Fuzzy Boundaries: Understanding the Tourette-Functional Tic Dichotomy from patient and clinician perspectives

MAY 20, 2023
TOURETTE ASSOCIATION OF AMERICA, TIC-CON 2023

JOSEPH SEXTON (HE/HIM), BS
INDEPENDENT RESEARCHER, PATIENT
JOSEPH.F.SEXTON@VANDERBILT.EDU

JOE MCGUIRE (HE/HIM), PHD
ASSOCIATE PROFESSOR IN PSYCHIATRY AND BEHAVIORAL SCIENCES, JOHNS HOPKINS
JFMCGUIRE@JHMI.EDU
Situating me

My tics emerged at age 13 in the Summer of 2014. I would hold my breath and cough uncontrollably. A lot of the time, I needed to take really deep breaths to feel like I was "actually" breathing. (This was really bad because I ran cross country!)

I started with an asthma diagnosis. Later I developed more obvious motor tics. A diagnosis of Tourette's soon followed. Over the years I have exhibited coprolalia, copropraxia, and physically violent tics. I was fortunate to be an excellent K-12 system (Forsyth County, GA) with good support for disabled students.

Me in the Fall of 2014. I would usually wind up in the medical tent post-race. "Why can’t this kid catch his breath?"
Situating me

Over time, I have become involved with the Tourette's community in different ways:

- I was a **camper at Camp Twitch and Shout** (Winder, GA) for a couple of summers.
- I was a **Rising Leader** in the TAA’s inaugural cohort (Summer 2019).
- I have **spoken** at a number of **workshops** for both clinicians and parents.
- I am now a **counselor at Camp Twitch and Shout** (this will be my third year!).

Me, my co-counselors, and our campers (collectively, a cabin!) at Twitch and Shout last Summer. Campers’ faces are hidden because they’re minors. Low-res, maybe, but highly sentimental...!
Situating me

The other things to know about me:

- **I (just) graduated (!)** from Vanderbilt on a full-tuition scholarship, triple majoring in mathematics; psychology; and medicine, health and society (an interdisciplinary program)
- **I am about to spend a year traveling the world** on a fellowship (see middle-right) to explore cross-cultural insights on mental health
- **Hope to stay in research** concerning suicide (see top-right, bottom-right), controversies in mental health care, and meta-level issues in research (e.g., all this research - why aren't things "better"?)

Two Vanderbilt students named 2021 Goldwater Scholars

Vanderbilt graduates go global: Three students awarded Keeghan Traveling Fellowships
With all of that said: what are functional and Tourettic tics?

From my perspective as someone who (1) reads about mental health academically but also (2) is involved with the community, here is what I observed:

- There was a large increase in the onset of tics in 2020. This coincided with the pandemic.
- Many patients were presenting with tics that were "popular" online - not in the "I want to have that tic" sense, but in the "a popular advocate with Tourette’s has these tics" sense.
- Clinicians notice that many patients are coming in with a shared set of tics. The social component seems odd. Additionally, the onset is oftentimes in people who are older (e.g., mid-to-late adolescence) and female.
With all of that said: what are functional and Tourettic tics?

From my perspective as someone who (1) reads about mental health academically but also (2) is involved with the community, here is what I observed:

- Unable to call this "Tourette Syndrome" given these peculiarities, the assigned diagnosis is "functional neurological disorder". This is a catch-all for "we don't know exactly what this is, but obviously something is happening."
- There is a resulting divide between "real" or "Tourettic" tics and functional tics. Clinicians and patients alike are left to wonder what their clients or peers are experiencing. Are we the same, or are we different?
In peer-reviewed literature...

Authors included in photos.
First and third are published in Movement Disorders. The second is in the American Journal of Medicine.
...in popular press...

Teen Girls Are Developing Tics. Doctors Say TikTok Could Be a Factor.
When teens started turning up in doctors’ offices with sudden, severe physical tics, specialists suspected social media: The girls had been watching Tourette syndrome TikTok videos.

How Teens Recovered From the ‘TikTok Tics’
A wave of teenagers who developed tics during the pandemic has receded, illustrating the powerful influence of stress on the body and the resilience of adolescents.

No, Tik Tok Is Not Causing Tourette Syndrome.

Nancy Doyle  Contributor ©
Professor of Business Psychology specializing in neurodiversity

The Wall Street Journal (2021)
The New York Times (2023)
Forbes (2021)
...in our social lives...

@thistripphippie on TikTok (left, middle)  
@josies_journey on TikTok (right)
...and in online spaces.
Exploring my own tics

While "functional tics" appear like a more novel phenomenon, the notion that social influences affect tics is not novel.

My tics get worse when I go to camp, when I talk about my tics, and when I am stressed. This common feedback loop - one you are probably familiar with - is at right. I can even "catch" tics. None of this is surprising to us as people who live with or care for or treat people with tics.

The question then becomes: can I even have functional tics? How would we ever know? Or am I immune by nature of having a diagnosis of Tourette's?
Where does advocacy fall?

How can we disrupt this feedback loop? It seems your options are: (1) your neurology simply calms down (how lucky you are...) or (2) you or a caretaker seek help (e.g., through self-advocacy, the advocacy of a parent).

Yet, advocacy while necessary can also maintain tics. I talk about, think about, and reflexively do still tic. I can tell you now: in all likelihood, if I were not involved in this space, I would be ticcing less. I know others who share this experience. Yet, we have no other choice, especially when our tics require regular explanation.
Where does advocacy fall?

This leaves us with important questions to answer:

1. What is the line between "Tourettic" and "functional" tic?
2. If engagement with the online community (e.g., for advocacy, for support) increases my tics, is that effect separate from the "functional tic" effect?
3. Why does any of this matter in terms of how we treat individual people?
4. And why do we ourselves want to have "real" rather than "functional" tics?
5. What are the implications of this discourse?
Understanding the Management of Tics & “Functional Tics”

Joseph F. McGuire  PhD
Division of Child and Adolescent Psychiatry
Department of Psychiatry and Behavioral Sciences
Objectives

• Review evidence-based assessment and treatment of tics

• Discuss differences in the assessment and treatment of tics and ‘functional tics’

• Highlight how skills can be utilized to address functional and/or acute-onset tic-like behaviors
Tics and Tourette Syndrome

• Tics are common

• Symptom presentation

• Developmental trajectory
Tics and Tourette Syndrome

- Premonitory urges / sensory phenomena

- Comorbid challenges
  - Inattention / hyperactivity
  - Impulsivity
  - OC symptoms
  - Fear and anxiety
  - Irritability and frustration
  - Disruptive behaviors
  - Suicidal thoughts / behaviors
Evidence-based Assessment of TS

- Comprehensive clinical interview
- Clinician-administered scales
- Parent- and self-report ratings
- Video observations and/or other measures/tests
Practice Parameters & Treatment Guidelines

• Conduct evidence-based assessment of tics

• Psychoeducation recommended for mild tics / mild tic severity

• Behavior therapy recommended as first-line treatment for moderate tics / moderate tic severity
Behavior Therapy for TS

- Habit reversal training (HRT)
  - Psychoeducation
  - Awareness training
  - Competing response training

- Comprehensive Behavioral Intervention for Tics (CBIT)
  - HRT
  - Relaxation Training
  - Function-based assessment / intervention
Behavior Therapy for TS

• Therapeutic outcomes from behavior therapy
  – Large treatment effects (Piacentini et al. 2010; McGuire et al. 2014)
    • Effect sizes = .67 - .94
  – Treatment response rates (Piacentini et al. 2010)
    • ~50% experience a treatment response
  – Remission of individual tic symptoms (McGuire et al. 2015)
“Functional Tics”

• Acute-onset tic-like behaviors
  – “Functional Tics”
  – “TikTok Tics”
  – Acute, adolescent, and sudden onset
    • Emergency department visits
  – Dramatic in presentation

  – Phenomenological differences
Assessing Tics and “Functional Tics”

• Conduct clinical assessment
  – Tic severity, tic impairment, and premonitory urges
  – Identify internal and external antecedents
    • Internal antecedents / factors
      – Premonitory urges
      – Affective states (e.g., stress, anxiety, mood)
    • External antecedents / factors
      – Avoidance / accommodation
      – Unintentional positive reinforcement
        » Social media use
Behavior Therapy for Tics and “Tics”

• Implement skills based on identified factors
  – Premonitory urges / early tic movements
    • Habit Reversal Training (HRT)
  – Affective states (e.g., stress, anxiety, and mood)
    • Relaxation Training
    • Function-based assessment / intervention
Modifying Behavior Therapy for TS

• Implement skills based on identified factors
  – Avoidance / accommodation
    • Function-based assessment / intervention
    • Habit Reversal Training (HRT)
  – Unintentional positive reinforcement
    • Function-based assessment / intervention
    • Habit Reversal Training (HRT)
Case Example

• 16 year old female
  – Acute onset ➔ emergency department
  – Anxiety, ADHD, and history of self-injury

– Internal antecedents / factors
  • Premonitory urges
  • **Affective states**: stress / frustration / irritability

– External antecedents / factors
  • Avoidance (school and work)
  • Accommodation (family)
Case Example

- 8 session of behavior therapy

Tic Severity, Tic Impairment, and Premonitory Urges
Case Example

• Improvement not universal
Conclusions

• Distinguishing tics and “tics” isn’t easy
• Behavior therapy can beneficial
• Tailor skills to specific antecedents / factors
• Further intervention likely needed