Word count: 499 words

3 references

Research letter

Perceived worsening of tics in adult patients with Tourette syndrome after the COVID-19 outbreak

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Running head: COVID-19 and worsening of tics in Tourette syndrome

Keywords: Tic disorders, Tourette syndrome, chronic tic disorder, COVID-19.

Conflicts of interest relating to this work: None.

Funding sources: None.

To our knowledge, there are no data on the perceived impact of the COVID-19 outbreak on tic severity in persons with Tourette syndrome (TS) or chronic tic disorder (CTD), although experts have warned of a potential exacerbation of symptoms.¹ As part of an ongoing global survey of driving experiences amongst adults with TS/CTD, we included the question: *Do you feel that your tics have worsened since the start of the coronavirus pandemic (since February-March 2020)?* Responses were recorded on a 5-point likert scale ranging from “My tics have become much worse” to “My tics have become much better.” Participants could expand their answers in an open field. Importantly, they were unaware that they would be asked a question about COVID-19. Data collection took place between April 27th and May 26th 2020.

Participants were 178 adult individuals with a diagnosis of TS/CTD (57% women, 40% men, 2% other/prefer not to say; 44% aged 18-25, 26% aged 26-35, 13% aged 36 to 45, 11% aged 46 to 55, 6% aged ≥ 56). Most participants were located in Europe (58%) or North America (35%). The majority (74%) reported psychiatric comorbidities, including anxiety disorders (43%), obsessive-compulsive disorder (35%), depression (34%), attention-deficit/hyperactivity disorder (33%), and autism spectrum disorders (10%). The mean tic severity, according to the Adult Tic Questionnaire (ATQ),² was 52.81 (SD=32.46; motor tics scale: 34.83, SD=18.14; vocal tics scale: 17.98, SD=16.77).

About half of the participants (48%) experienced that their tics were a little (33%) or much worse (16%) since the outbreak. Analysis of the open field revealed some frequent themes. Perceived tic worsening was associated with: increased stress and anxiety due to worries about finances, future and family, confinement and lack of physical exercise/activity, fewer distractions, change or lack of routines, having to go to work, and being exposed to the public. Some individuals reported perceived stigma regarding coughing tics, increased tics due to wearing masks, and an increase of self-injurious behaviours.

Another 44% of the participants reported that their tics remained unchanged. The remaining reported their tics to be a little (6%) or much better (2%). These individuals reported that working from home and limiting social contact resulted in reduced stress and tic severity.

Follow-up analyses explored whether perceived worsening of tics was associated with sociodemographic and clinical variables. Compared to participants whose tics remained unchanged or improved, participants experiencing a worsening of symptoms were more likely to be younger (Chi-square=14.08, $p=0.007$, with significant pairwise differences for the group aged 18 to 25 vs. older groups) and have more severe tics (ATQ mean difference: -12.07, $t=-2.52$, $p=0.013$; motor scale: -6.80, $t=-2.54$, $p=0.012$; vocal scale: -5.26, $t=-2.11$, $p=0.036$). Psychiatric comorbidities or deaths per capita attributed to COVID-19 in the country of origin were not associated with a perceived worsening of tics.

Despite the limitations of the subjective reporting of tic severity,³ a substantial proportion of patients with TS/CTD have perceived a worsening of their tics since the outbreak of the pandemic. These individuals may need additional support during these challenging times.

Ethical Compliance Statement

The authors confirm that the approval of the Swedish Ethics Review authority was not required for this work because participation in the survey is anonymous and no personal data is stored. Informed consent was therefore not needed but participants were asked to confirm that they were over 18 and that they understood that their anonymous data would be used for research purposes. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Authors' roles

Dr Mataix-Cols, Ms Ringberg, and Dr Fernández de la Cruz conceived and designed the survey. Ms Ringberg programmed the survey questions. Dr Mataix-Cols had full access to all the data and takes responsibility for the integrity of the data and the accuracy of the data analysis. Drs Mataix-Cols and Fernández de la Cruz drafted the paper. Ms Ringberg provided critical comments and edited the manuscript.

Financial disclosures

David Mataix-Cols receives royalties for contributing articles to UpToDate, Wolters Kluwer Health and for editorial work from Elsevier, all outside the submitted work.

Lorena Fernández de la Cruz receives royalties for contributing articles to UpToDate, Wolters Kluwer Health, outside the submitted work. Ms Ringberg reports no potential conflicts of interest.

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