Impact of Disrupted Botulinum Toxin Therapy in Movement Disorders Due to COVID-19 Pandemic

Dear Editor,

The COVID-19 pandemic has brought about unprecedented changes to healthcare systems owing to the necessity of resources to be diverted toward tackling the crisis with acute cases being placed in the forefront. Furthermore, several strategies enforced in order to curb the pandemic, which includes restricted movement during the lockdown and restricted access to healthcare, have interrupted the care of patients with chronic illnesses.\textsuperscript{[1,2]} Patients with chronic dystonia and hemifacial spasm (HFS) who receive botulinum toxin-A (BoNT-A) need regular access to consultation and therapy. Delay in scheduled BoNT-A injection, uncertainty regarding the effect of COVID-19 on illness, and concern regarding the safety of injection and medications at this time can result in unwarranted fear, anxiety, and depression, which may further worsen the underlying condition. More importantly, the economic impact of COVID-19 pandemic globally, as well as in developing countries like India, are grave. In this study, we report difficulties and challenges faced by patients with focal dystonia or HFS on regular BoNT-A treatment during the COVID-19 pandemic.

A hundred patients with dystonia or HFS on BoNT-A treatment with at least one dose taken within the last 1 year at the National Institute of Mental Health and Neurosciences, Bengaluru, India, were included in this study. As per hospital policy, directives, and as part of the strengthening of teleneurology services, the patients were contacted telephonically for routine follow-up. Responses regarding new/worsening of symptoms due to disruption of services, financial burden imposed by lockdown, which can affect the treatment and inconvenience faced in the last 3 months following the onset of the COVID-19 pandemic with respect to their illness were analyzed. Descriptive statistical analysis was performed for demographic and clinical features.

The mean age of patients was 47.66 ± 13.32 years with male predominance (59%) [Table 1]. Cervical dystonia (25%), HFS (23%), and blepharospasm (11%) were the common indications. The satisfactory outcome with >50% improvement was observed in 67% after the last injection. Approximately 50% of patients stayed more than 100 km away from the hospital. None of the patients reported any misconceptions pertaining to the safety of BoNT-A during the pandemic.

Worsening of dystonia led to an increase in pain, which was predominantly seen in cervical (31%), oromandibular (20.8%), focal limb dystonia (16.6%) followed by blepharospasm (12.5%). Mild-to-moderate low mood was reported by 27%. New-onset sleep disturbance was present in 25%, of which 20% needed medication (benzodiazepines/sleeping pills/painkillers) in order to sleep. Fourteen percent reported to self-medication or increasing dose of medication. Although 30% tried to contact the treating doctor, only 7% succeeded in doing so. Financial losses and travel restrictions posed a challenge, and 52% anticipated problems in taking the next injection.

Botulinum neurotoxin is currently the treatment of choice for HFS and focal dystonia with minimal or no adverse effects.\textsuperscript{[3]} An increase in dystonic movements, recurrence of pain due to missed doses of botulinum toxin, and stress due to present circumstances resulted in anxiety, low mood, and disturbances in sleep, which can further increase dystonia. Cervical and oromandibular dystonia involve larger muscles and lead to pain\textsuperscript{4} and was poorly tolerated compared to those with HFS. Apart from the lack of access to health care and travel restrictions, financial losses incurred due to the economic impact of the pandemic is an important factor. Several patients were apprehensive about the financial problems they were likely to face, and subsequent inability to afford BoNT-A therapy. An integrated approach to allay anxiety, online

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support, and oral drugs are necessary to control dystonia. Telemedicine will be a gamechanger in assessing the needs of patients with chronic illnesses and will aid in prioritizing treatment. However, in patients on Botulinum toxin therapy by experts, it may be of limited value as a visit to the hospital would be required. To tide over the crisis in patients on botulinum toxin therapy, patients can be segregated based on their clinical condition. Those with mild symptoms should be reassured with adjustment of oral medications if necessary, and those with severe symptoms should be injected on a priority basis and the hospital visit can be arranged.

Communication is necessary in health care to understand needs and concerns and adjust medications, especially in those with chronic illness. This pandemic has contributed to the accelerated growth of telemedicine, especially in the field of movement disorders, where videos play a key role, and timely teleconsultation could be highly beneficial.

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Conflicts of interest
There are no conflicts of interest.

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