Tic Disorders in Children

School Nurse Curriculum
2009
Tics are generally NOT a side effect of medication. There is current controversy regarding whether medications or other substances play a role in onset or exacerbation of symptoms. Researchers speculate that daily life stressors are more likely to determine tics and tic outcome than are major life stressors.

**Definition**

What are tics?
Tics are involuntary, stereotypic movements (motor) or sounds (vocal) that are quick, sudden, repetitive and generally purposeless.

Another interpretation:
“…fragments of normal motor action that are misplaced in context and that can be easily mimicked and at times are confused with goal-directed behavior.”

(Leckman, Bloch et al, 2006)
Demographics

- 20-25% of the population have tics at some point in their lives
- 1% of children have Tourette syndrome (TS), higher prevalence among children with special needs
- There are about 750,000 children with TS in the US
- Tics typically begin in first decade of life
Etiology

Etiology of Tics and Tourette syndrome

- Biochemical imbalance in basal ganglia
- Involves neurotransmitters dopamine and serotonin as messages are sent to frontal cortex of brain

http://www.tsa-usa.org/
Dopamine blocking agents such as haloperidol, pimozide, and risperidone are being successfully used in treating tics and Tourette Syndrome.
A thorough history and physical examination is necessary to diagnose tics. The ability to briefly suppress tics distinguishes a tic disorder from other movement disorders. Some children, such as those with pervasive developmental delay, have stereotypies. These may include touching, tapping, spinning, or other actions. Stereotypies are voluntary, intentional, and self-soothing. Tics are involuntary and non-intentional. Obtaining a family history of tics, other neurologic conditions, or comorbid disorders is often helpful (Zinner, 2004).
A thorough history including a social history and scholastic data may also add valuable information to the assessment of the child with tics.

Once a child has a known co-morbid condition, treatment and management strategies can be individualized for optimal academic results.
A typical report involves a brief bout of eye blinking of variable intensity beginning in early school years. The tic repertoire may change in character. Phonic or vocal tics appear several years after the onset of motor tics, between 8-15 years of age. Phonic tics show a similar progression of symptoms, from transient episodes to more sustained phonic symptoms. In most cases, tic severity is at its peak between 7-15 years of age, then there is a steady decline in tic severity.

Once established, tics often occur in discrete bouts over the course of a day. Speculation focuses on the “fractal” occurrence of tics, meaning that bouts of tics occur in bouts. There is a nonlinear temporal patterning of tics that remains constant (Leckman, Bloch et al, 2006).

In cases of Tourette syndrome, symptoms multiply and worsen by early adolescence so that even the waning phase of tics is troublesome.
### Description of Symptoms

Tics characterized by
- Anatomic location
- Number
- Frequency
- Duration – fluctuate in pattern and time
- Intensity or forcefulness
  - Can be quite exaggerated movement
- Occur while awake and cease with sleep

Children with tics will often be able to accurately describe the anatomic location of the tic. Older children will be able to describe the frequency and number of tics. Exaggerated or forceful movements can cause pain or repetitive motion discomfort. Often this is why families seek medical care – because the arm, shoulder, neck, or other area is painful.
Description of Symptoms

Simple Motor Tics

• Rapid, flitting, meaningless movements involving one muscle group
  – Blinking, grimacing, nose twitching, lip motion, shoulder shrug, arm jerk, head jerk, abdominal tensing, finger tapping, jaw motion, tooth clicking, frowning
  – Brief, last less than ½ second.
  – May occur in repeated bouts
The degree of impairment and disruption associated with particular motor tics is variable and an important clinical feature. Estimates of impairment depend on frequency, intensity, duration, and complexity of specific tics. Estimates of impairment also need to include the impact on self esteem, family life, social acceptance, school functioning, and general well being. (Leckman et. al, 2006)

Description of Symptoms

Complex Motor Tics

- Stereotypic movements involving more than one muscle group
  - Hopping, touching, throwing, smelling, bending, head banging, pinching, rolling eyes, facial contortions, squatting, repeated smelling of object, imitating gestures of others
  - Sustained duration or orchestrated pattern, appear more purposeful
Tics start as simple motor tics, followed by phonic tics and more complex motor tics in the next few years, although sometimes not until early or middle adolescence (Zinner, 2004). Over months or years, motor tics become increasingly complex progressing over time in a top to bottom and central to peripheral direction. Also, the movements can become more elaborate or sustained and can include combinations of movements e.g. touching and tapping. Motor tics may also become self injurious.

At onset, phonic tics are meaningless and simple. Over time, more complex phonic tics can occur including palilalia (repetition of own words), echolalia (repeating someone else’s words), coprolalia (obscenities or socially inappropriate remarks). Coprolalia occurs in a minority of patients although it is closely associated with TS.

**Description of Symptoms**

**Simple Vocal (Phonic) Tics**

- Single sounds and noises with no meaning
  - Throat clearing, coughing, spitting, sniffing, barking, grunting, gurgling, clacking, hissing, sucking, snorting, syllable sounds
  - Vocal = phonic
  - Produced by vocal cords (sniffing widely accepted as vocal tic).
Other classifications of which the nurse should be aware:
Transient Tic Disorder – Single or recurrent episode, onset before 18 years of age, no past diagnosis of tic disorder, tics occur many times per day for 1-12 consecutive month, single OR multiple motor and vocal tics combined OR single OR multiple motor tics OR vocal tics.

Chronic Motor or Vocal Tic Disorder – Single or multiple motor OR vocal tics (but not both) present at some point, occur many times a day nearly every day, present for more than 12 months, onset before age 18, no tic-free period greater than three consecutive months, no past diagnosis of TS, not due to effect of substance or other medical condition.

Tourette syndrome - diagnostic criteria noted previously

Tic disorder NOS – Symptoms do not meet criteria of other tic disorders, duration less than 4 weeks, onset after age 18.
Tics wax and wane and for the most part are not harmful. The primary goal of tic management is to avoid social disability. “Benign neglect” is usually the best approach, this means ignoring or paying minimal attention to the tic activity, and not drawing attention to it.

Medication management is considered only when tics are bothersome to the child (not the parent) and physically or psychologically impairing normal activity. Tic medications generally have significant side effect profiles. A decision to use them generally weighs risk vs. benefit.

The nature of tics changes from time to time, fluctuating with periods of worsening and improvement. Stress is a common factor in tic exacerbation, if stressful situations can be anticipated and minimized, tics frequency may be reduced.

——

Description of Symptoms

Identify all current motor or vocal tics seen

- Describe onset, frequency, timing, duration, pattern, change in pattern, general status
- “Performing” the tic results in temporary relief or release.
- Described as a voluntary or semi-voluntary urge
- Suppression of tic can be more debilitating than the tic itself.
Because studies searching for the gene(s) associated with Tourette syndrome are under way at several centers around the world, the Tourette Syndrome Association (TSA), New York, NY, recognized the need for developing precise criteria to define the syndrome and related tic disorders. These criteria could be utilized not only in genetic research but also in other research activities as well as by clinicians in practice. Consistency in diagnosis is important so that investigators will be able to compare the same populations of patients, and all who read the scientific reports from the various research groups will be better able to interpret the results. The TSA, furthermore, recognized the need for clinical investigators to have available clinical rating scales to follow the natural history of the disease and to evaluate results of therapeutic interventions.

To these ends, the TSA organized a task force (The Tourette Syndrome Classification Study Group) to develop definitions and rating scales. The workshop participants were able to prepare and agree on research definitions of various tic disorders and have set up a subcommittee to develop clinical rating scales. The definitions were further discussed and modified several times until agreement was reached on this final report, which we now present to the biomedical community (Table 1). A subcommittee is developing a quantitative rating scale for tics, and we anticipate having available in the near future a rating scale that will prove valid, reliable, and easy to use. When such a scale is finalized, it will also be published.

Although definitions of Tourette syndrome are available in textbooks of neurology and psychiatry and also in the Diagnostic and Statistical Manual, Revised Third Edition (DSM-III-R) of the American Psychiatric Association (1988), they do not effectively differentiate among nor define the wide variety of all the tic disorders. Discussions centered on possible approaches to developing more effective acceptable definitions. The Study Group decided to keep the basic tenets of the DSM-III-R definition for Tourette syndrome, chronic tic disorder, transient tic disorder, and non-specified tic disorder, since these terms have become widely used, and there is no solid reason to abandon them. However, for research purposes we divided each of these DSM-III-R definitions into two categories: "definite," in which the tics have been witnessed by a reliable observer, and "historical," in which the putative tics have not been reliably witnessed. These definitions are reported here in greater detail, along with the definitions of other categories of tic syndromes that were developed at the workshop and are not covered by existing DSM-III-R criteria. These additional tic categories are chronic single tic disorder; definite tic disorder-diagnosis deferred; and probable Tourette syndrome.
Description of Symptoms

Transient Tic Disorder
- Single or multiple motor and vocal tics combined or single or multiple motor or vocal tics
- Occur many times per day for 1-12 consecutive months
- Onset before age 18
- Not due to substance or medication effect
- Single or recurrent episodes
- No past diagnosis of any type of tic disorder
Description of Symptoms

Chronic Motor or Vocal Tic Disorder

- Single or multiple motor or vocal tics (but not both) present at some point
- Occur many times a day or nearly every day
- Present for more than 12 months
- No “tic-free” period for greater than 3 months
- Onset before age 18
- Not due to effect of substance or medical condition
- No past diagnosis of Tourette Disorder

Tic Classification
APA Tic Disorder Classifications

Tourette Disorder
- Both multiple motor and one or more vocal tics present at some point, not necessarily concurrently
- Occur many times a day or nearly every day
- Present for more than 12 months
- No “tic-free” period greater than 3 consecutive months
- Onset before age 18
- Not due to effect of substance or other medical condition

Tourette Classification
APA Tic Disorder Classifications

Tic Disorder NOS

- Symptoms do not meet criteria for other tic disorders
- Duration is less than 4 weeks
- Onset is after 18 years of age
The urge may be described as tension, pressure, a tickle, itch, or other sensory experience. Urges may be described as a less physical sensation and more of a psychic phenomenon. External stimuli can provoke this urge. Patients often describe needing to feel “just right” to achieve relief. A single tic or a rapid succession of tics may be required. High level emotional excitement can exacerbate tics.
A typical report involves a brief bout of eye blinking of variable intensity beginning in early school years. The tic repertoire may change in character. Phonic or vocal tics appear several years after the onset of motor tics, between 8-15 years of age. Phonic tics show a similar progression of symptoms, from transient episodes to more sustained phonic symptoms. In most cases, tic severity is at its peak between 7-15 years of age, then there is a steady decline in tic severity.

Once established, tics often occur in discrete bouts over the course of a day. Speculation focuses on the “fractal” occurrence of tics, meaning that bouts of tics occur in bouts. There is a nonlinear temporal patterning of tics that remains constant (Leckman, Bloch et al, 2006)

In cases of Tourette syndrome, symptoms multiply and worsen by early adolescence so that even the waning phase of tics is troublesome.
Most children with tics do not require medication. Medication is only recommended if the ticcing interferes with physical or social functioning, i.e. if teasing or bullying is occurring. Over the past 10 years, a theory evolved in which tics were thought to be an late effect of a streptococcal infection. However, this theory is not evidence based, has not been rigorously evaluated, and is now losing favor in the scientific community.

The use of stimulant medication e.g. for ADD/ADHD does not cause tics. However, stimulant medication may lower the threshold, allowing tics to become more evident to observers. Alpha 2 adrenergists – Adverse effects include sedation, dry mouth, postural hypotension. Also treat co-morbid ADHD, anxiety, and insomnia. Clonidine is available as a skin patch. May take 8 or more weeks to achieve efficacy. Guanfacine is longer acting and less sedating than clonidine. Atypical neuroleptics – Adverse effects include sedation, weight gain, depression, galactorrhea, dystonia, prolonged QT interval, some risk of hepatotoxicity, and diabetes mellitus. Typical neuroleptics – Adverse effects include sedation, extrapyramidal effects (dystonia, parkinsonism), risk of tardive dyskinesia, prolonged QT interval. Benzodiazepines – Adverse effects include drowsiness, dizziness.
Most children with tics do not require medication. Medication is only recommended if the ticcing interferes with physical or social functioning, i.e. if teasing or bullying is occurring. Over the past 10 years, a theory evolved in which tics were thought to be an late effect of a streptococcal infection. However, this theory is not evidence based, has not been rigorously evaluated, and is now losing favor in the scientific community. The use of stimulant medication e.g. for ADD/ADHD does not cause tics. However, stimulant medication may lower the threshold, allowing tics to become more evident to observers. Side effects and efficacy of medications can be unpredictable. Patients may require a trial of more than one medication before achieving a satisfactory response. Dosing usually starts low and titration is slow to avoid unwanted effects. (Zinner, 2004)
The presence of tics is not an automatic indication that they be treated. Often, tics do not interfere with daily life too warrant use of medication and possible resulting side effects. It is important to note that no drug will eliminate tics entirely. Goal of medication use is to lessen tic frequency and severity, and optimize academic, psychosocial, and family functioning. Families and others involved with children with tics or Tourette Syndrome need to understand that medications treat symptoms but are not curative. A balance between tic reduction and tolerable side effects is optimal. (Zinner, 2004)

• Children do not always respond to the initial medication tried. Often finding a medication that treats the tics with minimal side effects is done through “trial and error.” Families should not become discouraged if the first medication tried is not “right” for that child.

• If a child is having unacceptable side effects from a medication, compliance will likely deteriorate. Families should be informed that the medication must be taken consistently for several weeks in order to assess its efficacy, even at a therapeutic dosage.

• Side effects vary among medications. Some cause sedation and fatigue, others may enhance weight gain. Other effects may include dry mouth, dystonia, cardi effects, and extrapyramidal effects such as dyskinesias (movement disorders) and dystonias (muscle tension disorders).

• Last, the child and parents may be reluctant to use medications for tics. Tic medication should ONLY be used when the effects of the tics are intolerable and affecting social, psychologic, academic and general daily functioning.
Trials with other behavior-based strategies are not well documented. Reduction in anxiety may be of some help.
Process Oriented Tic Assessment for the School Nurse
The Healthy Learner Model (HLM) for Student Chronic Condition Management is used to bridge gaps observed in medical models of disease management and programs that focus only on the environment at school. The Healthy Learner Model is an integrated, coordinated effort to optimize the health status and support the academic success of children with chronic conditions (Erickson, Splett, Mullett & Heiman, 2006).

The synergistic elements of the HLM are: 1) leadership, 2) evidenced based nursing practice, 3) capacity building, 4) resource nurse, 5) the healthy learner, 6) partnership with parents and 7) partnership with health care providers. Leadership, from the school and community, is responsible for promoting the vision across systems and securing the resources needed to manage the chronic illness. Evidence-based practice in nursing is the process of combining the best evidence available with nursing experience and patient/family preferences to determine the interventions for optimum outcomes (Adams & McCarthy, 2005).

The aim of the HLM is to enable students with chronic conditions to be healthy, in school, and ready to learn (Erickson, Splett, Mullett & Heiman, 2006). The HLM has been replicated for use with asthma management and ADHD management.
Baseline information is needed to work with children with tics and their families, in addition to teachers and other school staff.

Description and validation of symptoms is important to assess when communicating with the family or neurology provider.

If the child has already been diagnosed with ADD/ADHD or another neuropsychiatric disorder, certain school interventions may already be in place. Knowledge of whether or not the child is medicated and with which medication will also be helpful, particularly if the child is experiencing side effects.

Above all, an accurate description of what is seen at school is key.
Tics wax and wane and for the most part are not harmful. The primary goal of tic management is to avoid social disability. “Benign neglect” is usually the best approach, this means ignoring or paying minimal attention to the tic activity, and not drawing attention to it.

Medication management is considered only when tics are bothersome to the child (not the parent) and physically or psychologically impairing normal activity. Tic medications generally have significant side effect profiles. A decision to use them generally weighs risk vs. benefit.

The nature of tics changes from time to time, fluctuating with periods of worsening and improvement. Stress is a common factor in tic exacerbation, if stressful situations can be anticipated and minimized, tics frequency may be reduced.

---

**Description of Symptoms**

Identify and describe movements that are seen at school

- Onset
- Frequency
- Timing
- Duration
- Pattern or change in pattern
Most children with tics do not require medication. Medication is only recommended if the ticcing interferes with physical or social functioning, i.e. if teasing or bullying is occurring. Over the past 10 years, the PANDA theory evolved in which tics were thought to be an immunologic effect of a streptococcal infection. This theory postulates that antibodies produced against group A beta-hemolytic streptococcal infection cross-react with brain tissue resulting in onset or exacerbation of symptoms. 

Key point: This theory is not evidence based, has not been rigorously evaluated, and is now losing favor in the scientific community. It is considered a highly controversial diagnosis.

Key point: The use of stimulant medication e.g. for ADD/ADHD does not cause tics. However, stimulant medication may lower the threshold, allowing tics to become more evident to observers.
Sleep patterns should be considered, specifically snoring, sleep patterns, hours of sleep. Ongoing assessment regarding behavior at home and at school should occur. It is helpful to identify triggers that precipitate the behavior. In some cases the associated disorder (ADD/ADHD) itself is related to the tic disorder. Additionally, medication used to treat the disorder may affect tics.

Eliciting age appropriate information about speech and language abilities, social interaction, emotional attachment, eye contact, and peer relationships are key to a thorough evaluation. Additional information regarding imitative play, motor mannerisms such as stereotypies, self stimulatory behaviors, lining up objects, and other unusual sounds or noises can also be helpful.
General Health and Psycho-social

• Diagnosis of tics is often made after a mild upper respiratory infection with continued sniffing and/or throat clearing after the illness has resolved.
• Consider effects of stimulants such as cold, allergy, asthma medications.
• Consider effects of caffeine or other substances on tic improvement or exacerbation.
It is important that the parent and child or teen understand the nature of a tic disorder and receive support with coping. Assessment of knowledge, level of concern, and perception of tics and management are all critical aspects of care. Providing reassurance regarding the waxing and waning nature of tics, and offering a pathway for ongoing management may alleviate some concern. Directing patients and families to online educational materials or local support organizations can be particularly helpful. It is critical to emphasize that tics are not a “big deal” and “benign neglect” is the best approach.

Changes in family dynamics (new baby, divorce, death, financial concerns, etc.) can increase stress and impact the child’s tics.
It is also important to obtain information on non-medication therapies, prn or OTC medications that the child may be taking. This includes vitamins, herbals, homeopathic supplements.

Since the association of medications with tic causation or exacerbation is controversial, evaluation and counseling should take place on an individual basis.

Family Dynamics and Coping – Action Plan

- Discuss nature and etiology of tics with family
  - Wax and wane nature of tics
  - “Benign neglect” approach
  - Worsening tics or co-morbidities
- Discuss
  - Medication side effects, interactions
  - Improvement or exacerbation of tics
  - Status of co-morbidities, concurrent illnesses
- Provide support, education
- Encourage use of community resources
ADHD can have a negative effect on peer acceptance, school performance, and self esteem, and is often more of a source of impairment than the tics themselves. Increased irritability and rage attacks and increased vulnerability for drug use, depression, etc. is not uncommon among patients with combined Tourette syndrome and ADHD. Tic have the greatest effect on self-esteem and peer and family relationships from age 7-12 years, especially during periods of waxing forceful motor tics and loud phonic tics that can go on for hours. (Leckman, et al 2006)
Many children with tic disorders are in mainstream classrooms while others require special academic interventions at school. It is useful to understand the severity of tics at school and whether they interfere with motor activities (writing), or other tasks (reading, focusing, test taking). Tic disorders do not affect cognitive intelligence.
Sample School Letter
Sample letter for parent to address to either the school principal or the coordinator of the Special Education Department.

Dear ______________,

My child, ________________, has recently been diagnosed with Tourette Syndrome by Dr. _____________. Tourette Syndrome is a neurological spectrum disorder which is almost always accompanied by other neurological disorders. My child has thus also been diagnosed with (LIST RELATED DISORDERS). I have observed the impact that all of these disorders are having on his/her academic performance and social emotional well being. I have also learned from TS literature that a very large number of children with TS also exhibit learning disabilities especially in the area of non-verbal learning. These disabilities very often include sensory issues, processing difficulties and dysgraphia (difficulty with written language).

I am therefore requesting that my child be observed and receive a complete psycho-educational evaluation by the school psychologist as the first step in seeking from the IEP Team a classification of Other Health Impaired. I am also requesting evaluations in the following area(s) that I suspect as being areas of deficit. (LIST SPECIFIC AREAS OF DIFFICULTIES)

I am including a letter of diagnosis from the treating physician and materials from the Tourette Syndrome Association to be shared with my child’s teachers and the school psychologist. In the interim, I will be more than happy to meet with school personnel working with my child to discuss what behaviors he/she may be exhibiting in the classroom as a result of this diagnosis and what educators can do to assist.

http://www.tsa-usa.org/educ_advoc/getting_help_at_school.htm
An interval school assessment should include the child’s current level of academic performance (grades), ability to focus, status of learning disabilities, behavior or social issues, significant changes and response to educational interventions and specialized services or therapies.

If a child is medicated for attention, focusing, or behavioral issues, assessment should include a standardized questionnaire or teacher’s report to gauge response and efficacy.
School Resources

Teaching the Tiger A Handbook for Individuals Involved in the Education of Students with Attention Deficit Disorders, Tourette Syndrome or Obsessive-Compulsive Disorder (Plastic Comb)
by Marilyn P., Ph.D. Dornbush (Author), Sheryl K. Pruitt (Author)

Other school resources include:  (Available at http://www.tsa-usa.org/Professionals/ProfEducators/educators.html)

Books and Videos with Teachers' Resources
HBO Documentary, I Have Tourette's But Tourette's Doesn't Have Me.
The DVD features content shown on the HBO broadcast plus a variety of resources for educators, families, and children interested in learning more about Tourette Syndrome, and supplementary information from experts John Walkup, M.D., Susan Conners, M.Ed., and Evan Trost, M.D.

In this novel, Carrie, a seventh-grade girl has just been diagnosed with TS. Targeted to early teens, Quit It explores Carrie's struggles to cope with TS while trying to fit in with her peers.

Free School Reading Program and Sample Lesson Plan Using Quit It. Click here.
Future Study

Effort to determine why tics improve with age
- Maturing of frontal cortex
- Compensatory responses come “on-line”

Identification of specific genes
- Habit formation
- Procedural memory

Sensorimotor “gating” theory
- Tics result of impaired concentration, inability to filter perceptual “noise”
Long Term Outcome

- Greatest frequency and severity of tics in early adolescence
- Tics may improve over time while mood disorders or other problems worsen.
Provider Resources

Tourette Syndrome Association
www.tsa-usa.org

Tourette Syndrome “Plus”
www.tourettesyndrome.net

Planet Tic
www.planettic.com

NINDS Tourette Syndrome Information Page
www.ninds.nih.gov/health_and_medical/disorders/tourette.htm

Developmental and Behavioral Pediatrics
www.dbpeds.org