

Impact of Tele-Neuromuscular Clinic on the Accessibility of Care for Patients with Inherited Neuromuscular Disorders during COVID-19 Pandemic in India

Dear Editor,

Worldwide, healthcare systems are dealing with unforeseen challenges associated with the COVID-19 pandemic. A rapid transition to telemedicine became the need of the hour^[1-4] not only to avoid unnecessary exposure both for the patients and healthcare providers^[1] but also in order to provide patient care in the scenario of a complete lockdown. Although

tele-neurology was initially studied for Parkinson's disease two decades ago, it was mainly used for acute stroke management, with wider implementation being very limited.^[3,5,6] Global international agencies have attempted to address this issue but standard management guidelines for South East Asia have not been formulated as yet.^[7] Vishwanathan *et al.*^[7] strategized the management of inflammatory CNS disorders

during this pandemic. We planned to do the same in the field of neuromuscular disorders.

There are very few neuromuscular disorder (NMD) clinics functional presently in India with barriers to their timely diagnosis and management, including disease severity, distance, accessibility, affordability and the challenges of the COVID-19 pandemic.

We aim to describe the process of establishing All India Institute of Medical Sciences- Comprehensive Neuromuscular Disorders Centre (AIIMS-CNMD) Tele-neurology services and also describe the impact of this service on the accessibility of care for patients with Inherited NMD.

The virtual Comprehensive Neuromuscular Disorder Centre (AIIMS-CNMD) was set up in March 2020 by the Department of Neurology, AIIMS New Delhi, a partner centre of the International Centre for Genomic Medicine in Neuromuscular Diseases (ICGNMD). We were also one of the initial departments at AIIMS to start Tele-consultation services from March 28, 2020, at the beginning of the COVID-19 pandemic. ICGNMD Faculty fellow managed most of the inherited NMD patients via telephone-based services. Due to the limitations of telephone-based services, AIIMS CNMD started using an Open video platform (Jitsimeet), whose data server is located at AIIMS New Delhi. Patients were informed through NGOs, AIIMS OPD, social media (official twitter handle of AIIMS Neurology and AIIMS CNMD) and inter-patient communication about these services. An appointment was given via a dedicated email (aiimscnmd@gmail.com), telephone and WhatsApp numbers resulting in easy and transparent communication. Telemedicine Practice Guidelines' issued by Board of Governors, in supersession of the Medical Council of India were followed. Documentation during first visit and follow up was done as is done in a physical OPD. We have a neuromuscular proforma for data management which is collected in hardcopy and online using Redcap services. The coordinator makes a record of whole procedure including consent process at the beginning of interview and completing the proforma.

Between August to December 2020, we received 322 emails requesting teleconsultation, of which we gave an appointment to 287. Others did not receive appointment due to lack of minimum demographic information required to make an appointment. Out of these, 182 teleconsultations were successfully conducted, whereas 100 did not respond and five were incomplete. The mean duration of teleconsultation was approximately 33 minutes, with limb-girdle muscular dystrophy (LGMD) being the commonest diagnosis. Details of teleconsultation in inherited NMDs are mentioned in Table 1. Figure 1 shows the patient distribution across the country. Successful video consultation was possible at first attempt only in half the appointments. The most common reasons for delay or postponement of teleconsultation were patients defaulting on their appointments (34%)

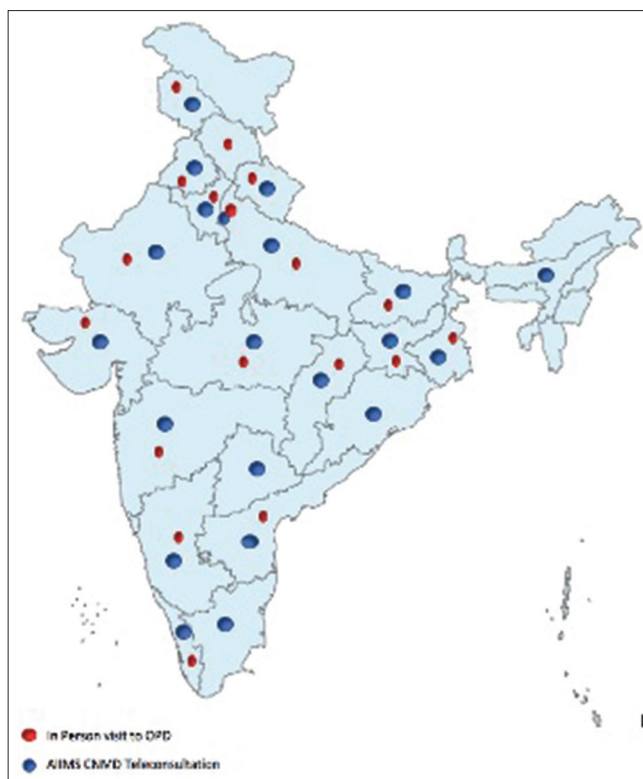


Figure 1: Patient distribution throughout India, the size of the dot indicative of the number of patients from that state

Table 1: Teleconsultation details

Details of Teleconsultation for inherited NMD	Percentage
Diagnosis	
LGMD	50%
DMD/BMD	24%
GNE Myopathy	12%
FSHD	6%
Others	8%
Prior treatment records	86%
Prior genetic testing	58%
Positive family history	46%
Electrophysiology	49%
Echocardiography	30%
Muscle biopsy	68%
CPK	86%
Wheel Chair bound	46%
Successful Video consultation in first attempt	51%
Mean number of messages sent by	
Patients/Relative	15
AIIMS-CNMD co-ordinator	14
Mean number of emails sent by	
Patients/Relative	6
AIIMS-CNMD co-ordinator	5
Mean duration of Video-consultation	33.19 min

and non-familiarity with the platform (33%), followed by poor connectivity (16%) and rescheduling by the neurologist (17%).

The COVID-19 pandemic gave telemedicine a much need push, with many medical societies and insurance companies taking it under its ambit.^[8] It eliminated non-essential face-to-face interactions (thereby limiting COVID-19 spread) and provided more accessible access to medical care, and reduced the burden of transport.^[3] It also helped catering to patients from remote areas. Bare minimum requirements of basic video conferencing of reasonable quality make it highly cost-effective. A gross neurological examination can be done looking for pronator drift, finger tapping, heel and toe walking and getting up from squatting position with crossed arms are surrogates.^[8] The number of registrations in our NMD clinic exceeded expectations and included patients from all across the country. Many patients on wheel chair and poor socio-economic status would never have reached our clinic during the pandemic. AIIMS – CNMD teleneurology services increased accessibility to affordable Neuromuscular expert consultation for many patients with inherited NMD across India. We intend to continue using this platform and created a telemedicine strategy for diagnosis and management of neuromuscular disorders including acquired neuromuscular disorders.

Acknowledgement

VVY is supported by a Medical Research Council strategic award to establish an International Centre for Genomic Medicine in Neuromuscular Diseases (MR/S005021/1).

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Conflicts of interest

There are no conflicts of interest.

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REFERENCES

1. Interim Guidance for Healthcare Facilities: Preparing for Community Transmission of COVID-19 in the United States. 2020. Available from: <https://www.cdc.gov/coronavirus/2019-ncov/healthcare-facilities/guidance-hcf.html>.
2. Cohen JK. New Telemedicine Strategies Help Hospitals Address COVID-19. Available from: <https://www.modernhealthcare.com/patients/new-telemedicine-strategies-help-hospitals-address-covid-19>.
3. Hatcher-Martin JM, Adams JL, Anderson ER, Bove R, Burrus TM, Chehrenama M, *et al.* Telemedicine in neurology: Telemedicine Work Group of the American Academy of Neurology update. *Neurology* 2020;94:30-8.
4. Guidon AC, Amato AA. COVID-19 and neuromuscular disorders. *Neurology* 2020;94:1-11.
5. Awadallah M, Janssen F, Korber B, Breuer L, Scibor M, Handschu R. Telemedicine in general neurology: Interrater reliability of clinical neurological examination via audio-visual Telemedicine. *Eur Neurol* 2018;80:289-94.
6. Hubble JP, Pahwa R, Michalek DK, Thomas C, Koller WC. Interactive video conferencing: A means of providing interim care to Parkinson's disease patients. *Mov Disord* 1993;8:380-2.
7. Vishwanathan S. Management of idiopathic CNS inflammatory diseases during the COVID-19 pandemic: Perspectives and strategies for continuity of care from a South East Asian Center with limited resources. *Mult Scler Relat Disord* 2020;44:102353. doi: 10.1016/j.msard.2020.102353.
8. Roy B, Nowak RJ, Roda R, Khokhar B, Patwa HS, Lloyd T, *et al.* Teleneurology during the COVID-19 pandemic: A step forward in modernizing medical care. *J Neurol Sci* 2020;414:116930. doi: 10.1016/j.jns.2020.116930.

Submitted: 18-Jun-2021 **Revised:** 02-Aug-2021

Accepted: 01-Sep-2021 **Published:** 12-Jan-2022

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DOI: 10.4103/aian.aian_565_21