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# **Epilepsy Research**

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## Letter to the editor

### Infantile spasms and COVID-19: Challenges and solutions in resource-limited settings



Dear Sir,

Infancy constitutes the age group with the highest incidence of epilepsy and infantile spasms (IS) constitute the majority (1). Management of IS during the current ongoing COVID19 pandemic poses a multifaceted challenge. Traditionally, care involves an urgent inpatient evaluation to coordinate video electroencephalogram (EEG) monitoring, imaging, laboratory studies, and initiation of treatment. However, at present every health care visit puts children, their caregivers, and their clinicians at risk for infection particularly related to asymptomatic carriers and airborne transmission (2).

The poorer neurodevelopmental outcome at four years of age in subjects with IS with longer time to spasm cessation reported by the UKISS trial underscores the importance of early treatment of IS (3). Recently, the Child Neurology Society has come up with a crisis standard of care guidelines on IS (4). But this may not be possible to be followed in resource-poor settings where the challenges and their solutions vary. Here we assess the challenges faced and their pragmatic solutions in managing children with IS during this pandemic, in resource-poor settings.

#### Challenges:

- Recognising spasms and availing secondary or tertiary care: Parents
  and occasionally primary care physicians overlook spasms or
  misdiagnose them as normal movements. The further referral is
  hampered by the restrictions in travel as well as fear of exposure to
  the virus.
- 2) EEG: As per ILAE recommendations of 2015, an EEG/video EEG is recommended especially in cases where spasm semiology is not typical(1). Apart from the risk of exposure to both the child and the caretaker, expenditure is also a concern since the private EEG laboratories charge extra for personal protective equipment (PPE) of the technician also.
- 3) Neuroimaging: ILAE provides a level A recommendation for initial neuroimaging, optimally MRI brain. Neuroimaging in infants needs sedation with proper respiratory monitoring which in turn increases the chances of droplet production.
- 4) Initiating therapy: Hormonal therapy remains the first line of choice globally. But India being a country with a high prevalence of tuberculosis, we get a chest X-ray and Mantoux test before initiating hormonal therapy.
- 5) Procuring drugs: Injection Adrenocorticotrophin Hormone (ACTH) being a costly drug, is available only in urban areas and caretakers from rural areas may not be able to procure it. For children with Tuberous Sclerosis (TS), vigabatrin is the first treatment of choice. But currently, the Indian market is experiencing a grave shortage of vigabatrin amid restrictions on international traffic and import(5).

- 6) Monitoring therapy: Repeat EEG recommended after 2 weeks of treatment for deciding about change in therapy is difficult to obtain currently. Monitoring of adverse effects of steroid therapy including blood pressure and blood sugar monitoring also is not feasible for most.
- 7) Rehabilitation: In contrast to the etiology of IS in western countries, perinatal ischemia contributes about 55% of cases in Indian children (6). Naturally, the incidence of cerebral palsy, vision, and hearing impairment are more in this population. Improper follow up for physiotherapy hamper with rehabilitation and may lead to complications.

Telemedicine can be utilised as an alternative to face-to-face consultation in unprecedented crisis periods like this. Multiple studies are being published worldwide reporting the successful implementation of telemedicine in managing adult patients with epilepsy(7,8). Our centre has a 24 × 7 national toll free helpline(1800117776) manned by the specialty nursing staff with the backup of neurology residents and consultants, functioning from 2018. Smartphones also are being utilised for receiving videos and images of concern. A prospective study assessing the effectiveness of telemedicine was conducted in our centre in 2014 among 78 children between 4 months and 7 years of age with West syndrome or Lennox-Gastaut syndrome. Compared to face to face consultation (gold standard) teleconsultation had a sensitivity of 93.94% (85.19-98.29) and specificity of 100% (98.50-100.4) in diagnosis(9). We are currently using this system for IEC (Information, Education, and Communication) and the out-patient management of children with IS as well as other neurological issues.

#### **Solutions:**

- 1 The peculiar features of IS (flexors/extensor/mixed spasms, occurring singly or in cluster, occurring especially on waking up) can be recognised by making videos at home and the same can be analysed by the teleconsultation team. This may also be utilised to detect potential clues towards etiology like ash leaf macules in TS.
- 2 Clinicians may avoid procuring an EEG provided the other clinical features strongly support IS. If in a diagnostic dilemma, an outpatient EEG recording may be obtained after assessing the riskbenefit ratio.
- 3 The neuroimaging can be delayed unless there is a diagnostic dilemma.
- 4 Before starting hormonal therapy history of contact with TB, BCG vaccination status, recent weight loss or failure to gain weight, etc may be asked to ascertain the chances of a coexisting tuberculous infection, if Mantoux test or chest X-ray is not feasible.
- 5 The first-line treatment options in IS are ACTH/Prednisolone/Vigabatrin. For the non-TS group, oral prednisolone is the preferred

treatment as it is inexpensive, readily available, and orally administered and does not require training of parents or caregivers. It can be started at 3 mg/kg/day in 3 divided doses which can be titrated to maximum dose by 7-10 days to 6 mg/kg/day (max60 mg/day) depending on clinical response. If the spasm resolves by 2 weeks, EEG may be done to document hypsarrythmia resolution and gradual taper of prednisolone can be done over 6-8 weeks. In cases where baseline EEG is not available, clinical resolution of spasms and improvement in general activities in the infant may be used as a surrogate marker for the response. If spasms continue even after 2 weeks of maximum dose of steroid, then either ACTH or vigabatrin can be started depending on the availability. For the TS group due to the limited or non-availability of vigabatrin, oral prednisolone can be started as per the above regime. Video link explaining the domiciliary management of other types of seizures in English and the vernacular language Hindi, is provided to parents (http://pedn euroaiims.org/domiciliary-management-of-acute-seizure.html) along with seizure diary and general instructions (http://pedneuro aiims.org/pdf-2020/seizure-diary.pdf).

- 6 Monitoring of blood pressure and blood sugar may be deferred unless there are clinical indications like lethargy or poor feeding. Steroid therapy may further increase the risk of contracting SARS-CoV-2 infection. To prevent the exposure, general hygiene measures and social distancing can be advised. Wearing a mask is not recommended for children less than two years for fear of suffocation. Reverse quarantine where the susceptible individuals are protected by isolating them from the rest, inside the home may be considered (10).
- 7 Video links are provided to caretakers explaining various ageappropriate stretching exercises and developmental stimulation techniques http://pedneuroaiims.org/developmental-stimulation.ht ml

#### **Declaration of Competing Interest**

The authors report no declarations of interest.

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