




Reply: A call for caution: ‘stop that’ sentiments threaten tic research, healthcare and advocacy progress

 Kirsten R. Müller-Vahl, Anna Pisarenko, Ewgeni Jakubovski and Carolin Framer

Department of Psychiatry, Socialpsychiatry and Psychotherapy, Hannover Medical School, Hannover, Germany

Correspondence to: Prof. Dr. Kirsten R Müller-Vahl
Department of Psychiatry, Social Psychiatry and Psychotherapy
Hannover Medical School
Carl-Neuberg-Str. 1
D-30625 Hannover, Germany
E-mail: mueller-vahl.kirsten@mh-hannover.de

We appreciate the comments submitted in response to our recent article describing—in line with reports from other groups of expert clinicians from Canada, USA, UK, and Germany^{1–7}—a presentation of functional ‘tic-’ and ‘Tourette-like’ behaviour.⁸ There is general agreement among leading Tourette experts that these symptoms represent a phenotype of a functional movement disorder (FMD). Remarkably, this kind of FMD phenotype has never been described before, though functional tics are a well-known, albeit rare presentation of FMD.⁹

Similar to others,^{1–7} we point out that functional ‘Tourette-like’ behaviour can be differentiated from tics based on several clinical characteristics including relatively rapid onset of mainly complex and progressively increasing vocalizations and movements in adolescence.

While several authors speculated that change in FMD phenotype might be related to the COVID-19 pandemic,^{1,4–6} others also suggested an influence by social media.^{2,7} Based on a thorough examination of patients presenting in our specialized Tourette outpatient clinic and after rigorous evaluation of ‘Tourette syndrome’-related videos on social media, we identified a remarkable overlap between symptoms presented by our patients and the German influencer Jan Zimmermann on his YouTube channel ‘Gewitter im Kopf’ (‘Thunderstorm in the brain’). Even more: symptoms started only after the channel was launched and patients confirmed having watched these videos before symptom onset. Thus, we believe that the onset of this new ‘Tourette-like’ FMD presentation can be best explained as an outbreak of the motor variant of mass sociogenic illness (MSI).¹⁰ Since symptoms spread solely via social media, we suggested the more specific term ‘mass social media-induced illness’ (MSMI).⁸

Conelea *et al.* (doi:10.1093/brain/awac028) argue that making a diagnosis based on videos ‘conflicts with the ethical standard that psychiatrists refrain from offering a professional opinion without examination’. With respect to psychiatric diagnoses, in general, we agree with this statement. However, making the diagnosis of

movement disorders—including FMD¹¹—based on videos has a long tradition.^{12–15} In addition, there is a large agreement among Tourette experts that most symptoms presented by Jan Zimmermann on his YouTube channel—but also of several other influencers on social media—represent a manifestation of FMD instead of Tourette syndrome.^{16,17}

We believe that functional ‘Tourette-like’ behaviour can—and should—be differentiated from tics in Tourette syndrome at least in order to enable correct—and avoid inappropriate—treatment. In contrast, Conelea *et al.* argue that Tourette syndrome and FMD represent different parts of a spectrum of one and the same disease, with functional ‘Tourette-like’ behaviour being not a ‘modal Tourette syndrome presentation’. Accordingly, they suggest not to view Tourette syndrome and functional ‘Tourette-like’ behaviour as a ‘heterogeneous group’. This opinion is in clear contrast to recently published articles^{1–7} on functional ‘Tourette-like’ behaviour and experts’ statements, e.g., from the Tourette Association of America (TAA),¹⁸ the European Society for the study of Tourette syndrome (ESSTS),¹⁹ and the University of Calgary.²⁰ Conelea *et al.*’s position is also contrary to ICD (F95.2: Tourette syndrome, but F44.4: FMD) and DSM (Tourette syndrome: 307.23, but functional neurological disorder including FMD: 300.11) classifications, where tic and functional disorders are classified in different categories. Conelea *et al.*’s argumentation creates the impression that some patients with FMD may prefer and desire the diagnosis of Tourette syndrome instead.

Following Conelea *et al.*’s line of reasoning making diagnoses based on similarities in clinical presentations instead of underlying pathology, one would also have to diagnose patients with so called psychogenic non-epileptic seizures (PNES) as having epilepsy. The argument that both types of movements, tics and FMD, may occur within individuals does not constitute a valid argument against such a ‘categorical distinction’. About 30% of patients with epilepsy suffer in addition from PNES. Similarly, we made the additional diagnosis of Tourette syndrome in 47% of our patients with functional ‘Tourette-like’ behaviour (unpublished data). However, we agree

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with Conelea et al. that differentiating functional ‘Tourette-like’ behaviour from tics in Tourette syndrome may be challenging—at least for those unexperienced in care of patients with tics.

With respect to gender distribution, we did not at all make the claim that female preponderance is ‘in itself indicative of functional tics’. Instead we descriptively present data and demonstrate a larger proportion of females among patients with functional ‘Tourette-like’ behaviour compared to the well-known male-to-female ratio of 3–4:1 in Tourette syndrome.²¹ While in FMD—at least in younger patients—a female predominance is well documented,²² underlying mechanisms are unclear and both biological as well as sociocultural factors have been discussed.²³ We cannot see in the least that our article ‘echoes historical pattern..... attributed to hysteria’ by simply describing clinical characteristics. So far, we analysed data of 32 patients with functional ‘Tourette-like’ behaviour and—in contrast to recent publications reporting a sex ratio of about 9:1 (female: male)^{1,4,7}—we found an equal distribution with no clinical differences in functional ‘Tourette-like’ behaviour between females and males (unpublished data). Therefore, we disagree with Conelea et al.’s opinion that functional ‘Tourette-like’ behaviour represents the ‘female presentation’ of Tourette syndrome, while all the literature describes a presentation biased towards ‘male traits’.

It is correct saying that the course of tics in Tourette syndrome is ‘highly variable’. However, there is broad expert consensus that waxing and waning represents a hallmark of tics.²¹ In contrast, these typical spontaneous fluctuations are missing in patients with functional ‘Tourette-like’ behaviour and instead symptoms show a course with long periods of progression, often associated with the development of hundreds of different vocalizations within few months, sometimes followed by periods of complete remission (unpublished data). In other words, although both functional ‘Tourette-like’ behaviour and tics in Tourette syndrome typically change over time, several clear differences are obvious. In addition, we noticed very different environmental factors influencing the expression of functional ‘Tourette-like’ behaviour compared to tics in Tourette syndrome (unpublished data).

Conelea et al. imply that we would classify functional ‘Tourette-like’ behaviour as ‘malingered’ and ‘voluntary’ symptoms. It is true, however, that in our article, we do not say a single word about the underlying pathology of functional ‘Tourette-like’ behaviour. We would like to emphasize very clearly that we do not share the view that FMD are malingered. By using the term ‘attention-seeking behaviour’ we refer to a terminology introduced by Franck²⁴ arguing that ‘receiving attention means to play a role in the consciousness of another person’.²⁵ In FMD, attention plays a crucial role²⁶ in the way that attention to symptoms increases, while distraction decreases them.²⁷ In 97% of our patients with functional ‘Tourette-like’ behaviour, we identified maintaining factors including increased (loving and caring) attention from parents, partners, and friends at home and school, but also on social media (unpublished data). In order to achieve remission, not only early diagnosis is pivotal,²⁸ but also identification of maintaining—as well as triggering—factors.

We also disagree with the opinion of Conelea et al. that use of the term ‘bizarre’ reinforce stigmatization. According to the Association for Methodology and Documentation in Psychiatry (AMDP) System,²⁹ the adjective ‘bizarre’ is a neutral term describing a behaviour that is out of the ordinary or far from normal and thus in itself does not imply any stigmatization.

We agree that the chosen title of our article⁸ starting with the phrase ‘Stop that!’ is somewhat provocative. However, Conelea et al. seem to deliberately misunderstand it, since obviously we do not suggest to treat tics in patients with Tourette syndrome by

saying ‘Stop that’. When reading the article, it becomes unmistakably clear that the term ‘Stop that!’, refers to clinicians to ‘stop’ making incorrect diagnoses of Tourette syndrome and to explain to patients with FMD that symptoms may completely remit (‘stop’).

Furthermore, Conelea et al. accuse us of neglecting positive aspects of social media on patients’ well-being. However, it is obviously far beyond the scope of our article to give a comprehensive overview of the impact of social media. Within our article⁸ there is no statement given arguing against potential beneficial aspects of social media.

Conelea et al. state that ‘the Müller-Vahl et al. paper [...] 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.’ Leading experts worldwide agree that ongoing discussion on the topic of functional ‘Tourette-like’ behaviour—partly also induced by our article⁸—was already and is still helpful for probably thousands of patients, who meanwhile completely remitted from FMD after the correct diagnosis had been made. This includes also the Danish lady Stine Sara, one of the most influential influencers in Denmark, who claimed for months on social media channels to be suffering from Tourette syndrome, while well-known Tourette experts classified her symptoms as functional.³⁰ Remarkably, only recently, Stine Sara herself informed the public that overnight all her symptoms completely ceased.³¹

Worth mentioning, already in 2019, German Tourette advocacy groups spoke out against the social media channel ‘Gewitter im Kopf’—which Conelea et al. described as being helpful for patients with Tourette syndrome—because they found the contents to not only be misleading and incorrect, but also to increase stigmatization and marginalization of people with tics and Tourette syndrome.³²

Data availability

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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Deutschland GmbH, Neuraxpharm, Sanity Group, Stadapharm GmbH, Synendos Therapeutics AG, Syqe Medical Ltd., Therapix Biosciences Ltd., Tilray, von Mende Marketing GmbH, Wayland Group, and Zambon. She has received speaker's fees from Aphria Deutschland GmbH, Almirall, Camurus, Cogitando GmbH, Emalex, Eurox Deutschland GmbH, Ever pharma GmbH, Meinhardt Congress GmbH, PR Berater, Spectrum Therapeutics GmbH, Takeda GmbH, Tilray, and Wayland Group. She has received royalties from Deutsches Ärzteblatt, Der Neurologie und Psychiater, Elsevier, Medizinisch Wissenschaftliche Verlagsgesellschaft Berlin, and Kohlhammer. She served as a guest editor for *Frontiers in Neurology* on the research topic 'The neurobiology and genetics of Gilles de la Tourette syndrome: new avenues through large-scale collaborative projects', is an associate editor for 'Cannabis and Cannabinoid Research' and an Editorial Board Member of 'Medical Cannabis and Cannabinoids' und 'MDPI-Reports' and a Scientific board member for 'Zeitschrift für Allgemeinmedizin'. A.P., E.J., and C.F. report no competing interests.

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