

How It Feels to Have Tourette's

I pledge Allegiance to the Flag of the United States of America, and to the Republic for which it stands, one Nation under God, indivisible, with liberty and justice for all.

Tourette Syndrome & Other Tic Disorders

- Neuropsychiatric conditions
- Characterized by motor/vocal tics
- Begins in childhood and adolescence and persists over time
- Diagnosis is 3-4X more likely in boys than in girls
- Often accompanied by co-occurring conditions



Diagnostic Indicators (DSM-V)

- Transient Tic Disorder (F 95.0)
 - Single or multiple motor and/or vocal tics.
 - The tics have been present for less than 1 year since first tic onset.
 - Onset is before age 18 years.
 - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, post-viral encephalitis).

Diagnostic Indicators (DSM-V)

- Persistent (Chronic) Motor or Vocal Tic Disorder (F 95.1)
 - Single or multiple motor or vocal tics, but not both
 - The tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset.
 - Onset is before age 18 years.
 - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, postviral encephalitis).
 - Criteria have never been met for Tourette's disorder.

Diagnostic Indicators (DSM-V)

- Tourette's Disorder (F 95.2)
 - Both multiple motor and one or more vocal tics have been present at some time, not necessarily concurrently.
 - The tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset.
 - Onset is before age 18 years.
 - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, post-viral encephalitis).

Characteristics of Tics

- Mild/Moderate/Severe
- Degree of impairment or disruption in daily activities
- Variability over short and long term periods of time (less frequent during calm focused periods and more frequent with stress/excitement)
- Can be triggered by internal and external factors
- Wax and wane
- Is semi-voluntary (can be suppressed briefly)
- May cause pain, discomfort
- Is socially stigmatizing

Characteristics of Tics

- Motor
 - Simple: abrupt, brief, repetitive, stereotypic movements
 - Complex: orchestrated series of movements which may appear purposeful
- Vocal
 - Simple: meaningless sounds
 - Complex: utterances of words and /or phrases

List of Simple and Complex Motor Tics

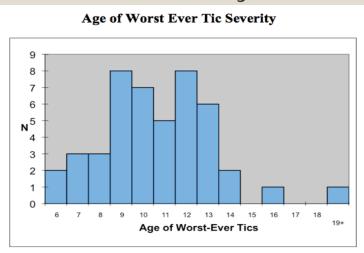
- Simple Motor Tics
 - Eye movements/blinking
 - Nose/mouth movements
 - Facial grimace
 - Head jerks
 - Shoulder shrugs
 - Arm movements
 - Abdominal tensing
 - Leg, foot, toe movements

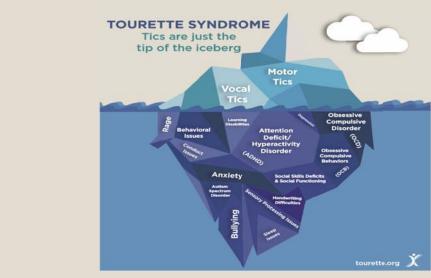
- Complex Motor Tics
 - Combination of simple motor tics happening concurrently
 - Dystonic/abnormal postures
 - · Bending
 - Rotating
 - Tic-related compulsive behaviors
 - Groups of simple tics

List of Simple and Complex Vocal Tics

- Simple Vocal Tics
 - Coughing
 - Throat clearing
 - Sniffing
 - Animal/bird noises/barking
- Complex Phonic Symptoms
 - Syllables
 - Words
 - o Coprolalia
 - Echolalia
 - Palilalia
 - Blocking
 - Disinhibited speech

Course of Tic Severity





86% of kids with TS have at least 1 co morbid condition

Etiology

- Neurochemical
 - Dopamine
 - Noradrenaline
 - Serotonin
- Neuroanatomy
 - Abnormalities in the Basal Ganglia
- Neurophysiological
 - Abnormalities in sensory-motor interactions and in inhibition

- Autoimmune
 - Pediatric autoimmune Neuropyschiatric Disorders Associated with Streptococcal infections (PANDAS)
- Genetics
 - Evidence that TS is familial
 - Not everyone who inherits the genetic vulnerability will express symptoms (5%-15% chance)

Prevalence of Tic Disorders

- 12-18% of school age children have tics (Scahill, Sukhodolshy, Williams, & Leckman, 205)
- 1-8 per 2,000 children diagnosed with Tourette Syndrome (TS)
- 50% of those with Tourette Syndrome also have ADHD
- 50-90% have obsessive compulsive behaviors (only 30-40% develop OCD)
- Individuals with TS have a higher prevalence of Depression,
 Anxiety, and Learning Disabilities in areas of math and reading
- 4%-10% of population will be diagnosed with a tic disorder sometime in their lifetime.

Treatment of Tic Disorders

- Depends on the severity and how disruptive the tics are to daily life activities
- For severe problems, initial focus of treatment needs to be on presence of any co-occurring conditions
- May include pharmacological treatment (medications) and behavioral approaches

Comprehensive Behavioral Intervention for Tics (CBIT)

- A behavioral intervention based on habit reversal training
- Helps individual manage tics

 Shown in a randomized controlled trial to be effective in children and adolescents with TS or chronic tic disorders of moderate to greater severity

Piacentini, J., Woods, D., Scahill, L., Wilhelm, S., Peterson, A. L., Chang, S., et al. (2010). Behavior therapy for children with Tourette disorder: A randomized controlled trial. *JAMA*, *303*, 1929-1937.

Principles of CBIT

- Not based on the assumption that tics are bad habits and thus within the child's behavioral control.
 - Tics are involuntary, but expression is influenced by environment and situational factors.
 - Child is taught self-awareness to pre-empt tics through a competing response.
 - Habit Reversal Training (HRT): The competing behavioral response is reinforced to become a new habit.

Components of CBIT

- Education about Tics/Tourette Syndrome
- Self-awareness training
- Habit reversal
- Function Based approach for environments and social situations
- Relaxation training
- Home programming



CBIT Process

- 8-11 sessions consisting of
 - Increasing the person's awareness of his/her tics
 - Determining the order for interventions (establishing a tic hierarchy)
 - Ascertaining the impact of the tics on the person's daily life functioning/occupations
 - Developing a reward system or methods of monitoring change in behaviors (for children)
 - Establishing a home program
 - Practice!!!

Sessions

- First Session: psychoeducation about tics, assessment, homework to promote self awareness and identification of first strategy (60-90 minutes)
- Sessions 2-6: held weekly and follow the CBIT intervention protocol involving homework review, habit reversal training, ongoing assessment, and environmental and situational modifications
- Sessions 4 & 5: add relaxation techniques to main protocol
- Sessions 7 & 8: occur two weeks apart with Session 8 focused on relapse prevention
- Sessions 9-11: booster sessions scheduled on an as needed basis

OT's as CBIT Providers

- Tics have tremendous effects on participation
 - Education
 - Social participation
 - Self care and feeding
 - Leisure/play
 - Rest/sleep
- We teach the client a competing behavioral response which becomes reinforced as a new habit opposite the tics
- We are easily accessible in schools, primary care, neurology
- We know how to structure opportunities to rehears skills in appropriate contexts and environments
- We are familiar with sensory influences on behavior



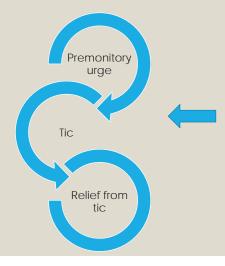
Tic Impact on Participation

- Tics effect participation in areas of occupation
 - Education
 - completing tasks in a timely manner
 - completing difficult tasks
 - Socialization
 - fear of ridicule
 - lost opportunities
 - Sleep/rest
 - o tics during sleep,
 - not being able to go to sleep
 - Waking through the night
 - Loss of self esteem and confidence





Cycle of Tics and HRT



Successful interruption of tic happens as soon as the premonitory urge is felt and before the tic occurs so that relief is gained from using competing response and not from tic itself

Function Based Intervention

- Fits perfectly with OT approach
- Determining what events happen before or immediately after that makes tics more likely to happen (antecedents and consequences)
- Make suggested modifications to activity, task, or environment
 - Minimizing or eliminating situations or settings that make a tic more likely to happen
 - Eliminating situations or events that occur right after the tic
 - Using strategies to minimize reactions when entering situations that cannot be modified

Future Directions

- CBIT training for more Occupational Therapists through the Tourette Association of America
- CBIT training manual being developed
- Handwriting studies (3 sites through TAA Centers of Excellence)



Resources

- Tourette Association of America https://www.tourette.org/
- Southeastern Center of Excellence http://tourettecarecenters.org
- Center for Disease Control and Prevention. *Tourette Syndrome*. http://www.cdc.gov/ncbddd/Tourette/data.html
- Woods, D.A., Placentini, J.C., Chang, S., et al. (2008). Managing Tourette Syndrome: A Behavioral Intervention for Children and Adults. New York, Oxford University Press.
- Rowe, J., Yuen, H. K., & Dure, L. S. (2013). Comprehensive behavioral intervention to improve occupational performance in children with Tourette disorder. American Journal of Occupational Therapy, 67, 194–200.

QUESTIONS

