OVERVIEW AND MANAGEMENT OF TICS AND TOURETTE SYNDROME

Laura Tochen, MD
Co-Director, Pediatric Movement Disorders Program
Children’s National Medical Center
Assistant Professor, George Washington University
Disclosures

• No relevant financial disclosures
• I will discuss off-label use of medications/treatments
“Repeated, individually recognizable, intermittent movements or movement fragments that are almost always briefly suppressible” (Sanger et al. 2010)

- Simple vs complex tics
- Motor (movement) vs vocal (noise-producing)
- Waxing/waning course
- Exacerbating factors
  - Anxiety, stress
  - Fatigue
- Premonitory urge/sensory phenomena
  - 90% of adults, 37% young children
- Suppressible
- Suggestible
Pathophysiology

- Cortico-striato-thalamo-cortical pathway
- Neurotransmitters
  - DA, 5-HT, GABA, glu
- Genetics
Coprophenomena
- < 20% lifetime prevalence
  - Coprolalia (15-19%)
  - Copropraxia (5-6%)
- Males > females
- Associated with ↑ tic severity & comorbidities
Epidemiology

- Tics: ~15%
- Tourette Syndrome: 0.5%
- Male:Female 3:1 – 4:1
- Occurs across ethnicities
- Onset 4-7 years
- Peak 11-12 years
- Outcome/prognosis:
  - ~ 25-50% resolve by teenage/adulthood
  - ~ 25-50% significant improvement
  - ~ 25-33% continue to have fluctuations into adulthood
Comorbidities

- Lifetime prevalence of psychiatric comorbidity: 85%
  - ADHD 54%
  - OCD 50%
  - Anxiety 36%
  - Mood disorder 30%
  - Disruptive behavior 30%
- 57% met criteria for 2 diagnoses

(Hirschtritt et al, 2015)
Are tics causing problems?

- no
  - Education and observation

- yes
  - First Line
    - Behavioral therapy
      - CBIT
  - Second Line
    - Pharmacotherapy
      - Neuroleptics
        - Atypicals: aripiprazole*, risperidone
        - Typicals: pimozide*, fluphenazine, haloperidol*
  - Third Line +
    - Pharmacotherapy: tetrabenazine, chemodenervation
    - Surgical therapy: DBS

*FDA approved
Cater treatments to patient goals and comorbidities

Are tics causing problems?

no

yes

First Line

Behavioral therapy

CBIT

Minimize side effects

Pharmacotherapy

α2-agonists

clonidine

guanfacine

anti-convulsants

topiramate

Education and observation

Education and observation

Treat comorbid

ADHD

Treat comorbid

migraines

Pharmacotherapy

Neuroleptics

Atypicals

does not apply

Typicals

pimozide

fluphenazine

haloperidol

Pharmacotherapy

tetrabenazine

Chemodenervation

Pharmacotherapy

Neuroleptics

Atypicals

aripiprazole

risperidone

Typicals

pimozide

fluphenazine

haloperidol

FDA approved

Treat comorbid behavior

Surgical therapy

DBS

Third Line +
Monitoring for side effects

• $\alpha_2$-agonists
  – Blood pressure
  – Heart rate

• Atypical antipsychotics
  – Fasting lipids, glucose
  – BMI
  – Extrapyramidal signs
When should a patient be seen in the movement disorder program?

- For any help in diagnosing, classifying tic disorders
- If any additional education or counseling needs to be provided
- For initiation of any treatments beyond those provided by the primary provider
Referrals

• Child Neurology Movement Disorder Program
  (202) 476-3611
• ltochen2@childrensnational.org

Additional Resources for patients

• www.tourette.org
• https://www.cdc.gov/ncbddd/tourette/index.html
• https://dystonia-foundation.org/

CDC Data and Statistics on Tourette Syndrome
https://www.cdc.gov/ncbddd/tourette/data.html, accessed June 10, 2019


Tourette Syndrome
CBIT
Comprehensive Behavioral Intervention for Tics

Lauren M. Dome MSN, RN, MHS, CPNP
Children’s National Medical Center
Pediatric Neurology
What is CBIT

• CBIT is a non-drug treatment consisting of three important components
• Training the patient to be more aware of tics
• Training patients to do competing behavior when they feel the urge to tic
• Making changes to day to day activities in ways that can be helpful in reducing tics
Who is a good fit for CBIT

• Patients over 10 years of age
• Patients who's symptoms of comorbidities are well controlled
• Patients that are excited to try CBIT
• Patients and Families that are committed to weekly or bi-weekly sessions
• Patients and families with realistic expectations
Comprehensive Approach

School

- 504 Plan
- Education for teacher or peers
- Ignoring tics when possible
- Tic breaks
- Untimed tests
- Private room for tests
- Seating preference
- Flash Pass

Home and family

- Family education
  - Avoid pointing out tics
  - Set realistic expectation
  - Mange families emotional response to tics
  - Educate siblings
Evaluation of Antecedents and Consequences

Antecedent; stimuli that immediately precede tics

- Internal antecedents include mood states: (e.g., anxiety, excitement), thoughts (e.g., “If I don’t tic, it will bother me more than when I do tic”), and premonitory urges.

- External antecedents include specific settings (e.g., classroom, home, public places), activities (e.g., exercise, sedentary activities), and the presence of specific people.

Consequences; Consequence variables are outcomes that occur after tics (i.e., contingent on tics) that may make tics more or less likely to occur, within a particular antecedent context

Patient: “I always tic when I watch TV with my brother
Me: “what happens then”
Patient: “my brother makes fun of me”
Me: and then??
Patient: “my mom gets mad and sends my brother to his room
Scales

1. The Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989)

2. Premonitory Urge for Tics Scale (PUTS) By Douglas Woods, Ph.D.

# Tic Hassle/Sud Score

<table>
<thead>
<tr>
<th>Tic Hassle</th>
<th>Suds Rating (From 0 to 100)</th>
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<tr>
<td></td>
<td>0 – No Distress</td>
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<td>100– Maximum Distress</td>
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100 – Highest anxiety/distress that you have ever felt
90 – Extremely anxious/distressed
80 – Very anxious/distressed; can’t concentrate. Physiological signs present.
70 – Quite anxious/distressed; interfering with functioning. Physiological signs may be present.
60 – Moderate-to-strong anxiety or distress
50 – Moderate anxiety/distress; uncomfortable, but can continue to function
40 – Mild-to-moderate anxiety or distress
30 – Mild anxiety/distress; no interference with functioning
20 – Minimal anxiety/distress
10 – Alert and awake; concentrating well
0 – No distress; totally relaxed

Note: “SUDS” stands for “Subjective Units of Distress Scale.” Physiological signs may include, for example, sweating, shaking, increased heart rate or respiration, gastrointestinal distress.

The SUD-level; Joseph Wolpe in 1969.
Competing Response (CR) Training

• Choose a competing response that will prevent the tic from happening. It needs to use the same muscles but in a different way so it is not possible to do the tic at the same time. Have someone else model the competing response so you can see if any problems might occur.

• Remember to do the competing response:
  a.) as soon as you do a tic
  b.) as soon as you notice a warning sign.
  c.) Do the Competing response for one minute or until the urge fades away
# Examples of Competing Response

<table>
<thead>
<tr>
<th>Tic</th>
<th>Competing Response, CR</th>
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<tr>
<td>Arm movements</td>
<td>Push hand down on thigh or torso and push elbow towards hip</td>
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<td>Eye blinking</td>
<td>Controlled, voluntary, soft blinking at a rate of one blink per 3-5 seconds</td>
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<td>Head jerks</td>
<td>Head in central position, contract neck so head tilts downwards</td>
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<td>Mouth/facial movements</td>
<td>Clench jaw and press lips together</td>
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<td>Vocal tics</td>
<td>Purse lips together, or breathing deeply if this is not possible</td>
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Mindfulness, Yoga, and Breathing techniques.

Diaphragmatic or "belly breathing"

1. Lay on the floor or sit up straight with your feet supported.
2. Put one hand on your chest and the other hand over your belly.
3. Exhale all your air, until your belly pulls in slightly.
4. Imagine you have a balloon underneath your belly button that inflates as you inhale and deflates as you exhale.
5. Breath in through your nose and pull the air deep into your lungs. Feel your belly expand, like a balloon blowing up. Exhale slowly through your mouth. Feel you belly go back in, like a balloon deflating. Say "haa" as you exhale.
6. Breath in slowly inhale to the count of 3 seconds and exhale to the count of 7.
7. Keep your shoulders as relaxed as possible; they should not rise as you inhale.
Yoga

5. Upward Mountain
With your feet connected to the ground, bring your arms overhead into Upward Mountain, palms facing each other. Take a deep breath in and out. Saying to yourself, "I am strong." Feel that strength in your body.

6. / 7. Fold Forward and Upward Mountain
Now fold your body in half so your head goes below your heart and take three deep breaths. Saying to yourself, "I feel my body stretch." Gently bring your body up into Upward Mountain with arms overhead and bring your hands together and in front of your heart. Saying to yourself, "I can do this."

Do this three times, coming into Upward Mountain and bending into Forward Fold. Each time you fold forward let go of anything that is bothering you.
Progressive Muscle Relaxation PMR

**Progressive Muscle Relaxation**

*Whole Body Script*

1. **Forehead**
   - Scrunch up your forehead like you are thinking hard! Squeeze it tighter, tighter! Now you can relax. (Hold for around 10 seconds)

2. **Eyes**
   - Squeeze your eyes tight like you are about to blow out the candles on your cake and make a wish! No peeking! (10 seconds)

3. **Cheeks**
   - Puff your cheeks out so far as you can! Make them bigger, like you have a mouth full of food! Now relax. (10 seconds)

4. **Mouth**
   - I want you to pretend you are chewing a really big piece of gum! It’s really hard to chew, but keep chewing! (10 seconds)

5. **Shoulders**
   - I want you to try and touch your shoulder blades together! Squeeze tighter, you’re almost there! Now you can relax. (10 seconds)

6. **Arms**
   - I want you to make your arms as straight and stiff as possible! Pretend you are frozen. Now you can relax. (10 seconds)

7. **Lower Back**
   - Sit up super straight and try to be as tall as you can! Tilt! Tilt! And now relax. (10 seconds)

8. **Legs**
   - I want you to make your legs as straight as you can. Pretend you are frozen again. Now you can relax. (10 seconds)

9. **Feet**
   - I want you to press your feet into the ground as hard as you can! Push, Push! And now relax. (10 seconds)

10. **Toes**
    - Pretend you are at the beach, and squish your toes in the sand! So squishy! And now relax. (10 seconds)

*Tykes of Tomorrow*
Scheduling

• To Schedule an appointment with Lauren M. Dome CPNP for CBIT patients should call 301-765-5469.

• To schedule a CBIT appointment with:
  
  Laura Gray, PhD
  Sarah Hornack, PhD
  Mi-Young Ryee, PhD

Call: 202-476-5980, opt. 2 for psychology
References

- https://www.tichelper.com/
- https://tourette.org/
Son, your teacher told me that you’re having trouble focusing, and other things that I zoned out on.