



Diagnosis and Treatment of Tourette Syndrome and other Tic Disorders

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1

Our Mission

The Tourette Association of America is dedicated to making life better for all people affected by Tourette Syndrome and Tic Disorders through efforts that raise **AWARENESS**; advance **RESEARCH** and understanding; and provide **SUPPORT**.



2

AWARENESS



Awareness & Understanding



Advocacy

RESEARCH



Grants & Studies



Centers of Excellence & Training Institutes

SUPPORT



Chapters and Support Groups



Education & Accommodations

3

Resource Development

- ▶ What is Tourette Syndrome?
- ▶ Comprehensive Behavioral Intervention for Tics (CBIT)
- ▶ Tool kits
 - ▶ Patient
 - ▶ Provider
 - ▶ Educator
 - ▶ Law Enforcement
 - ▶ Children
 - ▶ Young Adult
- ▶ Comic Book Series: Exploring Life with Tourette

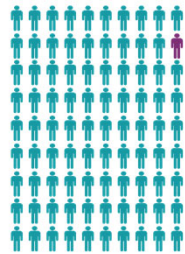
These resources are available in pdf on our website, www.tourette.org, and in print form. To have them mailed to you, please email support@Tourette.org!



4

Prevalence of Tourette Syndrome

1 out of every 160 children (0.6%) between the ages of 5 and 17 in the United States has Tourette Syndrome



1 out of every 100 children (1%) has Tourette Syndrome or another Tic Disorder



5

Disclosures

- ▶ None

6

Objectives

- ▶ Identify criteria used to diagnose Tourette Syndrome and other Tic Disorders
- ▶ Understand the potential health disparities in individuals with Tourette Syndrome and other Chronic Tic Disorders
- ▶ Ways to optimize the educator-provider relationship
- ▶ Outline the range of effective management and treatment strategies for patients with tics, including both medication and non-medication approaches
- ▶ Determine the common co-occurring conditions seen in patients with Tourette Syndrome and other Tic Disorders

7

What is a tic?

- ▶ Tics Are Not:

- ▶ Insects
- ▶ Tic-tacs
- ▶ Contagious
- ▶ Sign of Mental Instability



- ▶ Phenomenology:

- ▶ Sudden, brief, rapid, **repetitive, stereotyped, non-rhythmic** movements or utterances
- ▶ Sensory or "premonitory urge", temporary suppressibility, release or relief phenomenon, "just rightism"

8

What types of tics are there?

- ▶ Motor Tics → involuntary contraction of muscle. Typically in craniofacial distribution, though can involve trunk and limbs
- ▶ Vocal Tics → involuntary production of a sound
- ▶ Simple Tics → eye blinking, eye rolling, facial grimacing, nose flaring, neck movement, throat clearing, sniffing, grunting, squeaking
- ▶ Complex Tics → sequences of coordinated movement or sounds, such as bizarre gait, kicking, jumping, echopraxia, echolalia, copropraxia, coprolalia

9

Types of Tic Disorders

- ▶ Provision Tic Disorder:
 - ▶ Formerly known as Transient Tic Disorder
 - ▶ Presence of motor or vocal tics for less than a year
 - ▶ Common in children → ~10-20% prevalence
 - ▶ Tics resolve within 1 year
 - ▶ ~1% of those individuals will have persistent tics for greater than 1 year

10

Types of Tic Disorders

- ▶ Chronic Motor Tic Disorder:
 - ▶ Presence of only motor tics for greater than 1 year
 - ▶ No vocal tics
- ▶ Chronic Vocal Tic Disorder:
 - ▶ Presence of only vocal tics for greater than 1 year
 - ▶ No motor tics
- ▶ Tourette Syndrome:
 - ▶ Combination of at least 2 or more motor tics and at least 1 vocal tic for greater than 1 year

11

Tourette Syndrome

- ▶ Background and Epidemiology:
 - ▶ Named after Dr. George Gilles de la Tourette in late 1800's
 - ▶ Initially regarded as a psychological condition → understanding of disease has transformed significantly over time → complex neurodevelopmental disorder with likely genetic component
 - ▶ Prevalence ~0.5-1%
 - ▶ Male:female → 4:1
 - ▶ 2X more commonly diagnosed in Non-Hispanic Whites

12

Health disparities in Tourette Syndrome – What do we know?

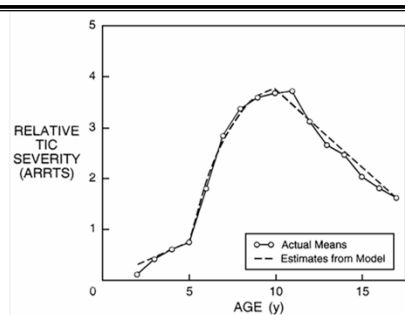
- ▶ There is limited research in health disparities in patients with Tourette Syndrome
- ▶ What we know:
 - ▶ Lower socioeconomic status identified as a risk factor for TS/chronic tics (Miller et. al 2013)
 - ▶ Publically insured TS patients have higher tic severity and higher comorbidity rates than privately insured patients (Olsson et. al 2011)
 - ▶ Diagnosis is more common among White Non-Hispanic children compared to Hispanic or Black Non-Hispanic Children (Olsson et. al 2011; Bisko et. al 2014)
- ▶ Limited data on:
 - ▶ Time-to-diagnosis
 - ▶ Tic severity
 - ▶ Co-morbidity rates across racial/ethnic minorities and socio-economic background

13

Tourette Syndrome

- ▶ Clinical Features:
 - ▶ Onset of symptoms <18 years old
 - ▶ Average age of onset ~6 years old
 - ▶ Onset after age 21 is unusual
 - ▶ Tic severity peaks between 9-13 years old
 - ▶ Tics wax and wane (hour-to-hour, day-to-day, week-to-week)
 - ▶ Worse with stress, anxiety, heightened emotions, or anticipation
 - ▶ In general tics improve with age in ~75% of individuals
 - ▶ High association with ADHD, OCD, Anxiety, Depression
 - ▶ Co-morbidities tend to persist into adulthood

14



15

The Educator-Provider Relationship

- ▶ Providers can be helpful with a patient who is struggling at school by:
 - ▶ Recommending and encouraging outside therapies
 - ▶ Writing a letter to the school
 - ▶ stating the child's diagnoses
 - ▶ recommending accommodations and a full school psychological evaluation
 - ▶ Being on a school call for 10 minutes during a school meeting
- ▶ Students can struggle in school due to one or more of the following:
 - ▶ Tics
 - ▶ OCD
 - ▶ ADHD
 - ▶ Learning disabilities
 - ▶ Executive Function Deficits
 - ▶ Sensory Processing

16

13

14

15

16

Additional Resources For Educators

- ▶ Provider Toolkit: <https://tourette.org/resource/provider-tool-kit/>
- ▶ Educator's Guide: <https://tourette.org/resource/educators-guide-planning-support-tool-kit/>
- ▶ Supporting a child at school: <https://tourette.org/resources/overview/tools-for-educators/accommodations-education-rights/iep-504-accommodations/>
- ▶ What can the School Psychologist do?
<https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:7cb43f52-a6c6-41ab-9165-d858da4b22f8>
- ▶ School Staff - What they need to know:
<https://www.youtube.com/watch?v=kMtpyp6W-g0&list=PLnu9s6GulKv6VOkpwMFxxfkxWW6ga2-k>
- ▶ Education Rights and Accommodations for TS:
<https://www.youtube.com/watch?v=kMtpyp6W-g0&list=PLnu9s6GulKv6VOkpwMFxxfkxWW6ga2-k>

17

Video

18

Considerations in Treatment of Tourette Syndrome and Other Tic Disorders

- ▶ Most important question is whether to treat!
 - ▶ Consider impact of tics on activities, school, social interactions, self-esteem, etc.
- ▶ Education is often sufficient
- ▶ If treating, goal is tolerable suppression, not elimination of symptoms
- ▶ Treatment of tics to appease parents is not recommended
- ▶ Treat the most bothersome symptoms first
- ▶ Other considerations:
 - ▶ Tics wax and wane
 - ▶ Any new life event can be associated with worsening of tics
 - ▶ Tics typically improve with age

19

SPECIAL ARTICLE

Practice guideline recommendations summary: Treatment of tics in people with Tourette syndrome and chronic tic disorders

Tamara Pringheim, MD, MSc, Michael S. Okun, MD, Kirsten Müller-Vahl, MD, Davide Martino, MD, PhD, Joseph Jankovic, MD, Andrea E. Cavanna, MD, PhD, Douglas W. Woods, PhD, Michael Rebrin, Elizabeth Jarvie, MSW, LCSW, Ves Roesner, MD, Maryam Oskoui, MD, Yolanda Holler-Margay, MD, and John Piacentini, PhD

Neurology® 2019;92:896-906. doi:10.1212/WNL.00000000000007466

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Abstract

Objective
To make recommendations on the assessment and management of tics in people with Tourette syndrome and chronic tic disorders.

Methods
A multidisciplinary panel consisting of 9 physicians, 2 psychologists, and 2 patient representatives developed practice recommendations, integrating findings from a systematic review and following up findings of Medicine, consultant resources, to ensure recommendations are best.

RELATED ARTICLE
Comprehensive systematic review summary: Treatment of tics in people with Tourette syndrome and chronic tic disorders
Page 907

MORE ONLINE

<https://n.neurology.org/content/92/19/896>

20

Comprehensive Behavioral Intervention for Tics (CBIT)

- ▶ Considered first line treatment intervention for bothersome tics
- ▶ A form of Habit Reversal Therapy (HRT)
- ▶ Methodology:
 - ▶ Trains patients to be aware of tics
 - ▶ Trains patients to develop a "competing motor response" when they feel the urge related to the bothersome tic
 - ▶ Make changes to day to day activities in ways that can be helpful in reducing tics
- ▶ Typically offered by psychologists, neuropsychologists, occupational therapists
 - ▶ Tourette Association of America has training program for providers
 - ▶ Typically one session per week for 8 weeks

21

21

Empirical Support for CBIT

- ▶ RCT of 126 children ages 9-17 with TS or CTD
- ▶ 8 sessions of CBIT during 10 weeks of behavior therapy (n=61) or a control treatment consisting of supportive therapy and education (n=65)
- ▶ Behavioral intervention with CBIT led to significantly greater decrease in Yale Global Tic Severity Scale (24.7 to 17.1) compared with control treatment (24.6 to 21.1); $p < 0.001$
- ▶ Significantly more children receiving behavioral intervention compared with those in the control group were rated as very much or much improved on the Clinical Global Impressions-Improvement scale (52.5% vs 18.5%, respectively; $p < 0.001$)
- ▶ Drop out rate was low at 9.5% (12/126)
- ▶ Treatment gains were durable, with 87% available responders to behavioral therapy exhibiting continued benefit 6 months post treatment

Piacentini, J., Woods, D.W., Scahill, L., Wilhelm, S., Peterson, A.L., Chang, S., Ginsburg, G.S., Deckersbach, T., Dziura, J., Levi-Pearl, S., Walkup, J.T., 2010. Behavior Therapy for Children with Tourette Disorder: A Randomized Controlled Trial. *Journal of the American Medical Association*, 303:1929-1937.

22

22

Empirical Support For CBIT

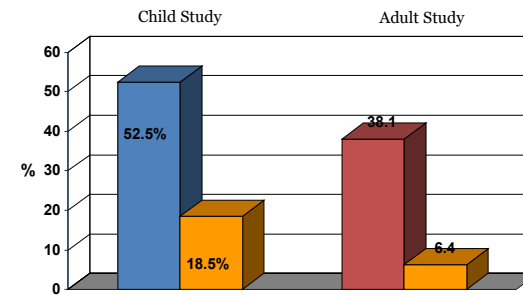
- ▶ RCT of 122 adults ages 16-69 with TS or CTD
- ▶ 8 sessions of CBIT or 8 sessions of supportive therapy over 10 weeks
- ▶ Behavioral Intervention with CBIT resulted in significantly greater decrease on the Yale Global Tic Severity Scale (24.0 to 17.8) compared with 8 sessions of supportive control treatment (21.8 to 19.3); $p < .001$
- ▶ Significantly more adults receiving CBIT were rated as being very much improved or much improved on the Clinical Global Impression-Improvement scale compared to supportive treatment (38.1% v 6.8%, respectively; $p < .001$)
- ▶ Drop out was 13.9% regardless of which treatment condition
- ▶ Treatment gains were durable, with continued benefit to 6 months post-treatment

Wilhelm, Peterson, Piacentini, Woods, Deckersbach, Sukhodolsky, Chang, Liu, Dziura, Walkup, Scahill. (2012). Randomized Trial of Behavior Therapy for Adults with Tourette Syndrome. *Arch Gen Psychiatry*, 69, 795-803.

23

23

Responder Status at Week 10 (CGI-Improvement = 1 or 2)



24

Pharmacologic Treatment of Tourette Syndrome

- ▶ Alpha-2 agonists:
 - ▶ Guanfacine (Tenex)
 - ▶ Clonidine (Catapres)
- ▶ Anti-dopaminergics:
 - ▶ Typical: Haloperidol (Haldol), Pimozide (Orap)
 - ▶ Atypical: Risperidone (Risperdal), Aripiprazole (Abilify), Ziprasidone (Geodon)
- ▶ Topiramate (Topamax)
- ▶ VMAT2 Inhibitors:
 - ▶ Tetrabenazine
- ▶ Botulinum Toxin
- ▶ Treatment of co-morbid ADD, OCD, and/or Anxiety

25

Alpha-2 Agonists

- ▶ MOA → agonist binding at alpha-2 receptors within the CNS
- ▶ Considered first line pharmacologic therapy for treatment of tics
- ▶ Also effective for ADHD symptoms
- ▶ Potentially less potent but fewer side effects than dopamine blockers
- ▶ Most common side effects are sedation, orthostatic hypotension, bradycardia, dizziness, and depression

26

Alpha-2 Agonist Continued

- ▶ Clonidine (Catapres, Kapvay):
 - ▶ Start 0.05mg-0.1mg qhs → increase slowly by adding 0.05mg-0.1mg every couple weeks divided BID or TID
 - ▶ Maximum dose 0.4-0.6mg daily
 - ▶ Kapvay is extended release form
 - ▶ AAN: "People receiving Clonidine are probably more likely than those receiving placebo to have reduced tic severity"
- ▶ Guanfacine (Tenex, Intuniv):
 - ▶ Start 0.5mg-1.0mg nightly → increase slowly by 0.5mg-1mg every couple weeks to daily or BID
 - ▶ Maximum dose is 4mg daily
 - ▶ Less sedating than Clonidine
 - ▶ Intuniv is extended release form
 - ▶ AAN: "People receiving Guanfacine are possibly more likely than those receiving placebo to have reduced tic severity"

27

Anti-Dopaminergics

- ▶ Typical Antipsychotics:
 - ▶ Considered most potent tic medications → have most D₂ receptor blockade
 - ▶ Haloperidol (Haldol), Pimozide (Orap)
 - ▶ Side effects are common
 - ▶ Sedation, weight gain, akathisia (restlessness), parkinsonism
 - ▶ Tardive dyskinesia is low risk, but can be permanent
- ▶ Atypical Antipsychotics:
 - ▶ Have lower affinity at the dopamine D₂ receptor than "typical" neuroleptics → potentially less effective
 - ▶ Risperidone (Risperdal), Aripiprazole (Abilify)
 - ▶ Weight gain is most common and most bothersome side effect
 - ▶ Risk of glucose intolerance and elevated serum lipids
 - ▶ Extrapyramidal side effects (including tardive syndromes) are still possible

28

Topiramate (Topamax)

- ▶ MOA → likely multiple mechanisms, including carbonic anhydrase inhibition and potentiate GABAA inhibition
- ▶ One phase III study in 29 children and adults with TS (mean age 16.5)
- ▶ Mean dose of Topamax ~118mg
- ▶ Study showed mild improvement in outcome scores for tics
- ▶ High drop out rate due to side effects
 - ▶ Cognitive dulling, reduced appetite, weight loss, paresthesias, kidney stones
- ▶ Start 12.5-25mg daily and increase by 12.5-25mg daily every 2-4 weeks
- ▶ AAN: "Topiramate is possibly more likely than placebo to reduce tic severity"

29

29

Medical Marijuana – Study #1

- ▶ Muller-Vahl KR, Schneider U, Koblenz A, et al (Class II Study):
 - ▶ Randomized, double-blinded, cross over study of 12 adults with TS in 2002
 - ▶ Single dose THC (5, 7.5mg, or 10mg) vs placebo
 - ▶ Tic severity rated over a single day, and cross-over to alternate treatment occurred 4 weeks later
 - ▶ Tic severity assessed using a self-rating scale (Tourette Syndrome Symptom List) and examiner rating scale (i.e. Yale Global Tic Severity Scale)
 - ▶ No significant differences between treatments and clinician-rated measure on the Yale Global Tic Severity Scale (YGTSS)

30

30

Medical Marijuana Study #2

- ▶ Muller-Vahl KR, Schneider U, Prevedel H, et al (Class III Study):
 - ▶ Randomized, double-blinded, placebo-controlled study of 24 adults with TS in 2003
 - ▶ THC group (10mg/daily) vs placebo
 - ▶ Treatment period was for 6 weeks, with 6 clinical visits for assessment using a self-rating scale (i.e. Tourette Syndrome Symptom List) and examiner rating scale (i.e. Yale Global Tic Severity Scale)
 - ▶ Seven patients dropped out or had to be excluded
 - ▶ No significant difference between THC and placebo group on the Yale Global Tic Severity Scale (YGTSS)

31

31

Medical Marijuana – AAN Summary and Recommendations

- ▶ Cannabis based medications should be avoided in children and adolescents, not only due to the paucity of evidence, but due to the association between cannabis exposure in adolescence and potentially harmful cognitive and affective outcomes in adulthood.
- ▶ Compared to placebo, cannabis-based medications are associated with increased risk of short term adverse events → dizziness, dry mouth, fatigue.
- ▶ There is limited evidence that THC, dronabinol, is possibly more likely than placebo to reduce tic severity in adults with TS

32

32

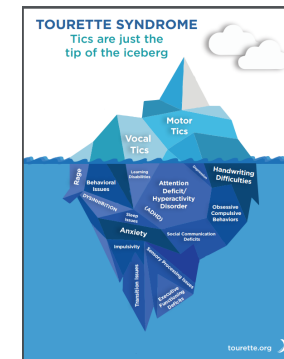
Primary Care Recommendations

- ▶ Most important question → Do I treat?!
- ▶ First-line treatment can be initiated and monitored by pediatric primary care practitioners
- ▶ Many primary care providers are increasingly familiar with using α_2 agonists to treat ADHD in children
- ▶ Strongly recommend consultation with specialist before initiating treatment with antipsychotic medications
- ▶ Important to screen for common co-morbid conditions in patients with Chronic Tic Disorders

33

33

Tourette Syndrome & Co-Morbidities



34

34

Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD)

- ▶ Present in ~60% of patients with TS or other Chronic Tic Disorders
- ▶ Treatment with stimulants does NOT worsen tic severity
- ▶ Treatment:
 - ▶ Cognitive Behavioral Therapy
 - ▶ Stimulant:
 - ▶ Methylphenidate (Ritalin, Concerta, etc.)
 - ▶ Amphetamine/Dextroamphetamine (Adderall, Vyvanse)
 - ▶ Alpha-2 Agonists:
 - ▶ Guanfacine (Tenex)
 - ▶ Clonidine (Catapres)
 - ▶ Non-Stimulant:
 - ▶ Atomoxetine (Strattera)

35

35

Mood Disorders

- ▶ Anxiety and Depression are also very common in patients with TS or other Tic Disorders
- ▶ Tend to persist into adulthood and can be very impairing from quality of life standpoint
- ▶ Treatment:
 - ▶ CBT can be very helpful as initial therapy → can be used in combination for other co-morbidities (i.e. OCD)
 - ▶ Medications:
 - ▶ SSRIs: Paroxetine, Fluoxetine, Sertraline, Citalopram, Escitalopram
 - ▶ SNRIs: Venlafaxine
 - ▶ Other: Wellbutrin

36

36

Obsessive Compulsive Disorder (OCD)

- ▶ Present in ~27% of patients with TS or other Tic Disorders
- ▶ Can have overlap in symptomatology → “Compulcic”
 - ▶ Can be difficult to differentiate complex motor tic from compulsion
- ▶ Treatment:
 - ▶ Cognitive Behavioral Therapy (CBT)
 - ▶ Medications:
 - ▶ SSRIs: Paroxetine, Fluoxetine, etc.
 - ▶ TCAs: Clomipramine

37

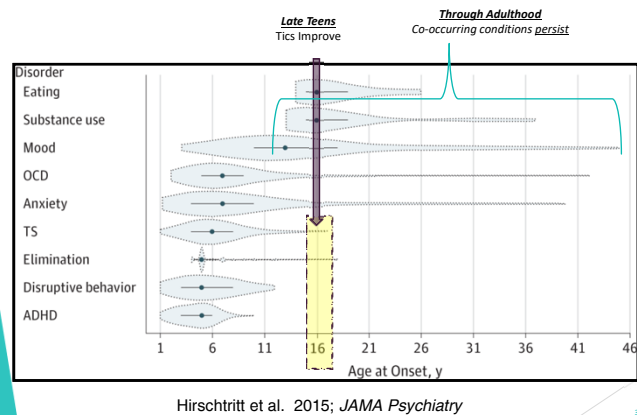
Other Co-Morbidities

- ▶ Behavioral Disturbances:
 - ▶ Conduct Disorder/Oppositional Defiant Disorder → ~15%
 - ▶ Rage episodes
- ▶ Treatment:
 - ▶ Cognitive Behavioral Therapy
 - ▶ Medications:
 - ▶ Mood stabilizers: Lamotrigine, Carbamazepine, Depakote
 - ▶ Anti-psychotics: Aripiprazole, Risperidone, Haldol
- ▶ Learning Disability:
 - ▶ Occurs in ~23%
 - ▶ May need IEP's, additional resources, etc.

38

37

38



39

Summary

- ▶ Tourette Syndrome is a complex neuropsychiatric condition
- ▶ Tics tend to improve with age
- ▶ Psychiatric co-morbidities tend to persist with age
- ▶ Treat the most bothersome symptom first!
- ▶ Consider both non-pharmacologic (CBT) and pharmacologic interventions for tics and co-morbid conditions

40

39

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References

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- ▶ Olfson et. al. Journal of the American Academy of Child and Adolescent Psychiatry. 2011.
- ▶ Bisko et. al. 2014
- ▶ Leckman et al. Pediatrics. 1998.
- ▶ AAN Practice Guideline Recommendations Summary: Treatment of tics in people with Tourette Syndrome and Chronic Tic Disorders. <https://n.neurology.org/content/92/19/896>
- ▶ Piacentini, J., Woods, D.W., Scahill L., Wilhelm, S., Peterson, A.L., Chang, S., Ginsburg, G.S., Deckersbach, T., Dziura, J., Levi-Pearl, S., Walkup J.T., 2010, Behavior Therapy for Children with Tourette Disorder: A Randomized Controlled Trial. Journal of the American Medical Association, 303:1929-1937
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- ▶ Muller-Vahl KR, Schneider U, Prevedel H, et al. Delta 9-tetrahydrocannabinol (THC) is effective in the treatment of tics in Tourette syndrome: a 6-week randomized. Journal of Clinical Psychiatry. 2003; 64: 459-65.
- ▶ Hirschtritt et al. JAMA Psychiatry. 2015

41

Questions?



42

Please take a moment to answer this brief survey!



Use your smartphone camera to scan the QR code. Open the link that pops up on the screen to access the survey! You may access the survey using the link below if you do not have a smartphone,
<https://www.surveymonkey.com/r/MedProgEval>. Thank you in advance for your feedback!

43