Identifying and Managing Pediatric Neuropsychiatric Disorders: OCD, Tics and Tourette Syndrome

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There Are No Disclosures
Learning objectives…

1. Identify simple and complex tics that are often symptoms of Tourette syndrome (TS)
2. Explain the neurological basis behind Tourette syndrome (TS) and identify other disorders that often accompany TS
3. Discuss the natural history of Tourette syndrome, understand its impact, and the impact of its associated disorders
4. Discuss appropriate treatment for pediatric patients with TS including behavioral treatments and medications
5. Identify the diversity of presenting symptoms of OCD
6. Recognize the importance of screening for OCD as a part of routine mental/behavioral health screening
7. Understand and differentiate between a motor tic and an OCD behavior, and communicate this with patients and their families
Georges Gilles de la Tourette and TS

- Worked at the famous Salpêtrière Hospital in Paris under Charcot
- Published his famous article in Archives de Neurologie in 1885
- Referred to the condition as “maladie des tics”
- Initially treated with haloperidol (Haldol) in the 1960s by Arthur Shapiro and colleagues
So just what is a tic?

- Any sudden, involuntary or semi-voluntary, non-rhythmic, repetitive movement, gesture or utterance that mimics some fragment of normal behavior.

- A motor tic is just what it sounds like. They can be brief, jerking movements (clonic tics), slow movements of sustained posture (dystonic tics) or an isometric contraction (tonic tics).

- A phonic, or vocal, tic includes any sound produced or, more simply, anything that arises from the movement of air through the windpipe.
Sensory urges and premonitory sensations

- A premonitory sensation or sensory urge is a focal perception or mental awareness that precedes a tic.

- Patients may describe the urge as a specific sensation such as an “itch,” “a dry throat,” “a tickle in the throat,” or that their “clothes are uncomfortable.”

- Or, they may describe a non-specific urge or feeling such as “anxiety,” “a spring tightening,” or “a rubber band winding up.”

- The actual tic is often described as a release of this tension and that the tic actually relieves the uncomfortable sensation that we refer to as the premonitory sensation.

- Approximately 80% of patients with Tourette syndrome describe having sensory urges or premonitory sensations that precede their motor and phonic tics.
What are the different types of tics?

- **Motor tics**
  - Simple motor tics – fast, darting, meaningless. Examples include eye blinking, head jerking, grimacing, jaw snapping, shoulder shrugs, neck tightening.
  - Complex motor tics – slower, cluster of simple movements or a coordinated sequence of movements that may seem to be purposeful. Examples include hopping, clapping, touching, tapping, poking, smelling, kissing, brushing the hair out of one’s eyes.

- **Phonic tics**
  - Simple phonic tics – fast, darting, meaningless. Examples include throat clearing, coughing, grunting, yelping, humming, sniffing, sniffling, animal noises.
  - Complex phonic tics – linguistically meaningful utterances. Examples include words, syllables, phrases, statements, mutterings, expressions.
  - Specific phonic tics
    - Echolalia – repeating what someone else says
    - Palilalia – repeating one’s own words or phrases
    - Coprolalia – utterance of obscene words or socially inappropriate remarks
DSM-5 Tic Disorders

- **Tourette syndrome**

- **Persistent (chronic) motor or vocal tic disorder**
  - One or more motor tic or vocal tics, but *NOT* both
  - Tics that occur many times a day, nearly every day or on and off throughout the period of more than a year
  - Tics that start before 18 years of age
  - Symptoms are not due to medications or another medical condition
  - Not diagnosed with Tourette syndrome

- **Provisional tic disorder**
  - One or more motor tics or vocal tics, but *NOT* both
  - Present for no longer than 12 months in a row
  - Onset before the age of 18
  - Symptoms are not due to medications or another medical condition
  - Not diagnosed with Tourette syndrome or persistent motor or vocal tic disorder
DSM-5 Diagnostic Criteria for TS

- Have both multiple motor tics AND vocal tics, although they are not required to happen at the same time
- Have had tics for at least one year. The tics can occur many times a day (usually in bouts) nearly every day, or on and off
- Have tics that begin prior to the age of 18 years
- Have symptoms that are not due to taking medicine or other drugs or due to having another medical condition
Where is the problem in the brain related to TS?

- **Neurotransmitter hypotheses in TS**
  - Dopamine – response to neuroleptics and exacerbation by stimulants
  - Serotonin – response to SSRI antidepressants
  - Norepinephrine – exacerbation by stress/anxiety and positive response to medications such as clonidine and guanfacine

- **The basal ganglia and TS**
  - The basal ganglia are hypothesized to participate in the selection, activation and termination of innate and learned motor programs (i.e. habits)
  - In addition, the basal ganglia facilitate the learning of appropriate context-dependent motor behavior, e.g. obtaining a reward or avoiding danger in a familiar situation. Once learned, such actions may become subconscious, i.e. habitual or automatic

- **The cortex and TS**
  - The prefrontal cortex has been implicated in TS, OCD and ADHD
The complex connections of the basal ganglia...
Tourette syndrome and the associated behaviors

- Tourette's syndrome
- ADHD (attention-deficit-hyperactivity disorder)
- OCD (obsessive-compulsive disorder)

Behavioral problems, poor impulse control, and other behavioral disorders

The overlap of TS, tics and OCD…

Tourette syndrome

Chronic Tics

OCD + Tics

OCD
What is the common timeline we see in TS?

- ADHD presents earlier than tics (4-6 years of age)
- Simple motor tics begin at 6-8 years of age with vocal tics later
- OCB or OCD typically presents shortly after tics (7-9 years of age)
- ADHD and OCD remain life-long as they are personality traits

Genetic epidemiology

- **Risk to male first-degree relatives: 50%**
  - 18% TS
  - 31% chronic motor tics
  - 7% OCD

- **Risk to female first-degree relatives: 30%**
  - 5% TS
  - 9% chronic motor tics
  - 17% OCD

- **Autosomal dominant with reduced penetrance and variable expressivity**

- **Semi-dominant model**
  - Bilineal transmission (tics and OCD)
  - Assortative mating may explain high density in families

- **Polygenic model may explain broader phenotype with ADHD, OCD**
The disabling nature of tics…

- The disabling nature of tics is not always as obvious as it seems.

- Though tics themselves can be disturbing to patients, it is often the mental energy expended to suppress tics and premonitory urges or the urges alone that are tremendously more disabling than the tics themselves.

- School children will suppress their tics at school and then release them at home after getting off the school bus.

- Premonitory urges and tics interfere with attention and focus which is only exacerbated by the effort to suppress the urges and tics.

- Tics will often increase in frequency when they are brought to one’s attention or are the focus of conversation.
The associated behaviors of TS…

- Inattention, disorganization, hyperactivity, impulsivity (ADHD)
- “The Sticky Brain” – hyperfocusing, “trouble letting go”
- Obsessions and compulsions (OCB and OCD)
- Chronic anxiety – social, generalized, specific phobias
- Emotional instability/lability – dysregulation of affect
- Mood disorders – depression, dysthymia, bipolar disorder
- Mirror phenomenon – echolalia, pallilalia, echopraxia
- Learning differences / disabilities
- Executive dysfunction
- Sensory processing issues
- Poor impulse control
Why is it important to identify these behaviors?

- The associated behaviors are often more disabling than the tics, especially in children and adolescents.
- ADHD accounts for almost all of the aggression and delinquency seen in the TS population (i.e. TS-only patients show same rates of these problems as the control population).
- Academic, social and occupational difficulties seen in ADHD+TS is virtually identical to those seen in ADHD-only patients.
- While ADHD is highly co-morbid with learning disabilities, TS-only patients do not have higher rates of LD than control population.
- ADHD carries significant risk for lifelong psychiatric morbidity in TS.
- 50-90% of patients with TS who present for treatment exhibit signs of ADHD and accompanying ODD or CD.
- The community prevalence of ADHD is 5%; the rate among children with tics is roughly 10 fold that of the general population.
Tourette syndrome and OCD

- Approximately 50% of TS patients will exhibit symptoms of obsessive-compulsive behavior
- Obsessive-compulsive behavior and OCD are an anxiety disorder and are characterized by:
  - Recurrent and unwanted obtrusive thoughts and images (obsessions), and/or
  - Repetitive behaviors (compulsions) that are done with the hope of preventing or reducing the obsessions
    - Performing the “rituals” provides only temporary relief
    - Not performing them significantly increases anxiety
- The rituals interfere with daily life and can be isolating and embarrassing
- Common problems seen in school as a result of OCD include:
  - Difficulty transitioning from one activity to the next
  - Not completing work or drifting to another activity
  - Constant erasing
  - Inability to tolerate mistakes
Principles of Intervention

- Clarify the clinical syndrome (course, prognosis)
- Target specific symptoms
- First consider behavioral treatments such as CBI-T or CBT
- Use medications only for psychosocial or physical disability stemming from symptoms
- Consider co-morbid conditions in choice and priority of any interventions
- Always employ a multi-modal treatment approach
  - Education of child, family, school, community
  - Parent and teacher training – behavior management
  - School interventions
  - Cognitive behavioral interventions
  - Medications (for target symptoms)
  - Social skills groups
  - Support groups
  - Results of the Pediatric OCD Treatment Study (POTS) Randomized Controlled Trial
Current Recommendations:

1. Counseling Recommendations: Natural History of Tourette Syndrome

2. Psychoeducation, Teacher and Classroom

3. Assessment and Treatment of ADHD in Children with Tics

4. Assessment and Treatment of OCD in Children with Tics

5. Other Psychiatric Comorbidities

6. Assessment of Tic Severity and Treatment Expectations

7. Behavioral Treatments
Common Obsessions and Compulsions in TS

Common Obsessions:
- Mental echolalia
- Need for exactness or symmetry
- Aggressive/violent thoughts
- Obscene thoughts (exposing oneself, kissing or having sex with others)
- Counting, grouping
- Somatic obsessions/bodily sensations

Common Compulsions:
- Placing objects just right (symmetry)
- Ordering/arranging
- Hoarding
- Touching/tapping
- Checking/rechecking
- Smelling/licking
- Cleaning/washing
- Repetitive speech
- Throat clearing
Assessment of TS Clinical Domains

- Tic Severity / Impairment
- Obsessions / Compulsions
- Anxiety / Mood symptoms
- ADHD Symptoms
  - Inattentiveness / Distractibility
  - Hyperactivity / Impulsivity
- Oppositional-Defiant / Aggressive Behaviors
- Learning Disorders
Yale Global Tic Severity Scale (YGTSS)

- Identify tics (motor, phonic / simple, complex)
- Quantify tics on scale of 0-5
  - Number
  - Frequency
  - Intensity
  - Complexity
  - Interference
- Obtain motor tic (0-25), phonic tic (0-25) and total tic (0-50) scores
- Quantify degree of impairment (0-50)
- Combine total tic and impairment score to obtain Global Severity Score
Assessing Obsessive Compulsive Symptoms

Children’s Yale Brown Obsessive Compulsive Scale (CY-BOCS) -

- Identify major obsessions and compulsions – choose 4 target behaviors for both obsessions and compulsions
- Quantify behavior on a scale from 0 – 4
  - Time spent on obsessions or compulsions
  - Interference
  - Subjective distress
  - Resistance to obsessions or compulsions
  - Degree of control over obsessions or compulsions
- Obtain obsession score (0-20), compulsion score (0-20), and total O-C scores (0-40)
- Total O-C scores of greater than 16 are significant
Children’s Yale-Brown OC Scale (CY-BOCS Self-Report Symptom Checklist)

Name of Child: ___________________ Date: ___________ Informant: ___________________

This questionnaire can be completed by the child/adolescent, parents, or both working together.
We are interested in getting the most accurate information possible. There are no right or wrong
answers. Please just answer the best you can. Thank you.

Please check all COMPULSIVE SYMPTOMS that you have noticed during the past week.

Compulsions are things you feel compelled to do even though you may know the behavior
does not make sense. Compulsions are typically done to reduce fear of distress associated with
obsessive thoughts.

Washing/Cleaning Compulsions

□ Excessive or ritualized hand washing (e.g., takes long time to wash, needs to restart if interruped, needs to wash hands in particular order of steps)
□ Excessive or ritualized showering, bathing, tooth brushing, grooming, toilet routine (see hand washing)
□ Excessive cleaning of items (e.g., clothes, linens, floors or important objects)
□ Other measures to prevent or remove contact with contaminants (e.g., using towel or foot to flush toilet or open door; refusing to shake hands; asking family members to remove insects, garbage)
□ Other washing/cleaning compulsions (Describe) __________________________

Checking Compulsions

□ Checking locks, toys, schoolbooks/items, and so on
□ Checking associated with getting washed, dressed, or undressed
□ Checking that did not/will not harm others (e.g., checking that nobody’s been hurt, asking for reassurance, or telephoning to make sure that everything is alright)
□ Checking that did not/will not harm self (e.g., looking for injuries or bleeding after handling sharp or breakable objects, asking for reassurance that everything is alright)
□ Checking that nothing terrible did/will happen (e.g., searching the newspaper or television for news about catastrophes)
□ Checking that did not make a mistake (e.g., while reading, writing, doing simple calculations, homework)
□ Checking tied to health worries (e.g., seeking reassurance about having an illness, repeatedly measuring pulse, checking for body odors or ugly features)
□ Other checking compulsions (Describe) __________________________

Repeating Compulsions

□ Rereading, erasing, or rewriting (e.g., taking hours to read a few pages or write a few sentences because of concern over not understanding or needing letters to be perfect)
□ Needing to repeat routine activities (e.g., getting up and down from a chair or going in and out of a doorway, turning the light switch or TV on and off a specific number of times)
□ Other repeating compulsions (Describe) __________________________

Counting Compulsions

□ Counts objects (e.g., floor tiles, CDs or books on a shelf, his/her own steps, or words read or spoken)

Arranging/Symmetry

□ Arranging/ordering (e.g., spends hours straightening paper and pens on a desktop or books in a bookcase, becomes very upset if order is disturbed)
□ Symmetry/evening up (e.g., arranges things or own self so that two or more sides are “even” or symmetrical)
□ Other arranging compulsions (Describe) __________________________

Hoard/Saving Compulsion (do not count saving sentimental or needed objects)

□ Difficulty throwing things away; saving bits of paper, string, old newspapers, notes, cans, paper towels, wrappers and empty bottles; may pick up useless objects from street or garbage
□ Other hoarding/saving compulsions (Describe) __________________________

Excessive Games/Superstitious Behaviors (must be associated with anxiety, not just a game)

□ Behavior such as not stepping on cracks or lines on floor/sidewalk, touching an object/self a certain number to times to avoid something bad happening, not leaving home on the 13th of the month

Rituals Involving Other Persons

□ Needing to involve another person (usually a parent) in rituals (e.g., excessive asking for reassurance, repeatedly asking parent to answer the same question, making parent wash excessively)
Non-pharmacologic therapies for TS+

- **Habit Reversal Training (HRT)**
  - Awareness training, self-monitoring, competing response training (where a movement is performed that is opposite to a particular tic)

- **Comprehensive Behavioral Intervention for Tics (CBI-T)**
  - Therapy increasing awareness of tics and the urge to tic, training to do competing behaviors when the urge to tic is felt and changing day to day activities that can be helpful in reducing tics

- **Cognitive Behavioral Therapy (CBT)**
  - The mainstay for non-pharmacologic treatment of obsessive-compulsive behavior and anxiety, but also valuable for ADHD

- **Neurofeedback for ADHD**
  - Typically involves computer-based exercises providing feedback regarding attention levels to promote self-regulation and enable behavioral training
Pharmacologic therapies for TS+

- All medications for TS and related behaviors are symptomatic; i.e. they are used only to mitigate the symptoms and are not curative
- Medications are chosen to treat the specific symptom that is disabling
- Some medications are effective in treating multiple symptoms associated with Tourette syndrome

Common medications for tics include:
  - Clonidine and guanfacine
  - Topiramate
  - Risperidone, aripiprazole
  - Haloperidol, pimozide, fluphenazine

Common medications for ADHD include:
  - Clonidine and guanfacine
  - Atomoxetine
  - Methylphenidate and amphetamine compounds

Common medications for obsessive-compulsive behavior include:
  - SSRI and SNRI antidepressants
  - Clomiprimine
Managing TS, OCD and ADHD in school

- Organizational skills and executive function are heavily impacted by both ADHD and OCD in children and adolescents, often greatly impacting their educational performance
  - Impaired attention and focus and easy distractibility
  - Difficulty with short-term memory
  - Difficulty starting and completing projects or staying on task

- Some common strategies to help with ADHD and OCD in school
  - Extended time for testing or testing in an alternative environment
  - Extra set of books for home
  - Reducing amount of homework (odd or even answers) or projects
  - Emailing assignments home each day
  - Allowing children to step out of class when necessary
  - Having a safe place for children to go when necessary
  - Reassuring a child is staying on task
  - Audio books for children with difficulty focusing when reading
Communicating with patients and families

- Encourage continued education on the topic by utilizing resources such as the New Jersey Center for Tourette Syndrome and the Tourette Association of America
- Stress their involvement and advocating for their children
- Connect with and tap into school resources such as 504 plans and IEPs
- Look for support from other families in similar situations
- Work on building your children’s esteem and coping skills
- Get your children connected to the things they enjoy – sports, clubs, and friends
- Be open to receiving coordinated care for your child and family
What to do when you identify a patient with possible TS and/or OCD?

- Reassurance
- Determine which symptom complex is most disabling
- For patients with primarily tics that are not disabling and little else in the way of associated disorders, consider watchful waiting
- For patients with tics that are disabling, consider referral to a pediatric neurologist or psychiatrist specializing in tic disorders
- For patients in who their behavioral disorders are the more disabling feature or are encountering issues in school, consider referral to a psychologist specializing CBT, CBI-T or similar
- For patients in who educational accommodations will be necessary, consider referral to a neuropsychologist or school psychologist
- Utilize referral resources to locate physicians, therapists and neuropsychologists specializing in or familiar with the treatment and evaluation of Tourette syndrome and associated disorders
  - New Jersey Center for Tourette Syndrome or other local organizations
  - Tourette Association of America
  - Tertiary centers
Piediatric Psychiatry Collaborative

Regional Hubs

- Atlantic Health Hub @ Newton Medical Center
- Atlantic Health Hub @ Goryeb Children’s Hospital
- Hackensack Meridian Hub @ Hackensack University Medical Center
- Hackensack Meridian Hub @ Palisades Center
- Hackensack Meridian Hub @ Saint Peter’s Family Health Center
- Hackensack Meridian Hub @ Jersey Shore University Medical Center
- Cooper Hub @ Cooper University Medical Center
- Cooper Hub @ Pennsville

Essex County served by Rutgers University Behavioral Health Care.

More information on the Essex Hub can be found here: https://ubhc.rutgers.edu/clinical/community/collaborative-behavioral-health-care-project-essex-hub/collaborative-behavioral-health-care-project-essex-hub.xml

Penn Medicine
PPC Hub Benefits

- A child and adolescent psychiatrist (CAP) available for consultative support through the Child Psych. consult line

- A psychologist/social worker available to:
  - Assist the pediatrician with diagnostic clarification and medication consultation,
  - Speak with a referred child’s family regarding the child’s mental health concerns and to assist in providing diagnostic clarification.

- One-time evaluation by a CAP at no charge to the patient when appropriate.
  - Based on the recommendation of the CAP, the PPC Hub staff will work with the family to develop the treatment and care coordination plan.

- Continuous education opportunities in care management and treatment in the primary care office for the common child mental health issues: ADHD, depression, anxiety, etc.
New Jersey Center for Tourette Syndrome

**NJCTS Programs**

**Family Support**
Services, support, and education for individuals and families affected by Tourette Syndrome and associated disorders

**Youth Development**
A continuum of services providing teens and young adults with opportunities for training in leadership and advocacy

**Education Outreach**
Promoting a more positive, inclusive, and successful classroom environment for students through in-service presentations

**Medical Outreach**
Unique education program for physicians at hospitals, providing opportunities to learn from TS individuals and families

**Webinars**
Free, online seminars for individuals, families, and professionals on topics of interest to the TS community

**NJ Walks for TS**
Step out and break the stigma of TS through 5k walks/family fun runs at locations throughout the state

**TS Clinic**
The nation’s first university-based, stand-alone teaching practicum and clinic for the treatment of TS

**Cell & DNA Sharing Repository**
The largest collection of Tourette Syndrome clinical and genetic data supporting genetics research worldwide

[https://njcts.org](https://njcts.org)
Physician Referral List: NJCTS’ Physician Referral List is comprised of more than 200 neurologists, psychiatrists, psychologists, counselors, and social workers with expertise in treating TS. Our referral is a direct link for families to medical professionals who treat TS, ADHD, OCD, anxiety, and depression. Please call us at 908.575.7350.

Webinars: NJCTS’ Wednesday Webinar series was launched in 2008 and today draws an audience from 48 states and more than 15 countries. The series has featured more than 100 online seminars for parents, educators and professionals on topics of interest to the TS and associated disorders community, such as anxiety, OCD, sensory issues, bullying, school accommodations, and much more. View our past webinars.

Education and Medical Outreach: For more than a decade, NJCTS has developed and offered the Faculty In-Service Program, which is geared toward education professionals in elementary and secondary schools, while Youth Advocate Presentations reach tens of thousands of children and adolescents through activities that emphasize understanding, empathy, compassion, awareness, and growth. Medical Outreach is provided through Patient-Centered Medical Education, a unique presentation in which physicians and residents hear directly from youth and families, and Grand Rounds presentations in which an experienced medical clinician provides an overview of diagnosis and treatment options for TS and tic disorders. Learn more.

Family Retreat Weekend: Since 2004, NJCTS has welcomed families to enjoy some time away from it all at the NJCTS Family Retreat Weekend at YMCA Camp Bernie in beautiful Hunterdon County. The “best weekend of the year” allows children and their families to meet others with TS, learn more about their diagnosis, and engage with peer mentors in a fun, safe environment. Would you like to join us for the next retreat?

NJCTS Tim Howard Leadership Academy: Launched in 2014, the NJCTS Tim Howard Leadership Academy is a four-day intensive program that takes place in state-of-the-art dormitories on Busch Campus at Rutgers University. Participants work, play, eat, and sleep at Rutgers and enjoy a wide range of activities aimed at developing self-leadership, advocacy skills, and resilience in teens with TS and its associated disorders.

NJCTS Tourette Syndrome Practicum and Clinic: NJCTS, in collaboration with Rutgers University, presents the nation’s first university-based, stand-alone teaching practicum and clinic for the psychological evaluation and cognitive-behavioral treatment of TS. The program trains a new generation of professionals with interest and expertise in treating TS. The TS Clinic offers individual, family, and group therapy; cognitive-behavioral therapy; habit reversal therapy; social skills development sessions; referrals to physicians and testing services. Learn more.

NJCTS Lending Library: NJCTS has a collection of helpful books and other publications and videos about TS and its associated disorders. To borrow any of these items, please e-mail us at info@njcts.org or call 908-575-7350. You can also stop by the office during regular business hours!

Volunteer: NJCTS would not be able to provide its myriad programs and services if not for its vibrant, dedicated volunteers! That’s YOU! We are always in need of teens, adults, and families to help spread the word, get some office work done, or help out at an event. If you would like to get involved and give back to an organization that has helped you, your family or friends, please take a moment to contact our office at info@njcts.org or 908-575-7350.
Thank you!

Michael Rubenstein, M.D., FAAN
Perelman Center for Advanced Medicine (Adults)  800-789-PENN   (800-789-7366)
Children’s Hospital of Philadelphia (Pediatrics)  800-TRY-CHOP (800-879-2467)
Questions for NJAAP

To Register to Participate:

http://njaap.org/programs/mental-health/ppc

Please contact:
The Mental Health Collaborative
609-842-0014
mhc@njaap.org