressed for brief periods of time. This feature of TS can be confusing to parents, teachers and children alike. Pointing this out to a child like Patrick can help him understand why his tics vary in different settings such as at school or at home. Stress, excitement and fatigue

usually aggravate symptoms. Therefore, during tests or prior to a special field trip, new tics may emerge and the frequency of tics may increase. Vacation times such as summer recess may be accompanied by a reduction in symptoms.

Some children may need help coping with teasing from their classmates. The nurse in the school setting can listen to the child and discuss better adaptive responses than fighting to deal with the anger and pain of being teased. Being an accepted member of the group is important for all children, and this is especially true for children with TS. Involvement in extracurricular activities such as sports, marching band, chorus and drama club permits the child to be an active member of a group. The nurse can advocate for the child to ensure that he or she is not barred from these activities unnecessarily.

The School Nurse as Educator

Education of School Personnel

The school nurse is often relied upon as a health educator for teachers and other school personnel. For children such as Patrick, the nurse should inform teachers and perhaps Patrick's classmates about TS and the medications used to treat his symptoms. Once the teachers and students understand the involuntary nature of tics, they may amend their view of Patrick and no longer see him as a troublemaker.

The nurse might lead a discussion with teachers on the ways in which TS can interfere in the classroom. For example, a boy like Patrick may be expending a significant amount of energy to suppress his tics, and have little remaining strength to learn his multiplication tables or spelling rules. Many children with TS have trouble with handwriting. In addition, hand or arm tics, or compulsive re-writing may further interfere with written work. Simple solutions such as the use of a tape recorder or computer can be helpful. The problems with handwriting or direct interference from tics often make test taking especially difficult for these students. Adolescents with TS may be at a considerable disadvantage when taking standardized tests such as the PSAT or SAT. Thus, in some cases, untimed testing should be considered. The educational team may also look to the school nurse to advise them concerning the impact of medication on academic progress. Clearly, the nurse in the school setting has a role to play in designing appropriate educational strategies and perhaps classroom placement for children with TS.

Education for Families

Families of children with TS often recount tales of misdiagnosis and unhelpful medical consultations. In such cases, the nurse may be able to help the family obtain an appropriate referral. When families learn about the genetic underpinnings of TS, some parents may also wonder whether they are somehow to blame for their child's tics. Occasionally, family members may reveal the presence of tics or related problems in themselves or in other family members. Some parents may also have a current or past history of compulsive behaviors. Parents with tics or obsessive-compulsive symptoms may feel responsible for the child's problems. Some families may also need to express their guilt about having punished their child prior to understanding the involuntary nature of the motor and phonic tics. Recognition of these issues will enable the school nurse to be supportive to families and explain these complexities to other school personnel.

Medication

In many cases, children with TS will not require medication for tic control. However, if the tic symptoms interrupt intended activity, interfere with interpersonal relationships or school performance, medication is then considered. Some medications need to be administered during school hours in which case the nurse will see the child to dispense medication. This offers an opportunity to evaluate both therapeutic and adverse effects of the medication as well as the child's overall adaptation. Even in cases where medication is not dispensed in school, periodic monitoring by the school nurse can help determine whether the medication is effective and well tolerated. The field of child and adolescent psychopharmacology has greatly expanded in recent years, and there are a number of new agents used in the treatment of TS and associated behaviors such as ADHD and obsessions and compulsions. The proliferation of these agents requires continued education for health care professionals including school nurses. Despite the promise of these new medications, they can have physical, behavioral and cognitive side effects. Finally, although medications may be helpful, they rarely eliminate the target symptoms. (See pages 7 to 9 for a summary of medications commonly used in the treatment of TS and related problems).

Antipsychotic Medications

Medications such as haloperidol (Haldol) and pimoziide (Orap) have been used in the treatment of Tourette Syndrome for many years. These medications block specific dopamine receptors in the brain and often achieve significant reduction in tic symptoms with small doses. Early in treatment there is a small risk of acute dystonic reaction in which muscles of the arms and neck stiffen. Occasionally this reaction can progress to oculogyric crisis in which the neck is craned to one side and the eyes roll upward. Anti-Parkinsonian agents such as benzotropine (Cogentin) are used to treat these side effects and may be prescribed prophylactically early in treatment. More common side effects may include sedation, mood changes, depression, school phobia, motor restlessness, blurred vision, cognitive blunting and excessive weight gain. As with other antipsychotic medications, long-term use of haloperidol or pimoziide carries a small risk of developing tardive dyskinesia. Despite the fact that tardive dyskinesia is also a movement disorder, there is no evidence to suggest that children with TS are at any greater risk for developing tardive dyskinesia.

Direct comparison studies of pimoziide and haloperidol suggest that they are equally effective in controlling tics, though doses of haloperidol are typically lower than pimoziide. There have been reports of cardiac arrhythmias with pimoziide; thus cardiac monitoring may be included in the treatment plan of children taking pimoziide. Because of their potential for short- and long-term side effects, use of these medications is typically avoided unless the tic symptoms are prominent and interfere with daily living activities. Although there may be differences in clinical practice, the most common approach aims for moderate control of tics at the lowest possible dose.

Risperidone (Risperdal) and ziprasidone (Geodon) are newer antipsychotic medications that differ from the traditional agents such as haloperidol and pimoziide. As noted above, the traditional antipsychotic medications primarily block dopamine receptors. Risperidone and ziprasidone retain this action and block serotonin receptors as well. This dual action is believed to offer protection against the well-known neurological side effects associated with traditional drugs such as haloperidol. Both risperidone and ziprasidone have been evaluated in carefully controlled studies in TS and both appear to be effective in reducing tics. The overall effectiveness on tic suppression appears to be equivalent to the traditional antipsychotic drugs, but the risk of neurological side effects is lower. Adverse side effects of risperidone

include weight gain and sedation. School phobia has also been observed. Ziprasidone does not appear to cause weight gain, but sedation, restlessness and insomnia have been reported.

Clonidine

Clonidine (Catapres) is an antihypertensive agent that is used to treat tics and/or ADHD. This medication acts on a different neurochemical system than the antipsychotics and may take two to three months to achieve a positive response. Clonidine is begun at low doses and slowly increased over several weeks. Adverse effects may include sedation, which is most evident when therapy is first initiated or when the dosage is being increased. Some children complain of dry mouth or headache and parents may report sleep problems (waking up at night) and increased irritability. Surprisingly, blood pressure is rarely a problem. However, when discontinued, clonidine should be tapered slowly to avoid a rebound increase in blood pressure, tics and anxiety.

Stimulants

Stimulants such as methylphenidate (Ritalin) are the most commonly used drugs in the treatment of ADHD. Some children with TS and ADHD who are treated with a stimulant may demonstrate an increase in the number, intensity and frequency of tics. Because ADHD often precedes the onset of tics, the tics may emerge following a trial of stimulant medication. Despite this chronology, there is no convincing evidence that methylphenidate *causes* a tic disorder. Moreover, several recent studies confirm that most children with TS can tolerate stimulants without unacceptable increases in their tics. Based on these recent findings, many clinicians prescribe the stimulants and then monitor the child closely for any change in tic symptom severity. Stimulants may also be used in combination with other medications such as clonidine or guanfacine.

Non-stimulant Medications for ADHD

Although it is now clear that stimulants do not invariably increase tics in children with TS and ADHD, some children do show a worsening of tics when treated with stimulant medication. In addition, ten to twenty percent of children with ADHD fail to respond to stimulant medication. Thus, children with TS and ADHD may be treated with a non-stimulant medication. In addition to clonidine, four non-stimulant medications have been shown to work better than placebo in clinical trials. These include: guanfacine (Tenex), desipramine

(Norpramin), bupropion (Wellbutrin) and atomoxetine (Strattera). Guanfacine is an anti-hypertensive drug that is similar to clonidine. As with clonidine, guanfacine is usually given in multiple doses throughout the day. However, it may or may not be given during school hours.

Desipramine and atomoxetine were developed as antidepressants. These compounds are not chemically related, but are presumed to exert primary effects on brain norepinephrine systems. Desipramine has been available for many years. Atomoxetine was released in early 2003, and appears to be well tolerated and effective for the treatment of ADHD. Although effective, many clinicians are reluctant to use desipramine because it has been associated with cardiac conduction problems in a small percentage of cases. Bupropion is also an antidepressant—but does not appear to affect the norepinephrine system directly. Several studies show that bupropion is superior to placebo for ADHD symptoms, but the magnitude of improvement is smaller than what is typically observed with the stimulants.

Antiobsessional Agents

As indicated previously, the co-occurrence of OCD and TS is common. The introduction of anti-obsessional medications over the past decade is a significant advancement in the treatment of OCD and several are approved for this purpose. Soon after the introduction of clomipramine (Anafranil), several more selective serotonin uptake inhibitors (SSRIs) entered the marketplace. The SSRIs include fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), sertraline (Zoloft), escitalopram (Lexapro), and citalopram (Celexa). Blocking the uptake of serotonin by the pre-synaptic nerve endings apparently accounts for their therapeutic action since other antidepressants without this property are not effective in reducing obsessive-compulsive symptoms. Clomipramine is a tricyclic medication, thus its side effect profile is similar to the other tricyclics such as desipramine. The most common adverse effect of the other more selective SRIs is behavioral activation—characterized by motor restlessness, over-activity, mildly provocative behavior and sleep disturbance. Other adverse events may include nausea and diarrhea.

Medications Used in the Treatment of Children with Tics

Name	Brand Name	Starting Dose	Usual Dose Range
haloperidol	Haldol	0.25-0.5mg	0.5-2.5mg
<i>Possible Side Effects – fatigue, weight gain, muscle rigidity, motor restlessness, tardive dyskinesia, school phobias, photosensitivity, depression, cognitive dulling</i>			
pimozide	Orap	0.5-1mg	1.0-4mg
<i>Possible Side Effects – same as haloperidol, EKG changes</i>			
clonidine	Catapres	0.05mg	0.1-0.25mg
<i>Possible Side Effects – fatigue, drowsiness, irritability, dizziness, headache, sleep disturbance</i>			
clonidine patch	Catapres Patch	TTS1 patch	TTS1-TTS3
<i>Possible Side Effects – same as clonidine tablets, localized skin rash</i>			
risperidone	Risperdal	0.25-0.5mg	1.0-3.0mg
<i>Possible Side Effects – fatigue, weight gain, depressed mood, school phobia</i>			
ziprasidone	Geodon	5-10mg	20-40mg (lowest available dose is 20mg capsule)
<i>Possible Side Effects – sedation, restlessness, insomnia</i>			

Note: The other newer anti-psychotics – olanzapine (Zyprexa™), quetiapine (Seroquel™), and aripiprazole (Abilify™) have not been well-studied in TS to date.

Anti OCD Medication

Name	Brand Name	Starting Dose (per day)	Usual Dose Range (per day)
fluoxetine	Prozac	4-10mg	5-60mg
<i>Possible Side Effects – hyperactivity, restlessness, insomnia, disinhibition</i>			
paroxetine	Pexeva	5-10mg	10-60mg
<i>Possible Side Effects – same as fluoxetine, weight gain</i>			
clomipramine	Anafranil	25mg	50-150mg
<i>Possible Side Effects – dry mouth, blurred vision, constipation, fatigue, EKG changes, weight gain</i>			
sertraline	Zoloft	12.5-25mg	75-200mg
<i>Possible Side Effects – same as fluoxetine, weight gain</i>			
fluvoxamine	Luvox	12.5-25mg	75-200mg
<i>Possible Side Effects – same as fluoxetine</i>			
citalopram	Celexa	5-10mg	10-40mg
<i>Possible Side Effects – same as fluoxetine</i>			

Note: A new selective serotonin reuptake inhibitor, escitalopram (Lexapro) has not been well-studied in OCD.

Non Stimulant Medications for ADHD

Name	Brand Name	Starting Dose (per day)	Usual Dose Range (per day)
bupropion	Wellbutrin	10-25mg	50-150mg
<i>Possible Side Effects – dry mouth, blurred vision, constipation, fatigue, EEG changes, weight gain</i>			
desipramine	Norpramin	10-25mg	50-150mg
<i>Possible Side Effects – drowsiness, tachycardia, dizziness, dry mouth, constipation</i>			
guanfacine	Tenex	0.25-0.5mg	2-4mg
<i>Possible Side Effects – fatigue, drowsiness, dizziness, sleep disturbance</i>			
clonidine	Catapres	0.05mg	0.1-0.25mg
<i>Possible Side Effects – fatigue, drowsiness, irritability, dizziness, headache, sleep disturbance</i>			
atomoxetine	Strattera	0.25 - 0.5mg/kg	20-60mg
<i>Possible Side Effects – decreased appetite, weight loss, abdominal pain, vomiting, dizziness</i>			

Stimulant Medications

Name	Brand Name	Starting Dose (per day)	Usual Dose Range (per day)	Duration
methylphenidate	Ritalin, Concerta, Metadate	5-10mg	10-60mg	
<i>Possible Side Effects – appetite loss, insomnia, irritability, increased tics, headache, stomach ache</i>				
Long-acting methylphenidate	Concerta	18 to 36 mg	18 to 54mg	8-12 hrs
	Metadate CD	20 mg	20 to 60mg	6-8 hrs
	Ritalin-LA	20 mg	20 to 60mg	6-8 hrs
<i>Possible Side Effects – same as methylphenidate</i>				
dextroamphetamine	Dexedrine	2.5-5mg	5-30mg	
<i>Possible Side Effects – same as methylphenidate</i>				
mixed amphetamine	Adderall	2.5-5mg	5-30mg	
<i>Possible Side Effects – same as methylphenidate</i>				
Long-acting mixed amphetamine	Adderall XR	5-10mg	5-30mg	10-12 hours
<i>Possible Side Effects – same as methylphenidate</i>				

Summary

Tics are common in school-age children. The presence of tics does not necessarily mean that the child will develop TS. Tourette Syndrome is a neurological disorder characterized by motor and phonic tics, and in some cases, associated symptoms of OCD and/or ADHD. The tics of TS are chronic with a tendency to wax and wane in severity over time. TS is not a progressive condition. Indeed, in most cases, tics decline after puberty. Although the cause is unknown, dysregulation of brain circuits involving frontal lobe and the basal ganglia appears to be important in the pathophysiology of TS.

Research over the past two decades suggests that TS is a genetic disorder with a broad range of expression from mild to severe. The TS phenotype appears to include obsessive-compulsive symptoms. Problems with attention, impulsiveness, hyperactivity and anxiety regulation are also common in clinical samples of children with TS, and may be the source of greater impairment than tics.

Children with TS may be subjected to teasing by peers and, sometimes, disparagement by uninformed teachers and family members. Some children require medication to help with tics, ADHD and/or OCD. The nurse in the school setting is in a unique position to monitor the child's condition and treatment response. The nurse can help school personnel to understand the

complexities of TS—especially with respect to which behaviors are part of the syndrome and which behaviors the child may be expected to control. Although this distinction may not be straightforward in some cases, careful discussion can usually lead to appropriate limit setting. In order to carry out this educational role, the nurse in the school setting must keep up with current knowledge about TS and its related conditions. This is especially critical regarding the medications used in TS treatment.

As with other chronic conditions, the child with TS often needs additional support and understanding. The student should be allowed, and indeed encouraged, to participate in school activities. In the process of monitoring the child's medication in the school setting, the nurse should also monitor the child's overall adjustment to having a chronic condition. The nurse may hear about teasing from classmates, apprehension about having tics during an upcoming school event, academic troubles, or fears of blurting out inappropriate comments in the classroom. Allowing the child to express these concerns may help to reduce their impact. In other cases, the school nurse can refer the child within the school or to outside health care providers. Thus, the school nurse can play an important role in the direct and indirect care of students with TS.

Sources for additional information

Keltner, N & Folks, D; *Psychotropic Drugs*; St. Louis, Mosby; 2001

Leckman, JF & Cohen, DJ (eds); *Tourette Syndrome: tics, obsessions and compulsions*; New York; Wiley; 1999

Martin, A, Scahill, L, Charney, DS, Leckman, JF; *Pediatric Psychopharmacology: Principles and practice*; New York; Oxford University Press; 2003

TSA website: www.tsa-usa.org

CHADD website: www.chadd.org

OC Foundation website: www.ocfoundation.org

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TSA gratefully acknowledges the counsel and guidance of its Medical Advisory Board in the review of this publication. Members of the TSA Medical Advisory Board welcome queries from colleagues and other professionals and can be reached by contacting the Tourette Syndrome Association.

This publication is intended to provide information about Tourette Syndrome, its management and the medications currently in use. Readers should always consult their physicians concerning all treatments and medications.

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ADDITIONAL TSA RESOURCES

Videos & Vignettes

AV-9 After the Diagnosis . . . The Next Steps

Produced expressly for individuals and families who have received a new diagnosis of TS. This video was developed to help clarify what TS is, to offer encouragement, and to dispel misperceptions about having TS. Features several families in excerpts from the Family Life With TS A Six-Part Series who recount their own experiences as well as comments from medical experts. Narrated by Academy Award Winner Richard Dreyfuss. 35 min.

AV-10 The Complexities of TS Treatment: A Physicians' Roundtable

Three internationally recognized TS experts, Drs. Cathy Budman, Joseph Jankovic and John Walkup provide colleagues with valuable information about the complexities of treating and advising families with TS. Emphasis is on different clinical approaches to patients with a broad range of symptom severity. Co-morbid and associated conditions are covered. 15 min.

AV-10a Clinical Counseling: Towards an Understanding of Tourette Syndrome

Targeted to counselors, social workers, educators, psychologists and families, this video features expert physicians, allied professionals and several families summarizing key issues that can arise when counseling families with TS. Includes valuable insights from the vantage point of those who have TS and those who seek to help them. 15 min.

AV-11 Family Life With Tourette Syndrome . . . Personal Stories . . . A Six-Part Series

Adults, teenagers, children, and their families . . . all affected by Tourette Syndrome describe lives filled with triumphs and setbacks . . . struggle and growth. Informative and inspirational, these stories present universal issues and resonate with a sense of hope, possibility, and love. 58 min.

AV-12 A Teacher Looks at Tourette Syndrome

Susan Connors presents a humorous and inspiring program to help teachers be effective and informed when teaching a child with TS. Susan introduces teachers to what it is like to have a student with TS in their classroom and gives techniques that help students learn best. Susan's years of teaching experience, personal insight and abundant humor make for compelling viewing. 30 min. and 60 min. presentations on the same video.

An up-to-date Catalog of Publications
and Videos can be obtained by contacting:



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