What you need to know about Tourette syndrome and tic disorders

A Primer

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Objectives of this Primer

• To define and characterize tics
• To discuss tics in relation to Tourette syndrome
• To describe co-occurring disorders
• To outline the recommended treatment for tic disorders
What are tics?
How is a tic defined?

A sudden, rapid recurrent and non-rhythmic motor movement or vocalization.

These are seen as normal motor movements or vocalizations that are out of their normal or usual context.
Tics are distinguished by type

**Motor (simple) – physical movement**
- blinking

**Vocal (simple) - audible noise**
- coughing
Simple Motor Tics

- Sudden, brief, meaningless movements
  - Eye blinking
  - Eye movements
  - Grimacing
  - Nose twitching
  - Mouth movements
  - Head jerks
  - Shoulder shrugs
  - Abdominal tensing
Simple Vocal Tics

- Sudden, meaningless sounds or noises
  - Throat clearing
  - Coughing
  - Sniffing
  - Screeching
  - Barking
  - Grunting
They are also distinguished by complexity

Motor (complex) – running hands through hair

Vocal (complex) - inappropriate/aggressive words
Complex Motor Tics

- Slower, longer, more “purposeful” movements
- Rarely seen in absence of simple motor tics
- Touching objects or self
- Gestures with hands
- Holding and twisting limbs
- Obscene gestures
Complex Vocal Tics

- Syllables, words, phrases or statements
- Odd patterns of speech
- Repetition of another person’s spoken words
- Obscene, inappropriate and aggressive words or statements
Characteristics of tics

- Suppressibility
- Distractibility
- Suggestibility
- Variability
  - Character of tics
  - Frequency of tics – waxing and waning
- Exacerbation with stress or excitement
- Premonitory urge
The causes of tics

Research suggests there are a number of factors that contribute to tics and how they express themselves.

- Genetic: heritable
- Neurobiological: neurochemical/neurotransmitters
- Environmental factors
Peak tic severity occurs between the age of 10 and 12
Many children experience an improvement in adolescence
Tic severity is measured using a scale
Tic severity might indicate impairment and therefore treatment. The goal of treatment is to reduce tic severity
Tourette Syndrome
Characteristics that identify Tourette syndrome

- Both motor and vocal tics are present for at least one year
- 1 year since first tic onset - waxing and waning
- Onset of tics is before the age of 18
- Tics are not attributable to the effects of a substance or another medical condition.
The natural course of Tourette syndrome

- Mean onset of motor tics at age 6
- Begin with simple tics of face
- Vocal tics appear after motor tics
- Tic severity peaks in pre-adolescence and declines in late adolescence
- High rate of natural remission between age 14 and 17 years of age
- Monitoring of tic-related impairment essential for making treatment decisions
Common problems associated with tics and Tourette Syndrome

Tics are often the behavioural symptoms that are noticed.

Psychiatric comorbidities include:
- ADHD – 54%
- OCD – 50%
- Anxiety disorders 36%
- Disruptive Behaviour Disorders 30%
- Eating disorders 2%
- Psychotic disorders 1%
- Substance use 6%
Quality of Life

- Quality of life is impacted more by comorbidity than tic severity
- In children, the severity of ADHD has greatest impact
- In adults, anxiety and depression have greatest impact
- Improving quality of life is paramount in treatment of tics
Predictors how Tourettes might develop

The strongest predictors of high tic scores and OCD and ADHD diagnoses in adulthood

Corresponding tic, OCD and ADHD severity scores in childhood

Being female and ADHD severity predict future emotional disorders
How common is diagnosed Tourette syndrome in Canada?

- Data from Canadian Community Health Survey 2010/2011
- Population-based survey of Canadians age 12+
- Prevalence of diagnosed Tourettes in adolescents was 3.33 per 1000
  - Male 6.03 per 1000
  - Female 0.48 per 1000
- Prevalence of diagnosed Tourettes in adults was 0.66 per 1000
  - Male 0.89 per 1000
  - Female 0.44 per 1000
How are tics assessed?
Clinical Assessment of People with Tics

- Family history
- Medication use
- Developmental history
- Past medical history
- History of tics
- Neurological exam
- Assessment of tic severity
In people with tics clinicians assess for OCD, ADHD and other psychiatric conditions to ensure appropriate treatment is provided for the different conditions.
Disorders commonly occurring with Tourettes

<table>
<thead>
<tr>
<th>Group</th>
<th>Conditions</th>
</tr>
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<tbody>
<tr>
<td>Females</td>
<td>more likely to have depression, anxiety and eating disorders</td>
</tr>
<tr>
<td>Males</td>
<td>more likely to have ADHD and disruptive behaviour disorders</td>
</tr>
<tr>
<td>Adults and Adolescents</td>
<td>more likely to have OCD, mood, anxiety, eating and substance use disorders</td>
</tr>
<tr>
<td>Children</td>
<td>more likely to have ADHD</td>
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</tbody>
</table>
ADHD and people with tics

<table>
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<tr>
<th>It is vitally important for clinicians to assess the impact on the lives of ADHD symptoms in people with tics</th>
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<tr>
<td>Individuals with both TS and ADHD are at a much greater risk for a variety of poor outcomes including greater academic and social impairment</td>
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<tr>
<td>Social difficulties – more aggressive and withdrawn - are amplified in a child with TS who also has ADHD</td>
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It is vitally important for clinicians to assess the impact on the lives of OCD symptoms in people with tics

The most common obsessive-compulsive symptoms encountered in TS patients are obsessions concerning a need for symmetry or exactness, repeating rituals, counting compulsions, and ordering/arranging compulsions

Obsessive-compulsive symptoms, when present, in children with TS, appear more likely to persist into adulthood than the tics themselves
Treatment of tics
When should tics be treated?

- No fixed symptom severity threshold to determine when we should treat
- An individual choice
- Recommend that the decision be based on disability
  - Physical
  - Social
  - Emotional
- Decision is made collaboratively between patient and doctor
The course of treatment

• It is vitally important to understand the typical course of treatment
• Psychoeducation

Treatment is individualized, and the two main treatments are:

Behaviour therapy
Pharmacotherapy
Psychoeducation

• This webinar and Tourette OCD Alberta Network are examples of psychoeducation
• touretteocdalbertanetwork.ca
• Psychoeducation provides resources and encourages families to accept and cope with challenging conditions
• Psychoeducation promotes family well-being – normalizes the difficulties families experience
• Improves quality of life
Psychoeducation: in the classroom

- Psychoeducation about TS with fellow students results in positive attitudes towards students with TS

- Psychoeducation about TS with teachers improves knowledge, making classroom more inclusive for a person with TS
Psychoeducation: Educational Outreach

Educational Outreach Program for Schools

The prevalence of Tourette Syndrome (TS) is approximately 1% of the student population, indicating that it is highly likely someone in your school will have the disorder. To complicate matters, most students with the diagnosis of TS also have co-occurring disorders such as ADHD and OCD.

We provide customized presentations for:
- Grade specific issues.
- Teacher, parent, and student specific presentations.
- Information on Tourette Syndrome (TS) and Obsessive-Compulsive Disorder (OCD).
- Information of what TS and OCD look like in the classroom.
- Strategies for the classroom.
- Short films to illustrate TS and OCD.
- Empathy exercises to help people of all ages understand what it feels like to live with TS and OCD.

All the presentations have been vetted by a team of neurologists, psychologists, and teachers to come up with the most current information available - and they range in length from 30 minutes to 2 or 3 hours.
The two primary evidence-based treatment options for tic disorders are:

- Cognitive Behavioral Therapy – 1st line
- Pharmacotherapy
Treatment Expectations

- Treatment may result in a range of reduction in tic severity
- Evidence has shown that a treatment response among youth with tic disorders corresponds with 25%-35% reduction in tic symptom severity
- Treatment rarely results in tics completely stopping
Behavioural Treatments: CBIT

Behaviour based therapies teach people with TS how to manage their tics, with the aim of reducing tic severity.

CBIT – Comprehensive Behavioural Intervention for Tics

Foregrounds competing behaviour when the urge is felt. This component of CBIT is known as HRT

Many people with TS use CBIT successfully – evidence shows over 50% experience tic reductions

A management strategy, not a cure

promotes awareness of tics and the urge to tic
Behavioural Therapy - caveats

• There are limitations to behavioural therapy, specifically CBIT, with regard to minimum age criteria

• Awareness of when tics are about to happen – awareness of the premonitory urge – requires a relative maturity found in children over 9 years old

• CBIT is not effective for children with severe ADHD or children with severe intellectual deficit

• Paucity of availability of CBIT therapists

• Locating them can be difficult – one of the aims of TS OCD Alberta Network to compile a directory of certified therapists
Components of Comprehensive Behavioural Intervention for Tics

- CBIT: Tic awareness training, self-monitoring, relaxation techniques, behavioural rewards

- HRT (Habit Reversal Training) - competing response: people learn to do a new behaviour that cannot happen at the same time as the tic

- It does not mean that it is possible for anyone to control them just by behavioral therapy, but 50% do experience tic reduction
Pharmacotherapy treatments

• Currently no preventative pharmacological therapies for tic disorder

• If tics do not cause significant functional impairment, non-pharmacological treatments are preferred

• Alpha-agonists –
  • clonidine, guanfacine
  • clonidine and guanfacine have demonstrated beneficial effects on both tics and ADHD symptoms

• Anti-psychotics drugs –
  • aripiprazole, risperidone
  • used to reduce tic symptom severity
Treatment recommendations

- The decision to use medication and the monitoring of its impact require careful assessment of the child's overall development and not only the presence of tic symptoms.

- Clinicians should prescribe medications for the treatment of people with tics when the benefits of treatment outweigh the risks.
• Tourette syndrome is a common neurological disorder
• Tic severity will improve for most children in late adolescence
• Quality of life is impacted more by comorbidity than tic severity
• Behavioural therapies are first line for tics which cause functional impairment
• There are medications which can help decrease tic severity