UPDATE

Stop that! It’s not Tourette’s but a new type of mass sociogenic illness

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Abstract

We report the first outbreak of a new type of mass sociogenic illness (MSI) that in contrast to all previously reported episodes is spread solely via social media. Accordingly, we suggest the more specific term “mass social media-induced illness” (MSMI).

In Germany, current outbreak of MSMI is initiated by a “virtual” index case, who is the second most successful YouTube creator in Germany and enjoys enormous popularity among young people. Affected teenagers present with similar or identical functional “Tourette-like” behaviours, which can be clearly differentiated from tics in Tourette syndrome.

Functional “Tourette-like” symptoms can be regarded as the “modern” form of the well-known motor variant of MSI. Moreover, they can be viewed as the 21st century expression of a culture-bound stress reaction of our post-modern society emphasizing the uniqueness of individuals and valuing their alleged exceptionality, thus promoting attention-seeking behaviours and aggravating the permanent identity crisis of modern man. We wish to raise awareness of the current global “Tourette-like” MSMI outbreak. A large number of young people across different countries are affected, with considerable impact on health care systems and society as a whole, since spread via social media is no longer restricted to specific locations such as local communities or school environments. Spread via social media is no longer restricted to specific locations such as schools or towns.

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Abbreviations:
ESSTS = European Society for the Study of Tourette Syndrome
FMD = functional movement disorder
IVTS e.V. = InteressenVerband Tic & Tourette Syndrom
MPI = mass psychogenic illness
MSI = mass sociogenic illness
MSMI = mass social media-induced illness
NOSI = non-obscene socially inappropriate behaviours
TGD e.V. = Tourette Gesellschaft Deutschland


Introduction

In several countries, currently we are facing a new type of mass sociogenic illness (MSI) (also known as “mass psychogenic illness” (MPI)) that in contrast to all previously reported episodes of MSI is spread solely via social media and hence is not locally restricted. So far, no such social media induced episodes have been described, although already in 2012, it has been speculated that MSI may not require in any case direct visual or verbal contact among the persons affected.\(^1\) For this new type of MSI, we therefore suggest the more specific term “mass social media-induced illness” (MSMI). Hereby, we want to raise awareness of its global occurrence, since only correct diagnosis enables appropriate treatment and termination of symptoms.\(^2\) Moreover, MSI outbreaks are socially and economically costly\(^3\), independently how they spread.

Prerequisites enabling current outbreak of social media-induced illness (MSMI)

Since recently, in several countries including Germany, UK\(^4\), US\(^5\), Denmark, France, and Canada (personal communication), an increasing number of videos was released on social media platforms such as YouTube, TikTok, and Instagram showing people, who claim suffering from Tourette syndrome - a childhood onset chronic combined motor and vocal tic disorder - while in fact most individuals have functional symptoms only resembling Tourette syndrome. On February 21\(^\text{st}\) 2019 – only shortly before the first patient with MSMI presented in our clinic in June 2019 – the German YouTube channel “Gewitter im Kopf” (English: “Thunderstorm in the Brain”) was launched by a 22-year-old man called Jan Zimmermann. Judging from the videos, he indeed suffers from a mild form of Tourette syndrome. On this
YouTube channel, however, he shows a countless number of movements, vocalizations, words, phrases, and bizarre behaviours that he claims are tics, but are clearly functional in nature. Tourette experts can easily tell the difference\(^6,7\), since the majority of supposed “tics” is complex and stereotyped and mimics those symptoms that lay people typically associate with Tourette syndrome: coprolalia, copropraxia, and non-obscene socially inappropriate behaviours (NOSI). For the majority of the shown symptoms, there are obviously strong situational contexts with exclamations of long sentences with insults, swear words, and obscenities that are in this form unknown in Tourette syndrome. Furthermore, the number of symptoms and in particular the number of different swear words and insults presented is countless and thus far beyond that of tics in Tourette syndrome. Finally, presented symptoms quickly change nearly on a weekly basis in parallel to newly released videos, while “most popular” symptoms are repeated several times.

Soon after it was started, the YouTube channel “Gewitter im Kopf” was rapidly spread on social media and reached 1 million subscribers in less than 3 months making Jan Zimmermann the top YouTube breakout creator in Germany in 2019. He earned further attention from the YouTube and Internet community by participating in other popular YouTube channels and TV shows, through posts of these shows on YouTube and reaction videos from the highest-earning influencers in Germany Unge and MontanaBlack, and by receiving special TubeAwards. Today, Jan Zimmermann is the second most successful YouTube creator in Germany and enjoys enormous popularity among teenagers (status on July 19\(^{th}\), 2021): “Gewitter im Kopf” is subscribed by 2.23 million people and 296 videos have been released that were in total viewed 301,440,636 times.\(^8\) Meanwhile, the channel is accompanied by a merchandising campaign and most popular exclamations are reproduced on products such as shirts and caps.\(^9\) Finally, a mobile App has been released including the most popular supposedly “vocal tics”.\(^10\)

Already on June 4\(^{th}\) 2019, the two most relevant German advocacy groups (Tourette
Gesellschaft Deutschland (TGD e.V.) and InteressenVerband Tic & Tourette Syndrom (IVTS e. V.)) distanced themselves from the YouTube channel\textsuperscript{11} and later on from the App\textsuperscript{12}, because of their obvious misrepresentations and disrespect to people with Tourette syndrome.

**Affected teenagers of MSMI present with functional “Tourette-like” symptoms**

Over the last two years, a remarkably high number of young patients has been referred to our specialised Tourette outpatient clinic presenting with symptoms closely resembling the ones Jan Zimmermann shows in his videos. All these patients had been pre-diagnosed with Tourette syndrome, partly even as treatment-resistant Tourette syndrome after having received pharmacotherapy with different drugs including antipsychotics. Remarkably, in none of these cases, neither the correct diagnosis of functional (“Tourette-like”) movement disorder (FMD) had been made, nor the interrelation with and influence by social media had been recognised. Although a detailed description of clinical characteristics is beyond the scope of this paper and is currently in preparation for publication elsewhere, here we want to briefly summarize, how in this group of patients diagnoses of “Tourette-like” FMD were confirmed. Firstly, all patients presented with nearly identical movements and vocalizations that not only resemble Jan Zimmermann’s symptoms, but partly are exactly the same such as shouting the German words “Pommes” (English: fries), “Bombe” (English: bomb), “Heil Hitler”, “Du bist häßlich” (English: you are ugly), and “Fliegende Haie” (English: flying sharks) as well as bizarre and complex behaviours such as throwing pens at school and dishes at home, and crushing eggs in the kitchen. Even more, similar to Jan Zimmermann, words and phrases are pronounced with changed voice in low pitch so that family members are able to differentiate normal conversation from supposedly “vocal tics” solely based on the tone of voice. Secondly, a substantial number of patients gave their supposed “Tourette syndrome” a name just as Jan Zimmermann does,
who calls his symptoms “Gisela”. Thirdly, patients often reported to be unable to perform unpleasable tasks because of their symptoms resulting in release from obligations at school and home, while symptoms temporarily completely remit while conducting favourite activities. Fourthly, in some patients, a rapid and complete remission occurred after exclusion of the diagnosis of Tourette syndrome.

Although some patients indeed suffered in addition from mild Tourette syndrome, for all newly emerged symptoms, it could be clearly ruled out that they were tics for several reasons: (i) onset was abrupt instead of slow, (ii) symptoms constantly deteriorated instead of typical waxing and waning of tics, (iii) “simple” movements (e.g. eye blinking) and noises (e.g. clearing one’s throat) were clearly in the background or completely absent, although being the most common and typical symptoms in Tourette syndrome, (iv) movements were mainly complex and stereotyped and predominantly located at arms and body, instead of at eyes and face, (v) overall, the number of different movements, noises, and words was “countless” and far beyond the typical number of tics in Tourette syndrome, and (vi) premonitory feelings were reported with atypical location, quality, and duration compared to tics in Tourette syndrome. Thus, worsening of pre-existing Tourette syndrome, for example due to COVID-19 pandemic as suggested elsewhere\textsuperscript{4,5}, can be clearly ruled out in our patients.

**MSMI is initiated by “virtual” index cases**

In general, an index case is necessary for the initiation of an MSI outbreak.\textsuperscript{3,13} In current MSMI outbreak in Germany, Jan Zimmermann can be regarded as a “virtual” index case. Meanwhile, more and more people with “Tourette-like” FMD – including some of our patients - appear on German internet and TV. Thus, spread via social media seems to induce “secondary virtual” index cases resulting in further spread without local restrictions. Because of the extremely high degree of recognition of these videos among young people, we assume that spread is also
possible simply by verbal communication. Interestingly, at the same time in other countries similar channels launched on YouTube and TikTok so that these influencers may act as further “virtual” index cases (personal communication). Based on the already initiated exchange among international Tourette experts, it seems that patients identified in Germany exhibit some differences compared to cases seen in other countries such as Canada (personal communication). While it appears that age at onset is very similar in different countries with a preponderance of adolescents and young adults, gender distribution seems to be different: while half of our patients are male, the group of Davide Martino and Tamara Pringsheim at the University of Calgary in Canada reports a female to male ratio of about 9:1. This difference might be related to the different gender of most influential “virtual” index cases in Germany compared to Canada. While we were able to clearly identify the German speaking man Jan Zimmermann as a “virtual” index case, in contrast, in Canada, tic-like symptoms in young patients seem to be mainly triggered by the presentation of such behaviours by the English speaking 20-year-old female Evie Meg or better known under her TikTok name “thistrippyhippie”.

**Justification of the concept of MSMI**

In 2012, Bartholomew et al.\(^1\) already stated: “It is unclear if MPI could spread solely via social media among people with no other pre-existing connection.” Besides spread through personal sight and sound, for current MSMI outbreak, all criteria for “classical” MSI are fulfilled meaning “a constellation of symptoms suggestive of organic illness, but without an identifiable cause, that occurs between two or more people who share beliefs related to those symptoms”.\(^3\) While our patients did not have *direct* personal contact neither to Jan Zimmermann, nor among each other, they got into *indirect* contact to Jan Zimmermann in the form of strong identification. Patients reported admiring Jan Zimmermann for his open approach to the
supposed “Tourette syndrome” and for being successful despite his condition, which causes strong emotions and hence further triggers contagion.\textsuperscript{14} Thus, current outbreak of “Tourette-like” symptoms can be regarded as a new variant of MSI, where social media serve as an “extension of our eyes and ears”\textsuperscript{1} and replace the necessity of being in \textit{direct} visual or verbal contact with others for spread. Besides general replacement of face-to-face communication by use of social media tools\textsuperscript{1}, increased use of social media during COVID-19 related lockdown and quarantine might be a reinforcing factor.\textsuperscript{15,16}

We do not believe that our patients should be simply diagnosed as “Tourette-like” FMD instead of being affected persons of an MSMI outbreak, since first patients presented in our clinic only four months after launch of the YouTube channel “Gewitter im Kopf” and all patients confirmed having watched these videos before – or in some cases even during - manifestation of similar or identical symptoms. Furthermore, functional movements resembling tics have been described only rarely in a very limited number of case studies.\textsuperscript{17–22} Accordingly, functional “tic-like” movements have been classified as a relatively rare type of FMD that occurs in only about 5\%\textsuperscript{23} and primarily affects adults.\textsuperscript{17} Interestingly, only recently an increase in FMD during COVID-19 pandemic has been reported from a US movement disorder centre with tremor being the most common presentation.\textsuperscript{5} Similar to our cases, however, one teenager developed functional tics after watching another teenager on TikTok apparently presenting with “Tourette syndrome”.

\textbf{“Tourette-like” MSMI episode represents a “modern” form of motor variant of MSI}

MSI is differentiated in two variants: an “anxiety variant” presenting with unspecific symptoms such as abdominal pain, headache, dizziness, fainting, nausea, and hyperventilation triggered
by extreme, sudden stress within a close-knit group, and a “motor variant” with hysterical
dancing, convulsions, laughing, and pseudoseizures.

While the “anxiety variant” was believed to represent the “modern” form of MSI in Western
cultures that is typically triggered by environmental factors with odour as the most common
and typical predictor, the “motor variant” seemed to be a more primitive form that mainly
occurred in the Middle Ages. For example, in 1374 and again in 1518 bizarre outbreaks with
exaggerated movements, known as dancing plagues, have been reported. Interestingly,
outbreaks of the “motor variant” developed in relation to natural disasters and required a
prolonged build-up of psychological tension associated with a mood of catastrophe and
desperation in social groups united by some strong religious belief. Furthermore, long-term
anxiety, uncertainty, and longstanding stress perceived not only as threatening, but also as
inescapable seem to play a major role. In Malaysia in 1978, a motor variant MSI outbreak
among college students was associated with higher education and intense competition for
prestige and leadership, while similar outbreaks in East Africa in 1962-1963 were closely
related to rapid socioeconomic changes. Most of these outbreaks took weeks or months to
subside.

Worth mentioning, in LeRoy, New York, in 2012, a "Tourette's epidemic" occurred in a high
school affecting 19 adolescents with sudden-onset “tic-like behavior”. Speculations about
the cause of this “LeRoy outbreak” as well as intensive media interest initially led to further
increase before symptoms rapidly declined once the diagnosis of MSI was established. Although schools are the most frequent settings for MSI outbreaks, already at that time,
influence by social media had been suggested and the treating neurologist David Lichter
commented: “This mimicry goes on with Facebook or YouTube exposure. This is the modern
way that symptomology could be spread.”
The 21th century motor variant of MSI is triggered by “eco-anxiety” and COVID-19 pandemic

About half of Generation Z feels stressed or anxious with climate change being the top concern. Eco-anxiety is associated not only with fear, panic attacks, feelings of anger, guilt, and helplessness, but also uncontrollability, unpredictability, and uncertainty. COVID-19 pandemic may cause additional increase in anxiety and restrictions because of the lockdowns may result in increased stress due to home schooling, significant changes in families’ living together associated with increased rates of conflicts and domestic violence, lack of communication with friends, reduced or no contact to peer groups, and boredom. Thus, current outbreak of MS1 represents not only the “modern” form of MSI motor variant, but can also be viewed as the 21th century expression of a “culture-bound stress reaction” of our post-modern society emphasizing the uniqueness of individuals and valuing their alleged exceptionality, thus promoting attention-seeking behaviors, and aggravating the permanent identity crisis of modern man. It can be assumed this is triggered by eco-anxiety, COVID-19 pandemic, and further challenges in post-modern society.

Based on recent reports and personal communication with experts in several countries an enormous number of young people affected with “Tourette-like” MS1 can be assumed with considerable impact on health care systems and society as a whole, since spread via social media is no longer restricted to specific locations such as local communities or school environments. Fortunately, first international efforts are already underway to expand our knowledge of this phenomenon such as an experts’ survey initiated by the European Society for the Study of Tourette Syndrome (ESSTS) and an informative website launched by Canadian experts at the University of Calgary. Presumably, different initiatives from different parties in different countries are needed to stop current spread of functional “Tourette-like” behaviours. This may include experts’ interviews in different languages in the media,
education and training of physicians, psychologist, and students on clinical characteristics of
tics and TS compared to functional movement disorders, information via TS advocacy groups,
possibly foundation of new advocacy groups specifically for patients with functional “Tourette-
like” behaviours, and finally, clear concepts to differentiate one from the other.

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AP, EJ, and CF report no competing interests.

Appendix 1

This study has been approved by the local ethics committee at Hanover Medical School, 15.04.2020, no. 8995_BO_S_2020.

References


