

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

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TOURETTE ASSOCIATION OF AMERICA, TIC-CON 2023

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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

MYVU
Vanderbilt graduates go
global: Three students
awarded Keegan 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...

Movement Disorders

RESEARCH ARTICLE

CLINICAL PRACTICE

TikTok Tics: A Pandemic Within a Pandemic

Caroline Olvera, MD,* Glenn T. Stebbins, PhD, Christopher G. Goetz, MD, and Katie Kompolti, MD

COMMENTARY | VOLUME 135, ISSUE 8, P933-934, AUGUST 2022 [Download Full Issue](#)

Tik Tok Tics

Martin A. Samuels, MD  

Published: March 17, 2022 • DOI: <https://doi.org/10.1016/j.amjmed.2022.02.040> • [Check for updates](#)

 **The recent surge of functional movement disorders: social distress or greater awareness?**

Christelle Nilles^a, Tamara M. Pringsheim^{b,c,d}, and Davide Martino^{a,c,d}

Authors included in photos.

First and third are published in Movement Disorders. The second is in the American Journal of Medicine.

...in popular press...

FAMILY & TECH: JULIE JARGON

Teen Girls Are Developing Tics. Doctors Say TikTok Could Be a Factor.

The Wall Street Journal
(2021)

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.

The New York Times
(2023)

No, Tik Tok Is Not Causing Tourette Syndrome.

Nancy Doyle Contributor @

Professor of Business Psychology specializing in neurodiversity

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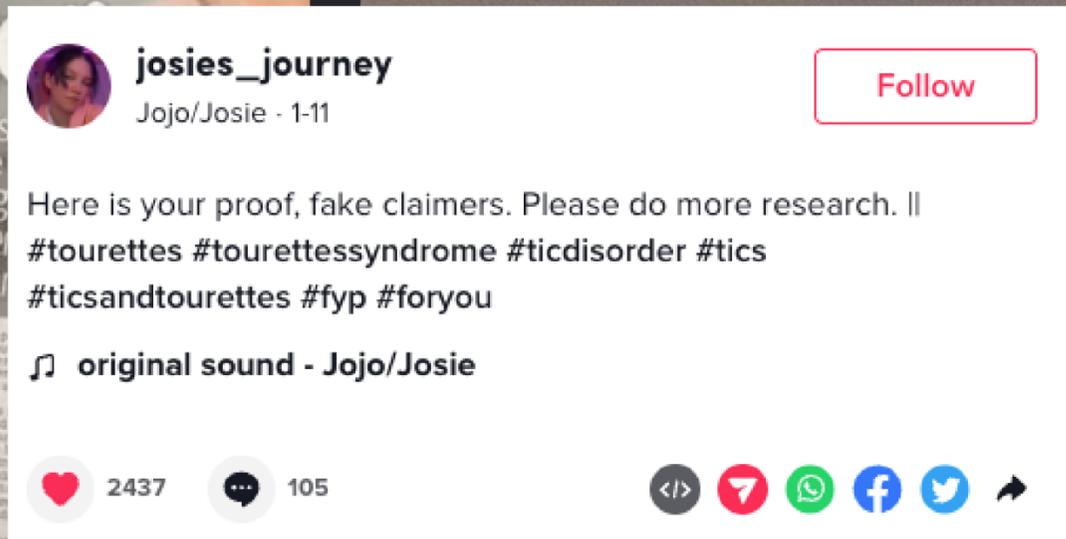
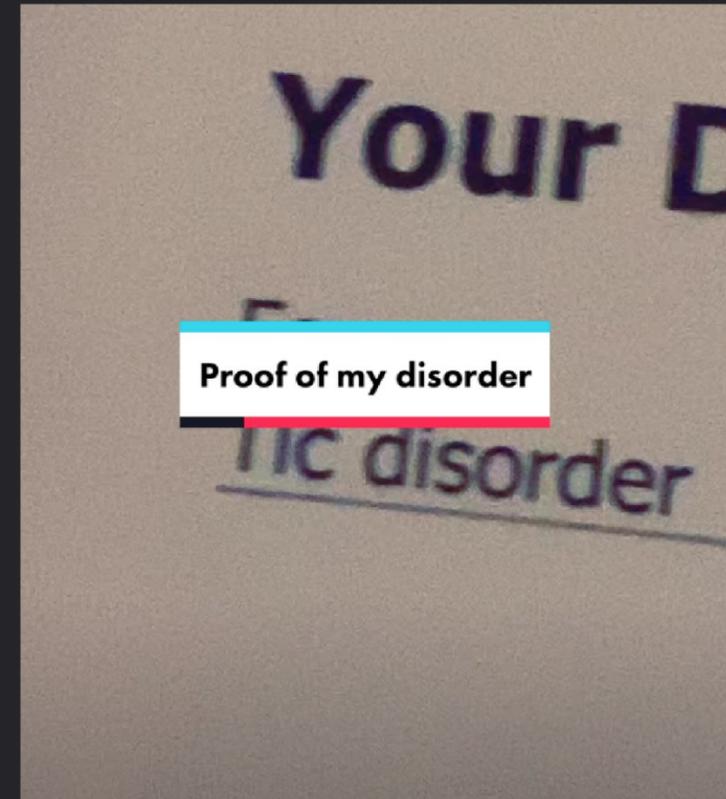
Nov 1, 2021, 01:05pm EDT

Forbes (2021)

...in our social lives...



@thistrippyhippie on TikTok (left, middle)



@josies_journey on TikTok (right)

...and in online spaces.

Discussion of Munchausen By Internet, Medical Deception and toxic "Chronic Illness Influencers" [Join](#)

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PINNED BY MODERATORS

535 Posted by u/MBIresearch 10 months ago

FOLLOW-UP DISCUSSION RE: Pausing Ash Thread; TOS Concerns; Update & Highlights. THANK YOU to everyone who contributed over the past 3 days! I've put together some highlights and responses based on feedback and discussion with you all...please come continue discussing with us here! [\[DISCUSSION\]](#)

236 Comments [Award](#) [Share](#) [Save](#) ...

162 Posted by u/thenearblindassassin 16 days ago

Imgur content removal and munchie timelines [\[DISCUSSION\]](#)

48 Comments [Award](#) [Share](#) [Save](#) ...

About Community

Discussion of Munchausen By Internet, related conditions and toxic "Chronic Illness Influencers" for whom evidence suggests they may be lying, feigning or exaggerating illnesses and medical crises for attention and/or profit. We speculate from a distance ONLY and forbid contact with those discussed in any form. We cannot diagnose anyone. Many here have CI; all concerned about MBI, parallels to post-Pro-Ana subculture and damage posed to CI support spaces. Please read rules before posting!

Created Feb 23, 2018

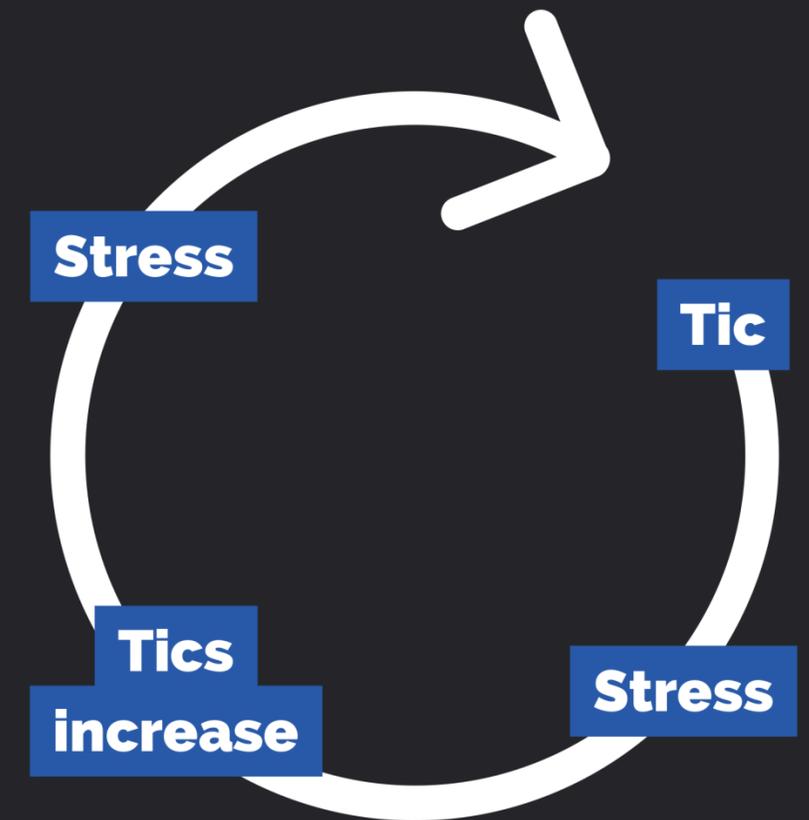
140k Members **181** Online

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.

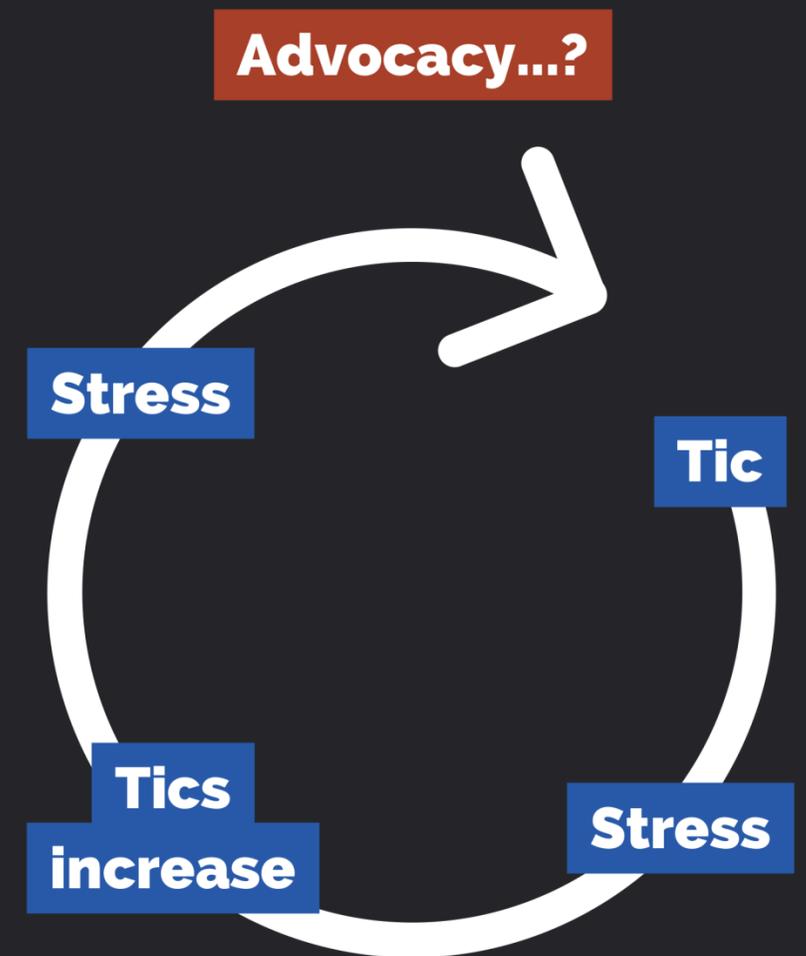
The question then becomes: can I even *have* functional tics? How would we ever know? Or am I immune by nature of having a diagnosis of Tourette's?



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?