



Tic Disorders and Tourette Syndrome

Evaluation, Diagnosis, and Treatments

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Disclosures:

1. No financial disclosures
2. Clinical vignettes are used but patient information is protected
3. Off-label medication use is described, as is common in pediatrics

Vignette #1:

- ▶ Smart, social 6 year old boy dx with ADHD at age 5 by PCP
- ▶ Continues to be disruptive, strong willed, anxious, and inflexible at home and school.
- ▶ Methylphenidate and Strattera have been tried, with mixed results...
- ▶ In the exam room he is fun and interactive, and frequently honks at me...
- ▶ On further questioning, he also has a history of repetitive throat clearing, grunting, crotch grabbing, and saying words over and over since toddlerhood

What is a tic?

- ▶ A fragment of normal behavior that occurs quickly and in isolation, but more repetitive and less variable
- ▶ Not voluntary and they are not involuntary, they are “*unvoluntary*”
- ▶ Can be easily described/reproduced by observers
- ▶ Wax and wane, and can be suppressed at least temporarily
- ▶ Feels like an itch that has to be scratched or a sneeze that is hard to suppress
- ▶ The tic itself is often not as much of a problem as the comorbidities...



Tics versus Stereotypic Movements

- ▶ *Tics*: generally ego dystonic, most have a premonitory sensation and while they can be suppressed, tension exists when the tic is not released
- ▶ *Stereotypies*: ego syntonic, (though kids can become embarrassed by them), and suppression of the stereotypy does not cause as much tension
- ▶ Hand flapping, shuddering, complex hand movements, head nodding and banging, body rocking, sometimes accompanied by open mouth and staring, and sometimes vocalizations



Common Childhood Motor Tics

- ▶ Hard/frequent eye blinks, winks
- ▶ Eyes darting
- ▶ Facial grimaces, jaw movements
- ▶ Opening mouth
- ▶ Shoulder shrugging, neck stretching
- ▶ Torso shifting, jerking
- ▶ Hand to face/GU area/head/etc...
- ▶ Scrunching nose
- ▶ Copropraxia (rude gestures) and echopraxia (imitating gestures)
- ▶ Hopping, twirling, jumping
- ▶ Repetitive tensing of abdominal/limb muscles
- ▶ Truly dangerous tics are rare, but muscle soreness can occur, as opposed to stereotypes, which can include significant self-injurious behavior

Common Childhood Phonic Tics

- ▶ Repetitive throat clearing
- ▶ Grunting, honking
- ▶ Meowing, hissing, barking
- ▶ Induced belching
- ▶ Making sounds with mouth
- ▶ Snorting, sniffing
- ▶ Gaspings, sharp inhalations
- ▶ Short, sharp vocalizations: “oop” “eep”
- ▶ Rarely, coprolalia and echolalia, and palilalia (repeating own words)
- ▶ Hooting, shouting
- ▶ Words or phrases that are not part of a conversation (can be barked or grunted)

Premonitory Sensation

- ▶ Burning in the eye prior to a blink
- ▶ Tension in neck relieved with a stretch or jerk
- ▶ Feeling of tightness relieved with extension
- ▶ Kids get referred to PT's for "neck problems", and what is really occurring is a motor tic

“People believe that if you can shut off your Tourette’s for a period of time, then you can always shut it off. I try to explain to people that if I spent my whole life trying to control my tics, that’s all I would have time for.” –
Dash Mihok (actor)



Types of Tic Disorders

- ▶ Transient: motor, phonic, or both for > 2 weeks and < 1 year
- ▶ Chronic Motor or Vocal Tic: Motor tic OR Vocal tic > 1 year
- ▶ Tourette Syndrome: At least 2 motor and at least one vocal tic > 1 year, (generally waxing and waning but mostly present)

Types of Tics

- ▶ Simple Tics: Sudden, brief, a limited number of muscle groups
- ▶ Complex Tics: coordinated between more than 1 muscle group (rolling eyes back while sniffing and shrugging shoulders)
- ▶ Complex Tic or OCD Ritual? Is a tic really a manifestation of OCD? On obsession followed by a compulsion?

Who gets tics?

- ▶ 1 out of 100 kids between 5 and 17 years of age has a tic disorder
- ▶ 1 out of 160 kids between 5 and 17 have Tourette Syndrome
- ▶ 3-4 boys diagnosed for every girl
- ▶ Tics tend to emerge around age 5/6, worsen around age 10/11, and improve by 18, then sometimes recur in middle age



Vignette #2:

- ▶ 8 year old boy diagnosed with ADHD, ODD, and Social Anxiety at age 6 at the CDRC here for f/u
- ▶ Parents and Psychiatrist still think it's autism
- ▶ He has a 1:1 aid at school
- ▶ He is a perfectionist and easily escalates saying "I want to die", and now curses and hits walls
- ▶ He can be sweet, is eager to please, makes great eye contact, and is socially engaged. He hates that he curses and gets violent with objects...
- ▶ The only medicine tried so far was Risperidone
- ▶ I notice that older brother in room has a phonic tic...
- ▶ On further questioning, he makes a lot of random noises and movements, and taps his forehead in a repetitive way...

Developmental Disability Services

- ▶ People seeking an autism diagnosis are sometimes seeking services...
- ▶ DDS offers respite care, personal support workers paid through the state, behavioral evaluations, and some money for the purchase of non-billable items (crash pads, sensory tools)
- ▶ Tourette Syndrome is now an eligibility for DDS, provided there is proof of global functional impairment, as are the diagnoses of an Autism Spectrum Disorder, Intellectual Disability, Global Developmental Delay, and FASD

Tourette Syndrome

- ▶ Most have normal IQ
- ▶ School performance often affected by OCD, anxiety, and ADHD
- ▶ Onset between ages of 2 and 15 years, the mean is around age 6 or 7 years
- ▶ Tics tends to be most severe in late childhood/early teen years
- ▶ Half of kids are tic free by age 18, though they can come back in middle adulthood
- ▶ Remember, mild cases are more common than severe cases!
- ▶ Only 15-20% have coprolalia or copropraxia

Vignette #3

- ▶ 14 year-old boy comes in with mom
- ▶ “Does he have autism or is he just a (a jerk)?”, mom asks in front of son
- ▶ Difficulty making friends; annoyed with others easily
- ▶ Many annoying habits, including throat-clearing, coughing, making body function noises, bouncing, tapping, head-rolling, and fidgeting
- ▶ Teased about these behaviors and he would like to stop
- ▶ He has been diagnosed in the past with ADHD and treated with stimulant, which caused exacerbation of sounds/movements, weight-loss, and diminished energy. He has begun to hoard things and was dx with OCD.
- ▶ Aggression towards sister and cat had escalated and the family was beginning to consider residential treatment...
- ▶ A psychiatrist dx high functioning autism and prescribed an anti-psychotic medication, with some improvement in behavior, but also significant weight-gain and sedation

Vignette #3

- ▶ On Exam he is pleasant, cooperative, with typical social referencing and reciprocity, typical prosody of speech
- ▶ A few subtle tics seen in office, some fidgetiness
- ▶ ADOS—non-clinical
- ▶ Normal cognitive and language skills
- ▶ Now he is obese, secondary to atypical antipsychotic med
- ▶ He gained 30 lbs. in one year, and kept increasing doses
- ▶ He is now teased more for his weight than for his tics...

Conclusions

- ▶ Tourette syndrome, with secondary social impairments.
- ▶ The key is that the teen was very bothered by these habits.
- ▶ With new diagnosis, mom softened and was more receptive to him
- ▶ He was referred to counseling, and school accommodations were recommended, as well as sports/exercise
- ▶ On follow-up he was doing well, both academically and socially, and off of all medication

Comorbidities

- ▶ ADHD
- ▶ Anxiety and OCD (20-40% have OCD, almost all have some elements of OCD)
- ▶ If you have OCD, you have a 20% risk of developing tics and 7% risk of TS
- ▶ Mood challenges
- ▶ “fiery temperaments”
- ▶ Social Development challenges
- ▶ Sleep challenges and parasomnias
- ▶ Comorbidities are often a bigger challenge than the tics!
- ▶ Target treatment to whatever causes the most interference with functioning

Heritability

- ▶ Tourette Syndrome tends to be a highly penetrant dominant trait, males tend to have ADHD and tics, females tend to have OCD (externalization versus internalization)
- ▶ Stimulants provoke tics in predisposed kids, as can steroids, stress, illness, and lack of sleep

Worsening Factors

- ▶ Sleep deprivation/Exhaustion
- ▶ Anxiety
- ▶ Excitement
- ▶ Anger
- ▶ Illnesses – virus, strep...
- ▶ Pain, injury
- ▶ Being alone (feeling more comfortable)
- ▶ Lack of exercise
- ▶ Feeling too hot or too cold
- ▶ Sensory irritants like tags, turtle necks, tight or itchy clothes

Do you Believe in Pandas?



- ▶ Tics and OCD tend to worsen with illness, and particularly with strep
- ▶ There is a theory that it's an immune mediated process, similar to Sydenham's Chorea

OHSU

Alleviating Factors

- ▶ Sleep
- ▶ Calm
- ▶ Focusing on a task
- ▶ playing a musical instrument, (drums!)
- ▶ Vigorous exercise
- ▶ Regulating body temperature
- ▶ Staying healthy

Lifestyle and Behavioral Management

- ▶ **First:** optimize sleep! Decrease screen time!
- ▶ **Second:** optimize physical activity and outdoor time
- ▶ **Third:** get child into a physical or musical activity they enjoy like martial arts, running, swimming, ball sports, drumming, other musical instruments
- ▶ **Fourth:** Cognitive Behavioral Therapy (CBT) for anxiety/OCD and Comprehensive Behavioral Intervention for Tics (CBIT)
- ▶ Parents and teachers can redirect or distract when child is having tics, but should not keep asking child to stop, or make the child feel ashamed
- ▶ Celebrate neurodiversity in the home, school, and community

Comprehensive Behavioral Intervention for Tics

- ▶ 1. Training the patient to be more self-aware of tics (but not more self-conscious)
- ▶ 2. Training the patient to do competing behaviors when they feel the urge to tic (slow breathing instead of throat clearing) → so, not suppressing the tic (which is exhausting), but practicing behaviors that are incompatible with ticcing until the urge goes away
- ▶ 3. making changes in daily routines that can be helpful in reducing tics (manage anxiety and stress)
- ▶ 4. Many people living with tics already use similar strategies they have discovered on their own

Medical Management: Optimize Sleep

- ▶ First, optimize sleep!
- ▶ Start with 0.25 mg Melatonin at bedtime if sleep onset is challenging, slowly increase as needed
- ▶ Next step would be Clonidine, start with 0.05 to 0.1 mg at bedtime
- ▶ Consider adding in long-acting Clonidine if waking up in night and ticcing
- ▶ If sleeping very well, AND still having problematic day time tics, consider day time medications as well, such as guanfacine

Medical Management: Day Time

- ▶ Consider starting guanfacine, usually short acting
- ▶ For young kids, start with 0.25 mg BID, then can slowly increase as needed
- ▶ If starting long acting guanfacine, start at night if not already on clonidine, then move to AM once adjusted to soporific effects
- ▶ Once sleep is optimized, and day time tics are improved, consider addressing ADHD if needed with stimulants
- ▶ Consider managing anxiety/OCD with an SSRI if needed

Medical Management for ADHD in kids with tics

- ▶ Stimulants usually worsen tics, but occasionally can help
- ▶ Kids with Tourette Syndrome/Tics tend to do better with stimulants when used synergistically with alpha agonists
- ▶ Kids tends to do better with Dexmethylphenidate (Focalin) than Methylphenidate (Ritalin)
- ▶ Strattera can be helpful for some, though many report feeling unwell on this

Tips and Tricks in the Classroom

- ▶ Consider a 504 plan to allow for tic accommodations, or an IEP if significant ADHD also present interfering with learning
- ▶ Tic Breaks, or timing tics with other loud noises in the class (such as clapping or laughing)
- ▶ Sports water bottle at desk can help
- ▶ Chewing gum
- ▶ Fidgets in the hands or pockets like putty, pieces of felt
- ▶ Movement breaks
- ▶ Subtle hand signals between teacher and student to communicate needs
- ▶ Treat the underlying Anxiety, OCD, ADHD, Sleep Disorders

Resources for Families

- ▶ The Tourette Association of America, www.tourette.org, established in 1972
- ▶ Check out the video: “I have Tourette Syndrome but Tourette Syndrome Doesn’t Have Me”
- ▶ If there are global adaptive impairments, kids can be eligible for Developmental Disability Services, and possibly SSI depending on family income