A Call for Caution: "Stop That" Sentiments Threaten Tic Research, Healthcare, and Advocacy

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Recent reports from Tourette Syndrome (TS) clinical researchers in North America and Europe[1,2] describe a recent increase in young patients presenting to TS clinics. Reported commonalities in clinical presentation include a female preponderance, older age of first detected symptoms, complex behaviors (e.g., phrases, coprolalia, long/sequenced movements), significant functional impairment, and similarities to behaviors recorded in videos on social media platforms, notably TikTok. This has raised important questions about etiology and how to best diagnose and treat these individuals. In their recent *Brain* paper, Müller-Vahl, Pisarenko, Jakubovski, and Fremer[3] postulated that this phenomenon is a "Mass Sociogenic Illness." The function of this assertion could be to caution clinicians and patients against using interventions contraindicated for those with functional movement disorder (FMD). However, this postulate does not follow neatly from the current state of the evidence, and the rhetorical language used risks negatively impacting patients by implying that these symptoms are "attention seeking" behaviors. In this response, written by a group of TS researchers, clinicians, and individuals with tics, we detail concerns with the paper.

First, Müller-Vahl and colleagues'[3] argument raises several scientific concerns. A preponderance of claims are made without supporting evidence that presumably should be available (e.g., rates of phenomena observed before and during the pandemic). The claims that "most individuals [on social media who experience tics] have functional symptoms only resembling TS" and that "experts can easily tell the difference [between TS and Functional Movement Disorder (FMD)]" are substantiated with citations to non-data-based commentary and newspaper interviews rather than empirical studies.

One key assertion by the authors is that "functional tics" clearly differ from TS tics. The risk in claiming there is a clear categorical distinction between these types of movements is that patients who do not have "modal TS presentations" will be erroneously categorized as "not TS." Literature on differential diagnosis of TS vs. FMD emphasizes that clinical distinction is prone to error due to symptom overlap and common coexistence of both types of movement within individuals, such that these conditions are not orthogonal.[4] Indeed, at least some of these patients have a confirmed prior history of tics.[2] Contemporary models of neuropsychiatric phenomena based on neuroscience principles also caution against the limitations of blunt categorization, given that observable behavior is driven by a number of dimensional systems (e.g., cognitive, sensorimotor, perceptual) that are influenced by dimensional contexts (e.g., genetic, biological, neurodevelopmental, environmental, social). It is therefore prudent to view these patients as a heterogeneous group. Finally, many

characteristics cited as evidence of "functional presentation" are also known characteristics of TS tics, such as wide topographical variation, high susceptibility to echoing/mimicking and the influence of feedback, contextual variability, stress and observational reactivity, significant co-occurrence with psychiatric illness, and variable tic suppressibility and premonitory urge experience across individuals.

Gender distribution of patients, particularly higher female prevalence than is expected given the observed male preponderance of TS, has been cited here and elsewhere[2] as further evidence of functional tics. We are concerned about the implication that greater female preponderance is in itself indicative of functional tics, a conclusion that echoes historical patterns of neurological illness in females being readily attributed to "hysteria." The risks of this framing are that it may introduce (or reinforce existing) gender-related biases toward female patients and deter research on sex and gender differences in TS. Research on other neurodevelopmental disorders, such as ADHD and autism, shows that sex and gender differences in symptoms have resulted in under- or misdiagnosis in females. It is possible a similar effect plays a role in our current understanding of TS--because TS research is based on predominantly male samples, the presumed "classic presentation" may be biased toward describing male traits. Evidence shows that TS tics in females are more likely to be complex, onset at an older age, carry greater functional impact, and worsen with age, and that females with TS are more likely to have co-occurring mood and anxiety disorders,[5] all traits that have been invoked to support an FMD diagnosis in recent papers.

The paper implies that symptom course is a distinguishing feature for FMD, yet TS symptom course is highly variable. Tic onset can occur in adolescence. Early tics, particularly simple tics, can go unnoticed or be attributed to other causes (e.g., attributing throat clearing to allergies), making it difficult to draw conclusions about age of onset and individual or family history. There is often a discrepancy between patient-reported and direct observation of tics, especially for milder symptoms. Thus, there is a strong possibility that patients with positive tic history are being undercounted in reports like the Müller-Vahl et al.[3] paper. Finally, the "waxing and waning" pattern of tic severity, noted to be indicative of TS, has only been evaluated in one study on the scale of seconds to minutes.[6] Though considered a "clinical truth," there is no evidence to suggest that a certain degree of waxing/waning distinguishes tics from other movements.

The Müller-Vahl et al.[3] paper postulates a causal mechanism for which there is no supporting data: "It can be assumed this is triggered by eco-anxiety, COVID-19 pandemic, and further challenges in post-modern society." Correlational evidence of a link between eco-anxiety and/or pandemic-related distress and onset of tic-like movements is not presented, and key constructs (e.g., "postmodern society") are not operationally defined in a way that enables systematic investigation. Even if such relationships were present, correlation would not itself imply causality. It is critical to not assume a causal link based on conjecture alone--this risks the creation of unfalsifiable "just-so" stories that impede scientific progress.

Second, it is clear that Müller-Vahl et al.[3] were concerned about patients being inaccurately diagnosed. However, in discussing social media advocates and individuals with TS, FMD, and other neurological and psychiatric illnesses, the paper uses rhetorical strategies that raise ethical concerns and risk reinforcing societal stigma toward such individuals. The provocative paper title and abstract may amplify a position that neuropsychiatric symptoms are malingered, voluntary, and/or "attention-seeking" behaviors, an existing societal perspective that TS and mental health advocates have worked hard to counteract. The authors name and diagnose social media TS and disability advocates, which conflicts with the ethical standard that psychiatrists refrain from offering a professional opinion without examination and proper authorization to make a statement. Language used to describe complex symptoms (e.g., "bizarre") that can and do occur in TS risks reinforcing stigmatizing interpretations of TS and FMD symptoms that already exist in our society.

Third, the authors caution against the potential harms of social media. However, by focusing only on potential harms, the possible benefits of technology, youth culture, and modern forms of disability advocacy are ignored. Negative portrayals of TikTok and other platforms in this and other recent, similar papers does not come as a surprise: panic about the impact of new technologies upon youth mental health has a "Sisyphean cycle" throughout history.[7] While some uses can be harmful, social media can be harnessed to improve physical and mental well-being, disseminate legitimate medical information, and deliver interventions.[8] Social media also provides interpersonal connection and support, which does not happen often in the offline world for something with a low base-rate like TS. Research shows online TS communities confer increased psychological well-being and acceptance and decreased isolation.[9] Suggesting patients simply abstain from social media as the best approach overlooks the ways social media is embedded in our lives and the desire of the TS community to feel connected, empowered, and heard. Unfortunately, the Müller-Vahl et al. article[3] risks

promoting a simplified story that appeals to generational concerns to gate-keep traditional conceptions of TS. As these technologies are here to stay, researchers should instead see the complexity of this new phenomenon as an opportunity to empirically investigate the complex relationships between relevant factors, including the brain, behavior, development, motor control, social learning, and the realities of living with tics. It will also behove TS and FMD research communities to systematically study the individual and contextual factors that contribute to healthy social media use and how these mediums can be harnessed to improve the well-being of this population.[8]

Fourth, the paper provides limited tangible guidance for clinicians and patients. The authors say, "only correct diagnosis enables appropriate treatment"[3] yet their title suggests that the only viable intervention is to "Stop That!" We agree that indicated treatments should differ based on etiological and/or maintenance factors driving tic-like movements. However, telling individuals their diagnosis, to discontinue social media use, and to voluntarily control involuntary movements is unlikely to be therapeutic. Notably, cognitive behavioral therapy (CBT) is the gold-standard treatment framework for TS and functional disorders, such that distinguishing between tics and functional tics may not be very consequential in clinical practice involving non-drug treatment.

We urge caution in how researchers and clinicians communicate about this phenomenon. Unlike the pre-Internet era, when publications were not so easily shared, the interface between academic outputs and the public is more fluid today. The open-access status of the Müller-Vahl et al. paper[3] has contributed to versions of this message "going viral" and is a troubling example of how open science (and subsequent popular media coverage) can be misused to promote narratives that are not firmly grounded in empirical evidence and are potentially detrimental to patients. For example, our observation is that many individuals on social media are experiencing negative scrutiny (referred to as "fake shaming") since publication of this paper.

Finally, we advocate for a person-centered approach in future research. The voices of people with TS and FMD, and their perspectives on online content, are typically omitted in these academic discussions. Gate-keeping a "pure" representation of TS commensurate with current clinical practice is at odds with scientific progress, which entails challenging and growing the existing knowledge base. We can create genuine opportunities to learn from the expertise of lived experience and engage with individuals who are underrepresented in existing

research, which will enrich our understanding of heterogeneity within TS and related movement disorders, and how best to support patients seeking help. A similar evolution in autism enabled researchers to develop theories that are better aligned with cognitive science and that resonate with autistic lived experience.[10] A key aspect of this work was empirical investigation of sex and gender differences in autistic presentation. Studying TS through a neurodiversity lens may contribute to the stated goal of many social media channels in question: accepting Tourettic difference and focusing on alleviating aspects of stigma and impairment that directly impact quality of life rather than focusing solely on tics.

Irrespective of giving TS or FMD labels for the phenomenon, there is no question that patients presenting for care are experiencing distress and are deserving of evidence-based and ethically-guided support. We urge caution in coming to quick conclusions about this complex phenomenon, and we call on scientists and individuals with lived experience to create generative relationships to develop research and care approaches that accommodate the evolving societal configurations in which patients live. We believe such an approach will ultimately lead to better understanding, care, and advocacy for individuals experiencing neurological and psychiatric disabilities.

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