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Understanding and Responding to Sudden Onset Tics in Teens:
An overview for individuals, families, schools, and clinicians.

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Webinar for NJCTS
February 23, 2022

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Webinar Agenda

- 1. What has been happening?
 - Overview of the recent rise in sudden onset tic cases in teens
- 2. Why is this happening?
 - Overview of factors thought to be involved in this surge
- 3. How do we help these individuals?
 - Overview of treatments and coping strategies
- 4. Resources
- 5. Questions

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What has been happening?

Overview of the recent rise in sudden onset tic cases in teens

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What has been happening?

- Since the start of the pandemic (~March 2020)
- There has been a sudden rise in cases of teens/young adults with rapid onset tic-like behaviors
 - "Functional Tic Like Behaviors" (FTLB)
- The phenomenon is occurring consistently and in a parallel fashion across the world
- Correlation between FTLB and social media such as TikTok identified
 - For many but not all cases
- Popular media outlets (WSJ, vice) reported on it in 2021

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What has been happening?

FTLB cases:

- Rapid onset (sudden, overnight) of complex motor and complex vocal tic-like behaviors
- Dramatic and exaggerated presentations
- Often extremely disruptive, destabilizing, potentially traumatizing for an individual and their family
 - Missed school, multiple doctors appointments, hospital/ER visits
- The vast majority of cases have been female, and adolescent (12-25 years old)

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What has been happening?

- Behaviors classified as "Tic-like"
- Different from traditional tics found in Tourette Syndrome other primary tic disorders
- Called Functional Tic-like Behaviors (FTLB), functional tics, psychogenic tics
- Consistent with Functional Neurological Disorder (FND)
 - Also historically known as Conversion Disorder
- Existed, studied, treated before the pandemic
 - But relatively rare
- Mass psychogenic illness suspected
 - Functional neurological disorder on a large scale

+ What has been happening?

There has also been an increase in:

- Referrals for primary (typical) tic disorders
 - Tourette Syndrome, Persistent Motor or Vocal Tic Disorder, Provisional Tic Disorder
 - Neurological disorders consisting of tics which are:
 - Sudden, rapid, recurrent, non-rhythmic, repetitive motor movements or vocalizations
- Tic severity level for individuals with primary tic disorders
- Referrals for people experiencing co-morbid disorders and stressors
 - anxiety, depression, OCD, social isolation, family discord, difficulty with school

+ What has been happening?

- Increasing numbers of referrals at tic specialty clinics for FTLB cases since COVID-19
- TS clinics in Canada, Australia, London, USA (Pringsheim et al., 2021)
 - Pre pandemic FTLB were reported in about 1-2% of referrals
 - After March 2020 FTLB were reported in ~20-30% of referrals
- A similar change observed at the Rutgers TS Clinic (where I was clinical director) and in my private practice

+ Why has this been happening?

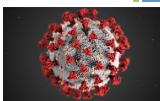
Overview of factors thought to be involved in this surge

+ Why is this happening?

- Recent events
- Functional Neurological Disorders
 - Functional Tic-Like Behaviors
- Social Media /Mass Psychogenic Illness
- What about PANS/PANDAS?

+ Why is this happening? Recent events

- COVID-19 spread - global pandemic
- Lock-down
- Virtual: work, school, socializing
- Increased stress, anxiety, uncertainty, isolation, sickness, death
- Sudden, major disruption to daily life, income, sense of security
- Collective worldwide traumatic experience?



+ Why is this happening? Functional Neurological Disorder

- Functional Neurological Disorder (FND)
- Also known as "Conversion disorder"
- FTLB are considered a type of FND
- Neurological symptoms (motor and sensory) that are not explained by an identifiable pathology
- Can present similarly to other neurological illness
 - Parkinson's, epilepsy, stroke
- 2-3 times more common in females than males

+ Why is this happening? Functional Neurological Disorder

- FND are common reason people see neurologists
- Difficult to treat, but treatable
- Disabling:
 - Heavy health care use, Tx coordination/ access
 - Inability to work/go to school, family disruption
- Very often associated with stress or trauma (past/present)
 - Can occur without stress though
- Co-morbidities: Anxiety-panic, depression, dissociation
- Can be associated with: Pain, insomnia, fatigue

+ Why is this happening? Functional Neurological Disorder: Presentations

- Abnormal movements
 - Tremor, gait, dystonia, posturing, tics
 - Functional tics are relatively rare
- Paralysis or limb weakness
- Sensory
 - Reduced, altered or absent skin sensation, vision or hearing
 - Double vision, intermittent blurring, loss of vision
- Psychogenic non-epileptic seizures
 - Shaking, impaired or loss of consciousness
- Episodes of unresponsiveness that resemble a coma or fainting
- Speech
 - Volume, articulation, lump in throat feeling, trouble swallowing

+ Why is this happening? Functional Neurological Disorder

- Etiology: Cause is unknown
- Conversion: Brain takes stimulus and converts it into a physical symptom
 - Trouble with how the nervous system functions
 - Brain software problem not hardware
 - Brain areas impacted
 - Hyperactive amygdala + less active cortex = less control over brain
 - Communication with brain (top) and body (bottom) impacted
 - TAA webinar has good explanation of this

+ Why is this happening? Functional Neurological Disorder

- Predisposing factors
 - Psychosocial adversity, gender (female), physical illness, Exposure to symptom/illness models
- Precipitating factors
 - Physical injury, mental health symptoms, interpersonal conflicts, other stressors
- Perpetrating factors
 - Avoidance, illness beliefs/expectations, social isolation
(Pick et al., 2019)

+ Why is this happening? Functional Tic-Like Behaviors

- Before COVID-19, FTLB were observed and studied, but was considered rare (Ganos et al., 2019)
- It is not brand new, small research base
 - New that is widespread and there has been a surge
- Difficult to diagnosis, identify and distinguish FTLB vs tics
- FTLB may occur on its own (w/o history of primary tic disorder)
- **FTLB and primary TD may co-occur**
 - Can have primary tics and FTLB
 - Either for the same movement (functional overlay)
 - Or for different behaviors

+ Why is this happening? Functional Tic-Like Behaviors: Examples

- Sudden, abrupt, dramatic, onset
- Mostly complex movements, often involving trunk and limbs
- Hitting self/others/ objects
- Coprolalia and echolalia
- Saying many different words, speaking with accents
- Whistling, wooping
- Complex leg and arm movements
- Other FND type symptoms:
 - Loss of functioning temporarily (can't speak, zoning out, can't move a part of body, legs give out causing a fall)

+ Why is this happening?

Functional Tic-Like Behaviors

Pringsheim et al. 2021 findings on recent FTLB cases:

- Anxiety and/or depression common
- Most had no history of previous tics
 - Of those with a history of tics, the tics were often mild
- Similarities to primary tic disorders:
 - Some can identify premonitory urge (tic signal) with FTLB
 - FTLB are susceptible to distractibility and suggestibility
- All in the study report exposure to TikTok tic videos
- No association was found between acute infections such as what is witnessed in PANDAS/PANS

+ What has been happening?

Tics vs FTLB

| | Traditional Tics | Functional Tics-Like Bx |
|----------------------------|---|--|
| Onset and Course | Typical gradual onset – simple tics first, Ages 4-10 | Atypical sudden onset- complex tics, Adolescence |
| Sex | 4:1 male to female | Mostly female |
| Most common tics | Eye blinking, throat clearing, head jerking | Complex tics |
| Premonitory urge | Yes, often report in area of tic | Mixed mostly no, but some yes often reported as whole body pulse of energy |
| Suppressibility | Often can temporarily suppress, like holding back an itch or sneeze | Sometimes can suppress, often feel pain, nausea, malaise, or dizziness |
| Influenced by context | Yes - can impact symptom expression, distraction | Yes - can impact symptom expression, distraction |
| Most common co-morbidities | OCD, ADHD | Anxiety Depression |
| Susceptible to suggestion | Yes, and reinforced by attention | Yes, and reinforced by attention |

+ Why is this happening?

Social Media and Mass Psychogenic Illness

- With social media tics more visible to the world
- TikTok, instagram, snapchat, youtube
- Popular channels, #tourettes has 5 billion views
- Popular influencers, Tourette alphabet challenge
- Many view, others also post about their tics



+ Why is this happening?

Social Media and Mass Psychogenic Illness

- Many experiencing sudden onset tics reported following social media influencers with tics
- Tics and FTLB are susceptible to suggestion
- Tics and FTLB are reinforced by consequences (attention, support, sense of belonging)
- Not all individuals experiencing a sudden onset of tics report watching tiktok or tic posts on social media

+ Why is this happening?

Social Media and Mass psychogenic illness

Mass psychogenic illness (Mink 2013)

- Rapid spread of FND symptoms among members of a cohesive group, social contagion (FND on group level)
- Noted in history: Salem Witch Trials, Le Roy NY (2012)
- Common characteristics
 - Cohesive group
 - Increased anxiety
 - Spread of symptoms via sight, sound oral communication, social media
 - High female ratio
- Confusion about cause, increased attn = symptoms worse
 - Disagreements between experts, in the media
- Not as studied as individual FND

+ Why is this happening?

What about PANS/PANDAS?

Pediatric Autoimmune Neuropsychiatric Disorder/
Pediatric Acute-onset Neuropsychiatric Syndrome

- Also sudden onset severe behaviors
 - OCD, restrictive eating, tics, irritability and aggression, anxiety (often severe separation), ADHD symptoms, depression, mood instability, muscle pain
 - Males 2:1, Median onset age 7
- Triggered by infection, inflammation, immune response
- Researchers (Pringsheim et al.) did not find connection between COVID infection causing PANS thus causing the recent surge
- PANS/PANDAS Remains controversial in medical community

+ Why is this happening? What about PANS/PANDAS?

- Some cases post-COVID might involve PANS/PANDAS, (as it was before COVID), but PANS is not currently linked to the current surge of cases
- Stressful events of COVID-19 (environmental, family, social) lead to worsening of conditions for those who have PANS/PANDAS
- Occurs in people with or without existing primary tics
- FTLB + PANS? FTLB + PANS +Primary Tics?
- Treatment typically involves medication, CBT, and parent management training (Guido, 2021)

+ Why is this happening? Taken together

- The shared global stress of the pandemic has led to an increase in mental health problems worldwide (including existing tic disorders)
- FTLB have existed before the pandemic
- Females historically have FND more than males
- FTLB can co-exist with Primary tic disorders
- Social media seems to have played a role in the mass development of FTLB, explains many but not all cases

+ My clinical experiences with FTLB Since COVID-19 surge

- Complex presentations, Majority female teens
- Often a mix of symptoms traditional tics, functional tics, other functional symptoms (can't speak, limbs can't move, shaking uncontrollably), possible PANS in some
- Some acknowledge use of tiktok/social media, but not always
- Often a history of at least mild tics, OCD, anxiety, depression, and/or identity related stress
- Comment on "La belle Indifference" - a beautiful ignorance
 - Paradoxical absence of psychological distress despite having a serious medical illness or symptoms related to a health condition
 - No longer used to diagnosis/ rule in/out FND
 - But I have found it occurring quite often in functional cases

How to help

Overview of treatments and coping strategies

+ How to Help Treatment and coping strategies: Overview

- Find professional help and get a diagnosis
- Personalized psychological-education
- Comprehensive Behavioral Intervention for Tics
- Address co-morbid anxiety and depression
- FND rehabilitation and motor retraining (if needed)
- Medication and alternative treatments
- School accommodations and coping strategies
- Take home strategies

+ How to Help Treatment and coping strategies

Find professional help and get an accurate diagnosis

- Can be one of the most challenging aspects:
- **First step is usually to see primary doctor**
- Multidisciplinary team
 - Medical: Neurologist (movement specialist, pediatrician, psychiatrist)
 - Psychological: Psychologist/other therapist trained to work with tics
 - School: Admin, counselors, CST, teachers, tutors, Accommodations,
 - Rehabilitation: If needed for more traditional FND: PT, OT, Speech
- Diagnostic picture: Primary tic? FTLB? PANS? Other? Combo?
 - Co-morbid: Anxiety? Depression? OCD? ADHD?
 - Life events: Stress, trauma, family, school, social media exposure, illness, injury, substance use, etc..

How to Help

Treatment and coping strategies

Personalized psychological-education

- First part of treatment for FTLB or any FND is giving diagnosis and explaining it to client and family
 - Better outcomes when patient and doctor are in agreement
- Explain that it is a “known unknown”
 - Don’t know the specific cause, but it is treatable, known, not your fault, and a problem with your brain software
- Treatment involves: Retaining your brain
- Review a treatment plan
 - Tx team should communicate and be on same page
 - Often tough to get consensus if PANS is suspected

How to Help

Treatment and coping strategies: CBIT

CBIT - Function-based strategies **Key for FTLB*

- Antecedent and consequences - what activities are associated with the symptoms
- Mitigate potential triggering exposures
 - Reduce/eliminate tic based social media exposure
- Reduce attention received for FTLB
- Modify parent and others responses
- Consider if there is secondary gain

How to Help

Treatment and coping strategies: CBIT

CBIT - Habit Reversal

- Works for primary tics, can try with FTLB if there is overlay
- Awareness training (AT)
 - Describing the tic in detail
 - Perceiving, describing, and practicing awareness of the “Tic Urge”
- Competing Response (CR)
 - Catching the tic before it happens and engaging in an incompatible or opposite behavior
 - Holding this CR for 1 minute or until the urge goes away
- Social Support from family and practice at home

How to Help

Treatment and coping strategies

Addressing co-morbid anxiety and depression

- Cognitive Behavioral Therapy
 - Cognitive restructuring, relaxation training, exposures, behavioral activation
 - Motivational Interviewing, DBT, ACT, mindfulness
- Stress management interventions
 - Problem solving, identifying stressors
 - Reducing social reactions to symptom expression
 - Examples: Conflict resolution, family therapy, adjusting school workload/schedules
- Supportive psychological treatment
 - Education, coping strategies, social skills, monitoring

How to Help

Treatment and coping strategies

Rehabilitation and motor retraining (if needed for FND)

Goal is re-establishing normal movement patterns, learning control over voluntary movements

- Rehabilitation (psychological and physiological:
 - Providing diagnosis and education
 - Retraining movement with diverted attention (Nielson et al., 2015)
 - Minimizing reinforcement of maladaptive movements
 - Avoidance of adaptive equipment and mobility aides
 - Identifying and challenging maladaptive beliefs
 - Relaxation and mindfulness
- Can be inpatient, outpatient, involves family
- Team: neurologist, PT, OT, speech, psychologist, social worker

How to Help

Treatment and coping strategies

Medication-Medical

- For primary tics: anti-hypertensive & neuroleptics common
 - Little effect on FTLB (sometimes placebo effect and miraculously works)
- Anxiety-Depression medication: SSRIs most common
- Botox, Deep brain stimulation has been tried in more severe cases for primary tics, not typically for FTLB
- Some docs might treat like PANS/PANDAS even if FTLB seems likely
 - Antibiotics, anti-inflammatory, not recommended for FTLB

Alternative Treatments

- Limited or anecdotal evidence but some families try
 - THC/CBD, supplements
 - Hypnosis - some research with FND shows it may help

+ How to Help

Treatment and coping strategies

■ Educational accommodations

- Modified work, home instruction, 504, IEP, liaison in school, extended time, scribe, test in separate location, remote option

■ Coping strategies

- Distractions, fidgets, Chew gum, breaks, stress ball, environmental adjustments

■ Helpful activities

- Sports, music, art, yoga, mindfulness, socializing, nature

+ How to Help

Treatment and coping strategies

Take home strategies for addressing FTLBs

- Greatly reduce social media exposure
- Reduce attention for the FTLB/ increase attn for other behaviors
 - Minimize response to it, talking about it
- Reduce general life stress
 - Consider course load/activities/exercise
- Increase stress reducing activities
 - Downtime, exercise, things they enjoy
- Work to get back to normal routines
 - School in-person, less time with parents, socializing, less Dr appt
- Reduce parental/family accommodation of behaviors

+ How to Help

Treatment and coping strategies

■ Roles for different stakeholders

■ Individuals w/FTLB:

Stay positive, work on motivation

■ Parents:

Find providers, reduce stress, minimize attention, stay calm in front of child/teen

■ Clinicians:

Communicate with each other

■ Schools:

Flexible, understanding, accommodating

+ Resources

■ If interested in finding referrals:

- In New Jersey
 - Contact NJCTS.org
- Nationally the Tourette Association of America
 - Has listings of trained CBIT certified providers

■ Online CBIT training:

tichelper.org

■ TAA information on FTLB

<https://tourette.org/rising-incidence-of-functional-tic-like-behaviors/>

■ TAA webinar on TikTok and tics

<https://www.youtube.com/watch?v=aI48hD6ESOA>

+ Resources

Websites for FND

■ Neurokid.co.uk

■ My FND help app

■ FND guide website

https://www.neurosymptoms.org/en_GB/

■ Stanford FND website https://med.stanford.edu/psychiatry/patient_care/fnd.html

<https://fndhope.org/about-fnd-hope/fnd-hope-au/>

+ Questions

■ Questions? Thank you

■ Contact information

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■ In person or virtual

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