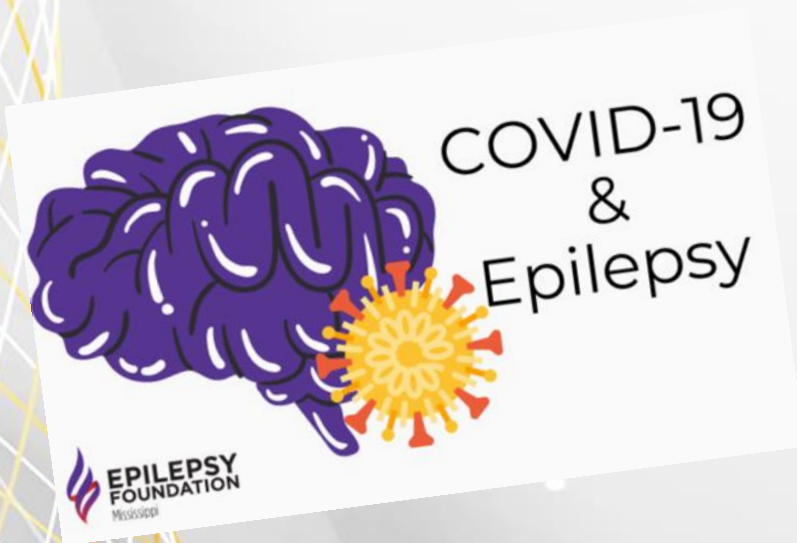




Optimal Care to People with Epilepsy During Covid-19 Pandemic; Children



*Assoc. Prof. Chaiyos Khongkhatithum, MD
Neurology Division
Department of Pediatrics
Faculty of Medicine Ramathibodi Hospital*



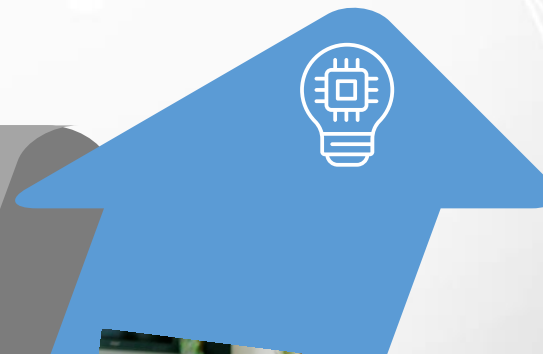
Outline



Impact of COVID-19 pandemic on children with epilepsy (CWE).

Telehealth or Remote care for Children with Epilepsy.

Sharing "TeleCare" experience @ RAMA.



Telemedicine
ปรึกษาแพทย์ โดยไม่ต้องมาโรงพยาบาล





Impact of COVID-19 Pandemic on Children with Epilepsy



Care Delivery for Children With Epilepsy During the COVID-19 Pandemic: An International Survey of Clinicians

Journal of Child Neurology
2020, Vol. 35(13) 924-933
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Elaine C. Wirrell, MD^{1,*}, Zachary M. Grinspan, MD, MS^{2,*},
Kelly G. Knupp, MD, MSCS³, Yuwu Jiang, MD, PhD⁴, Biju Hammeed, MBBS, PhD⁵,
John R. Mytinger, MD⁶, Anup D. Patel, MD⁶ , Rima Nabbout, MD, PhD⁷,
Nicola Specchio, MD⁸, J. Helen Cross, MBChB, PhD⁹, and Renée A. Shellhaas, MD, MS¹⁰ 

- From April 10 to 24, 2020, a sample of 212 respondents from 49 countries indicated that the COVID-19 pandemic has dramatically changed many aspects of pediatric epilepsy care.
- Telehealth use had increased, with 24.7% seeing patients exclusively via telehealth.

Care Delivery for Children With Epilepsy During the COVID-19 Pandemic: An International Survey of Clinicians

Journal of Child Neurology

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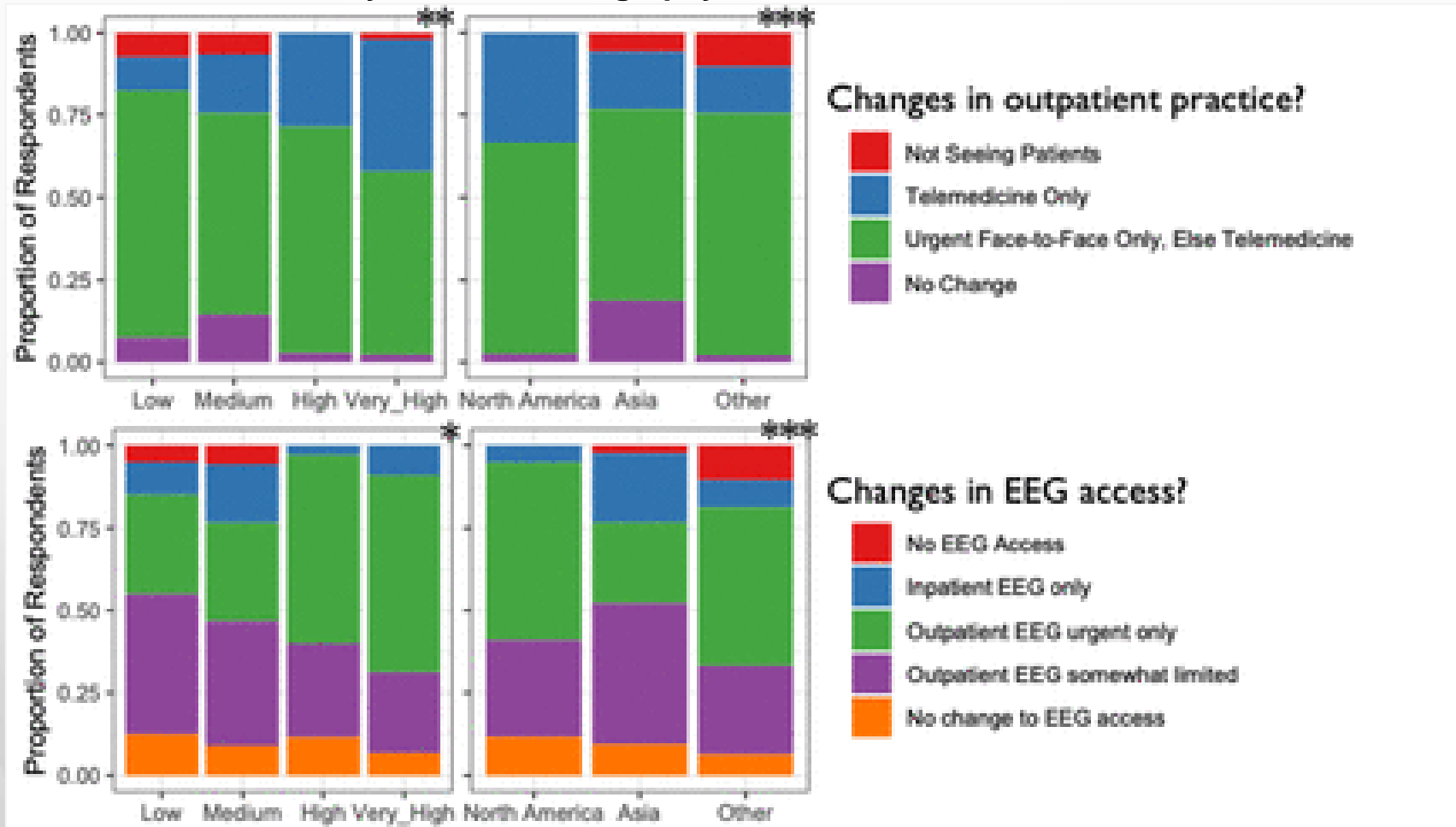


- 91.5% reporting changes to outpatient care
- 90.6% with reduced access to EEG
- 37.4% with altered management of infantile spasms
- 92.3% with restrictions in ketogenic diet initiation
- 93.4% with closed or severely limited epilepsy monitoring units
- 91.3% with canceled or limited epilepsy surgery.



Covid-Severity

Geography

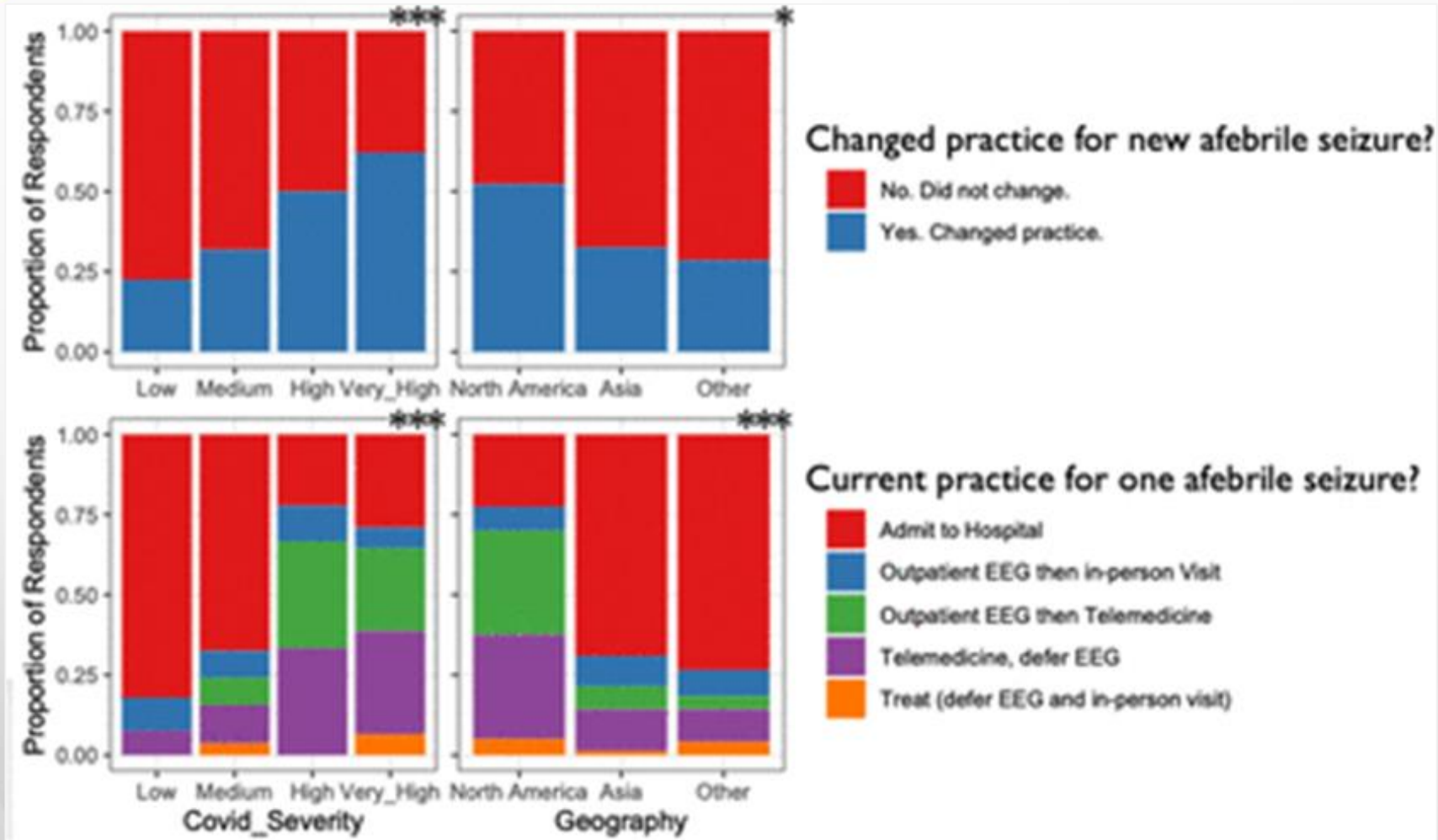


Wirrell EC, et al. *J Child Neurol.* 2020;35(13):924-933.



Covid-Severity

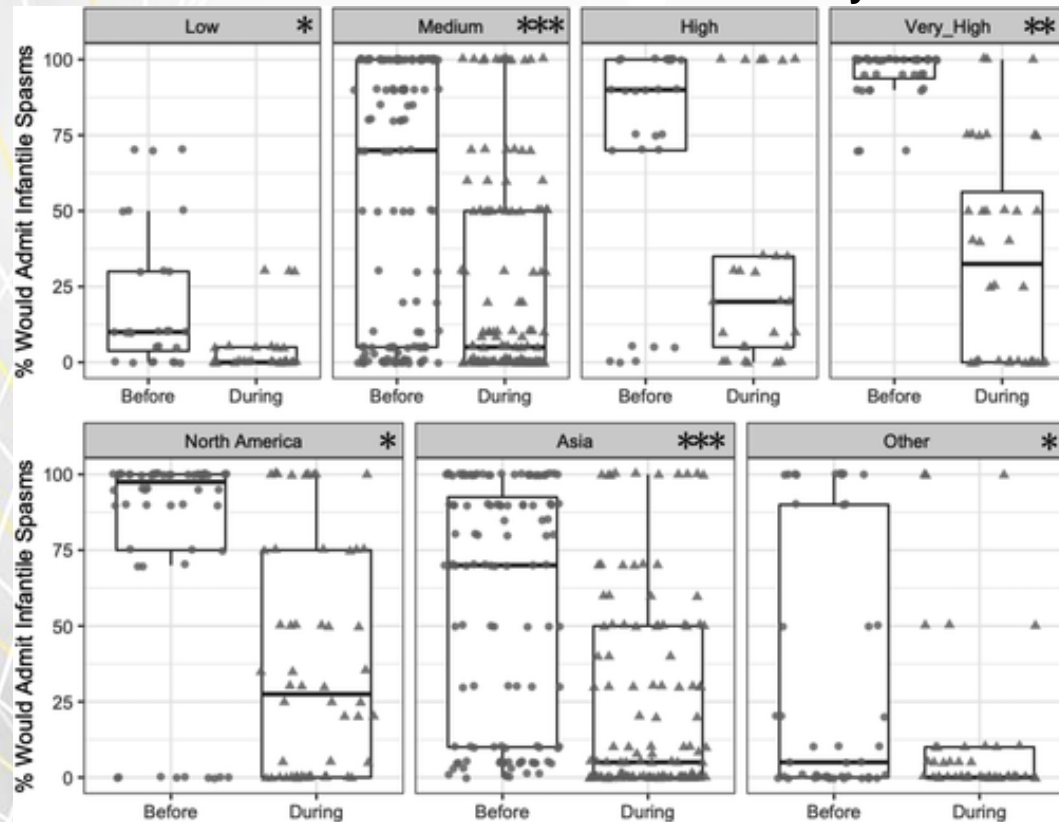
Geography





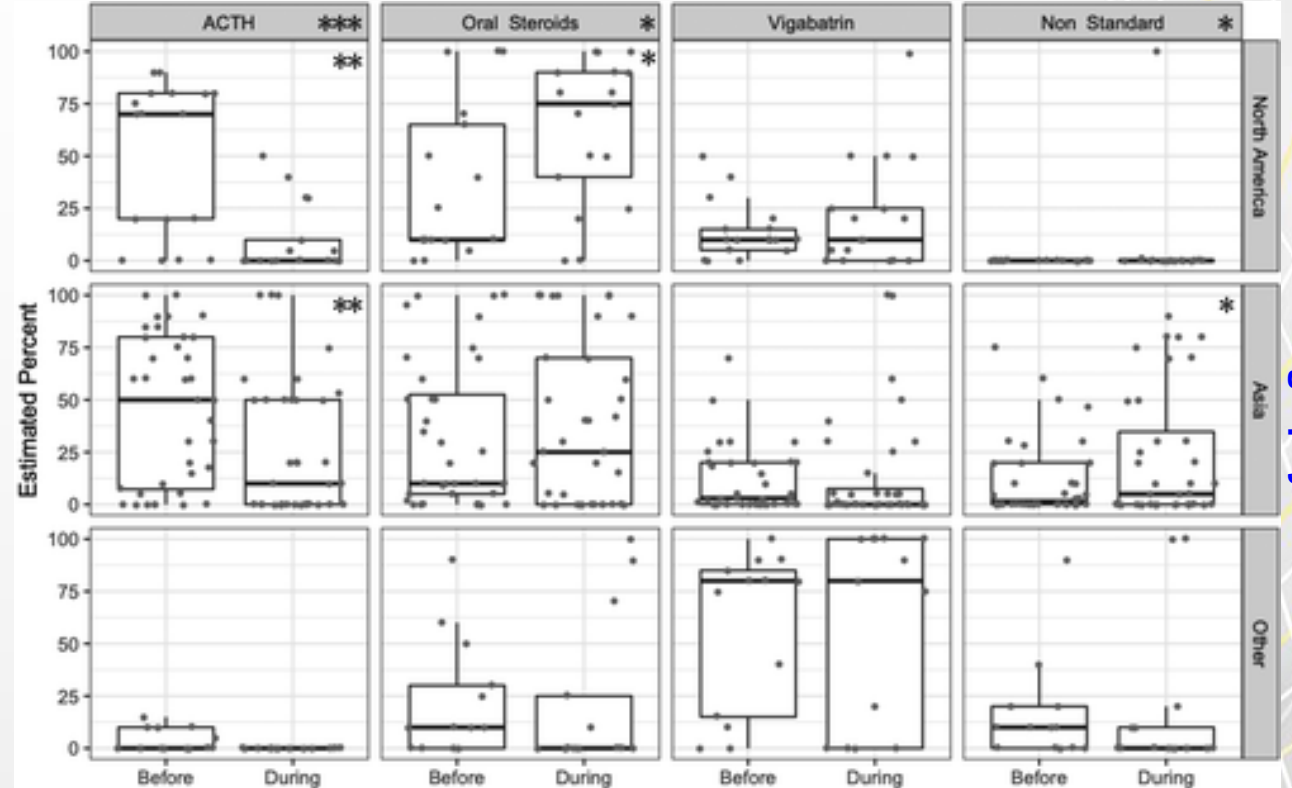
Altered Management of Infantile Spasms

Admission: Covid-Severity



Admission: Geography

Treatment

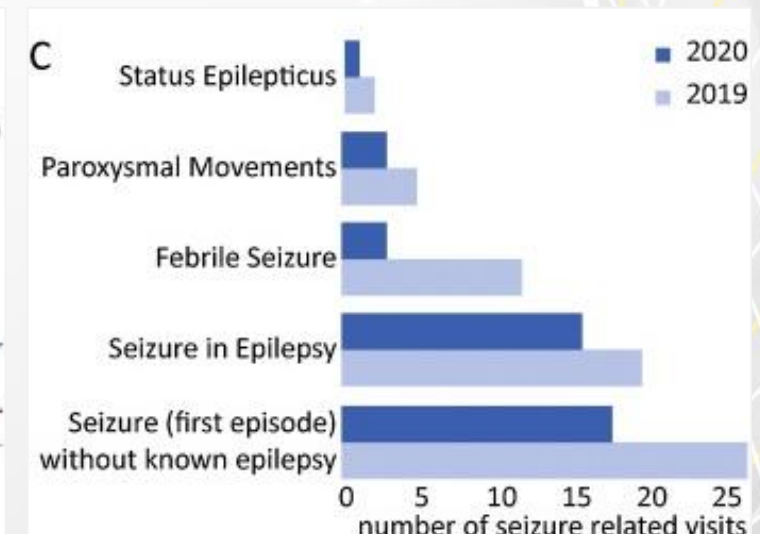
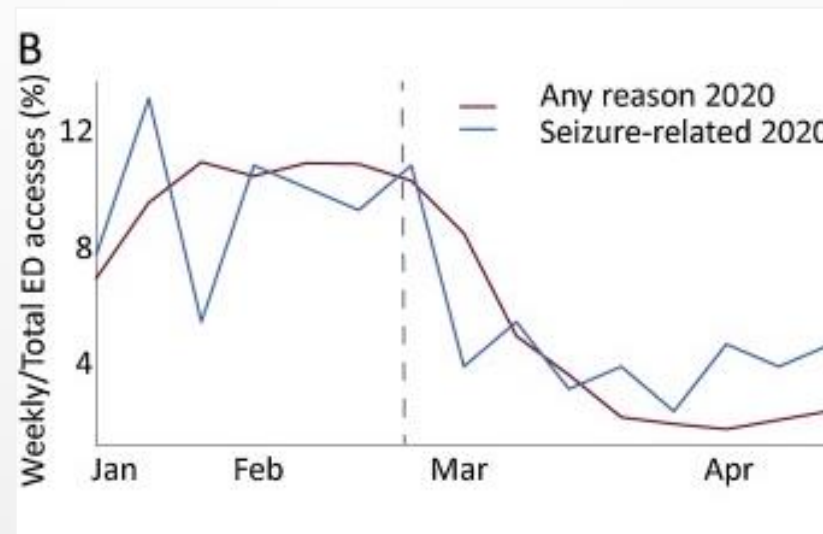
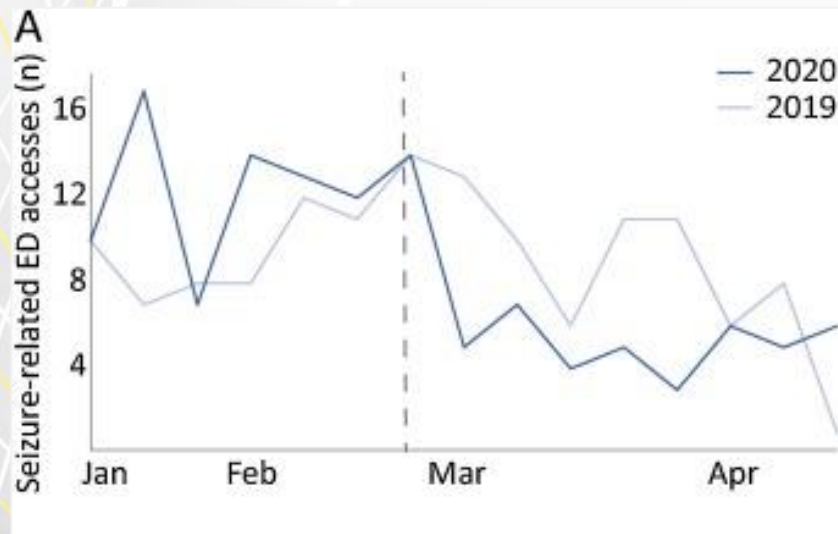


Geography

Wirrell EC, et al. *J Child Neurol.* 2020;35(13):924-933.



An Observational Study of Seizure-Related Accesses to ED at the Time of COVID-19



Turin and Rome, Italy

Davico C, et al. Seizure. 2020 Dec;83:38-40. doi: Epub 2020 Oct 5.



Impact of COVID-19 pandemic on pediatric patients with epilepsy – The caregiver perspective



Marina Trivisano ^{a,1}, Nicola Specchio ^{a,*,1}, Nicola Pietrafusa ^a, Costanza Calabrese ^a, Alessandro Ferretti ^a, Riccardo Ricci ^b, Tommaso Renzetti ^c, Massimiliano Raponi ^b, Federico Vigevano ^c

- Italy, lockdown, March 8 to May 4, 2020.
- Online survey on changes to healthcare and views on telecare.
- 6631 contacts of all patients diagnosed with epilepsy at the BambinoGesù Children's Hospital in Rome.
- 50% responses received.
- 55.6% of patients were seizure-free for at least 1 year before the COVID-19-related lockdown, 74.4% AEDs, and 59.7% had intellectual disability.



Impact of COVID-19 pandemic on pediatric patients with epilepsy – The caregiver perspective



Marina Trivisano ^{a,1}, Nicola Specchio ^{a,*,1}, Nicola Pietrafusa ^a, Costanza Calabrese ^a, Alessandro Ferretti ^a, Riccardo Ricci ^b, Tommaso Renzetti ^c, Massimiliano Raponi ^b, Federico Vigeveno ^c

- Seizure frequency remained stable for most patients during the lockdown period (increased in 13.2%; decreased in 20.3%)
- Seizure duration, use of rescue medications, and adherence to treatment were unchanged.
- Comorbidities were more affected (behavioral problems worsened in 35.8%; sleep disorder worsened in 17.0%).
- Visits were canceled/postponed for 41.0%, but 25.1% had remote consultation during the lockdown (93.9% were satisfied).
- Most responders (67.2%) considered continued remote consultations advantageous.



Experience during COVID-19 lockdown and self-managing strategies among caregivers of children with epilepsy: A study from low middle income country

- Cross-sectional all-island survey was carried out at pediatric neurology centers in Sri Lanka.
- Face-to-face interview after the lockdown period.
- Parental stress level was evaluated using a **self-rating Stress Assessment Questionnaire**.
- Caregivers of 140 children with epilepsy
- Majority were on 1 (52.1 %) or 2 (20 %) AEDs.
- No change in seizure control (87.3%)



Experience during COVID-19 lockdown and self-managing strategies among caregivers of children with epilepsy: A study from low middle income country

- Difficulties over regular reviews and prescription refills.
- 87.1 % of parents maintained dispensing AEDs to their child regularly.
- Caregivers demonstrated healthy **self-management strategies** such as awareness on medications and access methods to healthcare during lockdown and **remained confident of accessibility to services**.
- Stress was experienced in < 5%; Rural > Urban backgrounds.
- Only 2.1 % had accessed help through internet to resolve their concerns.



Impact of COVID-19 pandemic in pediatric patients with epilepsy with neuropsychiatric comorbidities: A telemedicine evaluation



Ludovica Pasca^{a,b,1}, Martina Paola Zanaboni^{a,1}, Serena Grumi^a, Martina Totaro^{a,b,1}, Elena Ballante^c, Costanza Varesio^{a,*,1}, Valentina De Giorgis^{a,1}

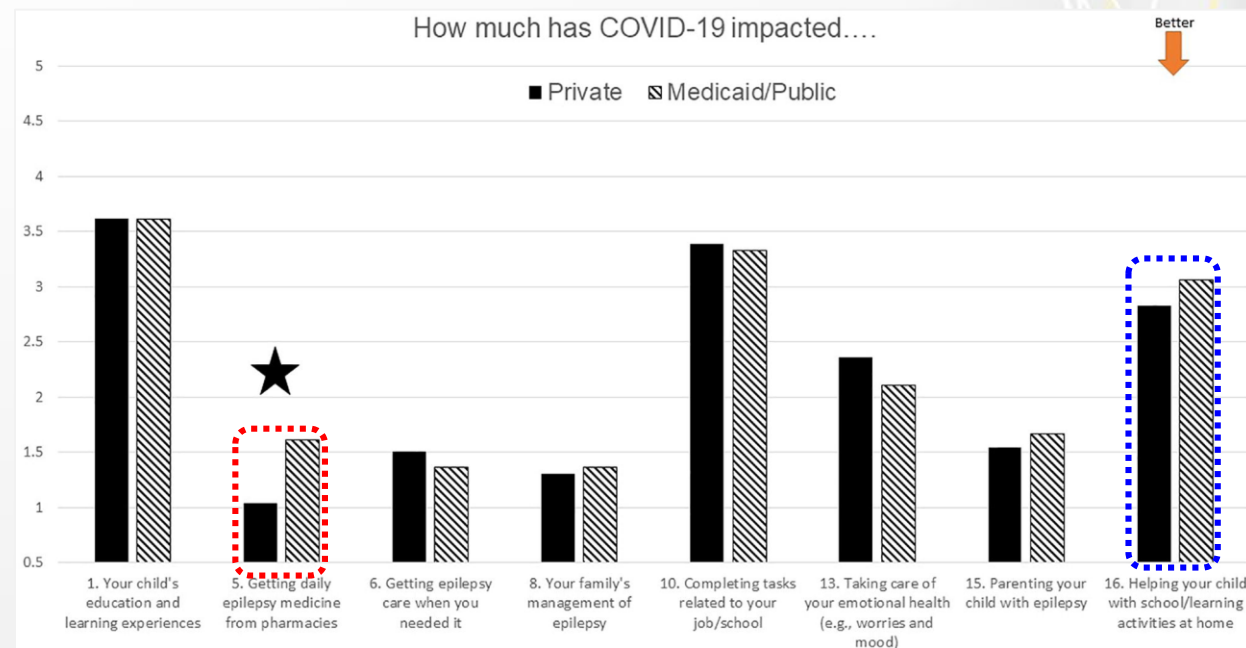
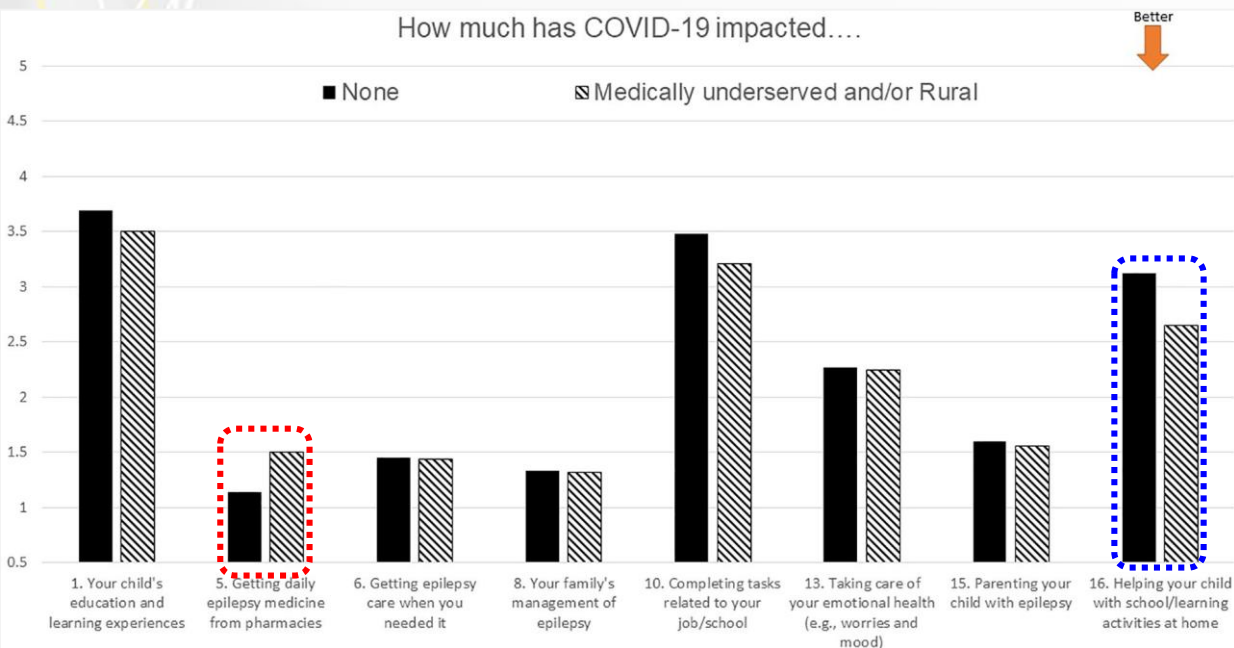
- Observational study involving pediatric patients with epilepsy with neurocognitive and emotional comorbidities.
- 23 pediatric patients during the COVID-19 pandemic. Parvia Italy.
- Compared **CBCL questionnaire** scores before and during the COVID-19 pandemic, and **PSI-SF** scores.
- Concerns for therapy monitoring in 43% of families, and 30% worries for an altered contact with the referring medical team.
- Patients with neurocognitive impairment were more likely to exhibit behavioral problems, especially externalizing problems compared with patients with anxiety/depression.

CBCL, Child Behavior Checklist
PSI-SF, Parenting Stress Index-Short Form

Pasca L, et al. Epilepsy Behav. 2021 Feb;115:107519.



The psychosocial impact of COVID-19 within the first 6 months of the pandemic on CWE and their caregivers (n=131, 4 large children hospitals, USA)



Modi AC, et al. Epilepsy Behav. 2021 Apr;117:107855. doi: Epub 2021 Feb 12.

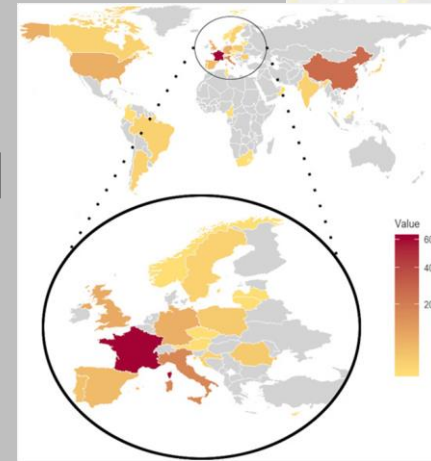


Telehealth or Remote Care for Children with Epilepsy



An accelerated shift in the use of remote systems in epilepsy due to the COVID-19 pandemic

- 172 respondents from 35 countries completed the survey.
- 80% used remote systems with video.
- 84.6% of respondents involved in academic activities transformed courses to online teaching.
- Few scientific meetings relevant to epilepsy was adapted to virtual meeting.
- Interestingly, before the COVID-19 pandemic, remote systems were significantly more frequently used in China for clinical activity compared with France or Italy. This difference became less marked during the pandemic.





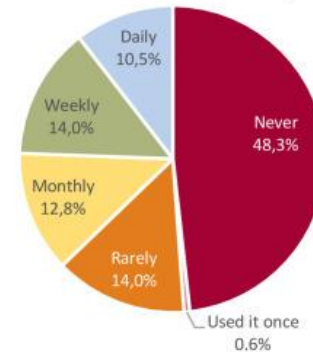
An accelerated shift in the use of remote systems in epilepsy due to the COVID-19 pandemic

Adult and child neurologists specialized in epilepsy care through

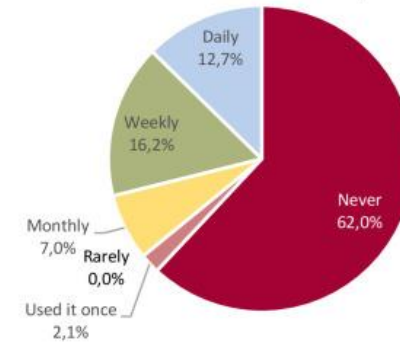
- The European reference network for rare and complex epilepsies (EpiCARE),
- International League Against Epilepsy (ILAE),
- International Child Neurology Association (ICNA),
- French League against Epilepsy (LFCE),
- French Society of Child Neurology (SFNP).

A. Frequency use before COVID-19 pandemic

Institutional remote work system

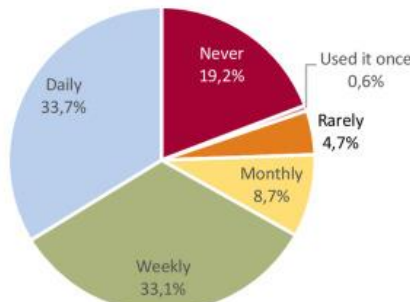


Personal remote work system

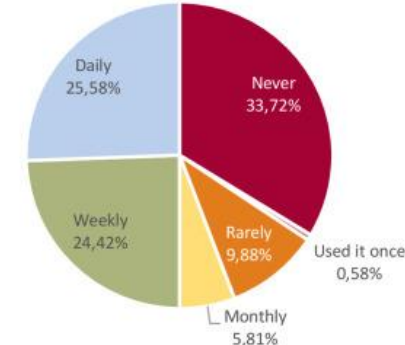


B. Frequency use during COVID-19 pandemic

Institutional remote work system



Personal remote work system

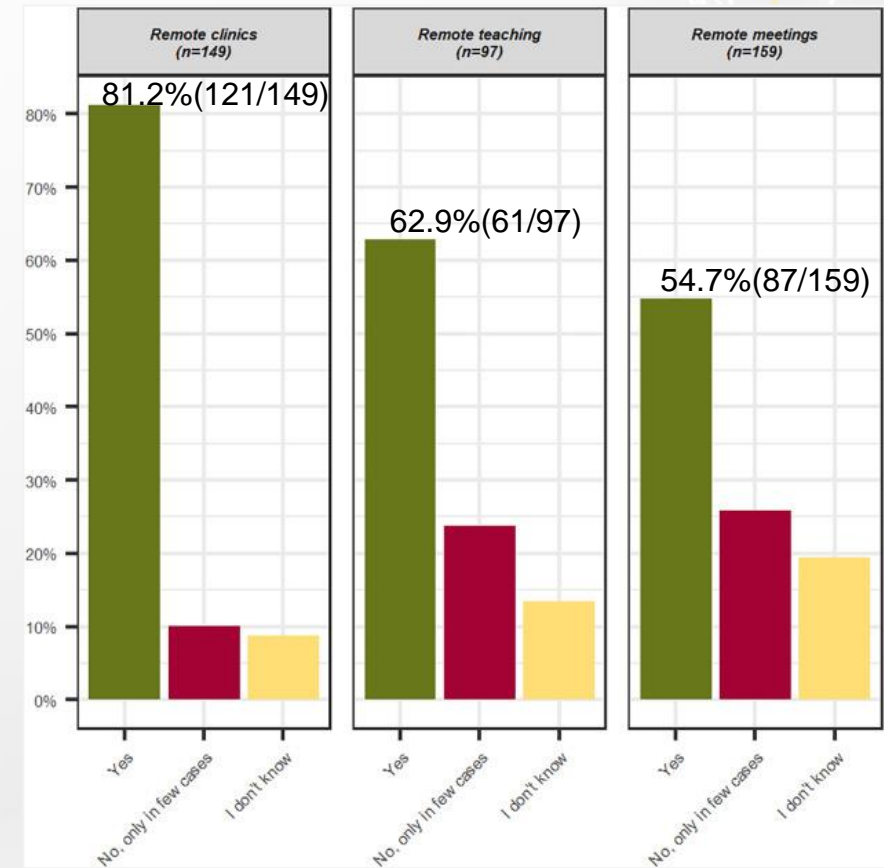
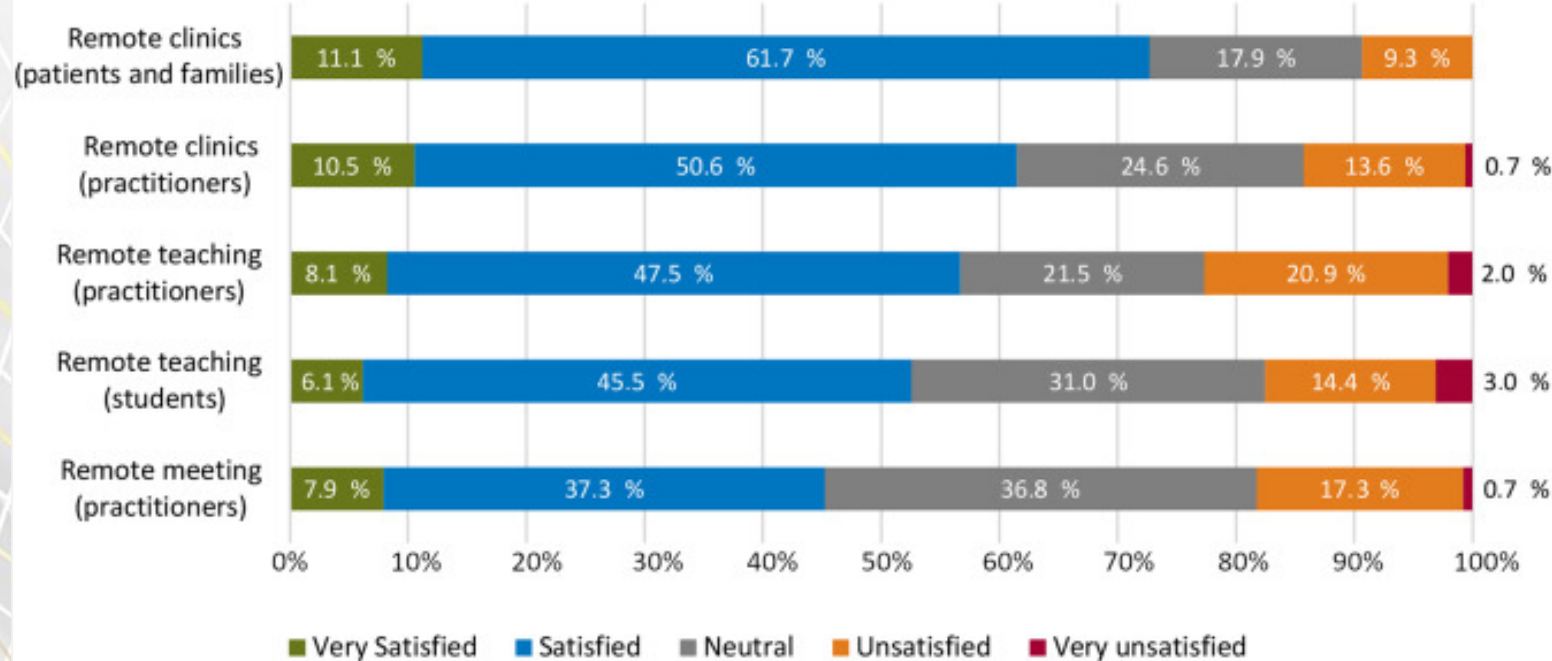




An accelerated shift in the use of remote systems in epilepsy due to the COVID-19 pandemic

Future use of remote systems after the COVID-19 pandemic

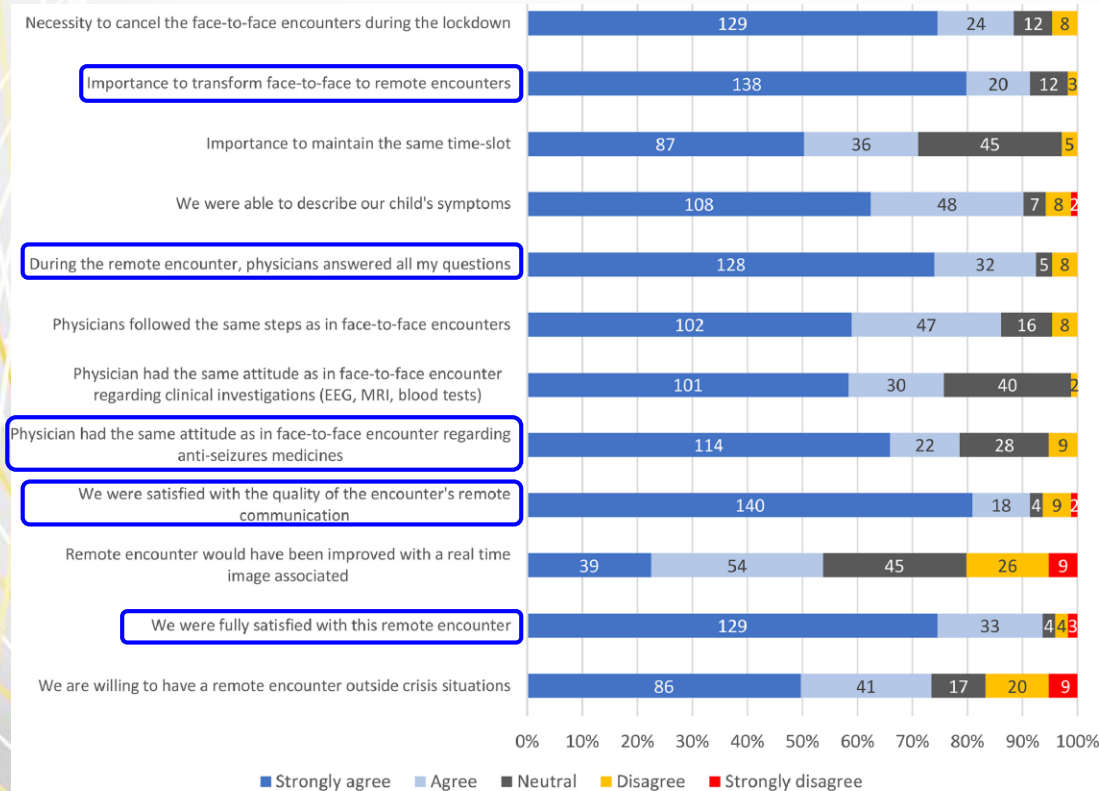
Satisfaction about remote systems



Kuchenbuch M, et al. *Epilepsy Behav.* 2020 Nov;112:107376.



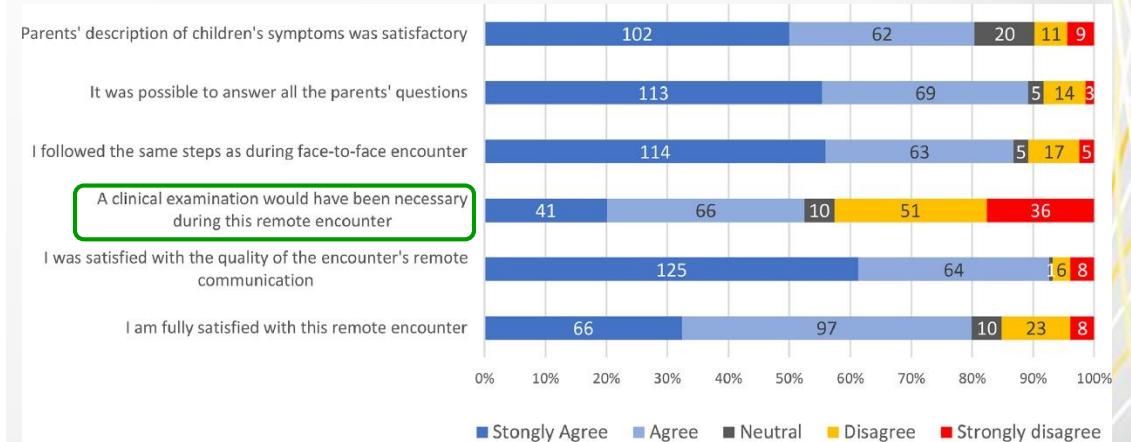
Physician and patient satisfaction with the switch to remote outpatient encounters in epilepsy clinics



Parents' impression on their remote encounters

Prospective monocentric study, [France](#), a total of 224 responses, by physicians and parents.

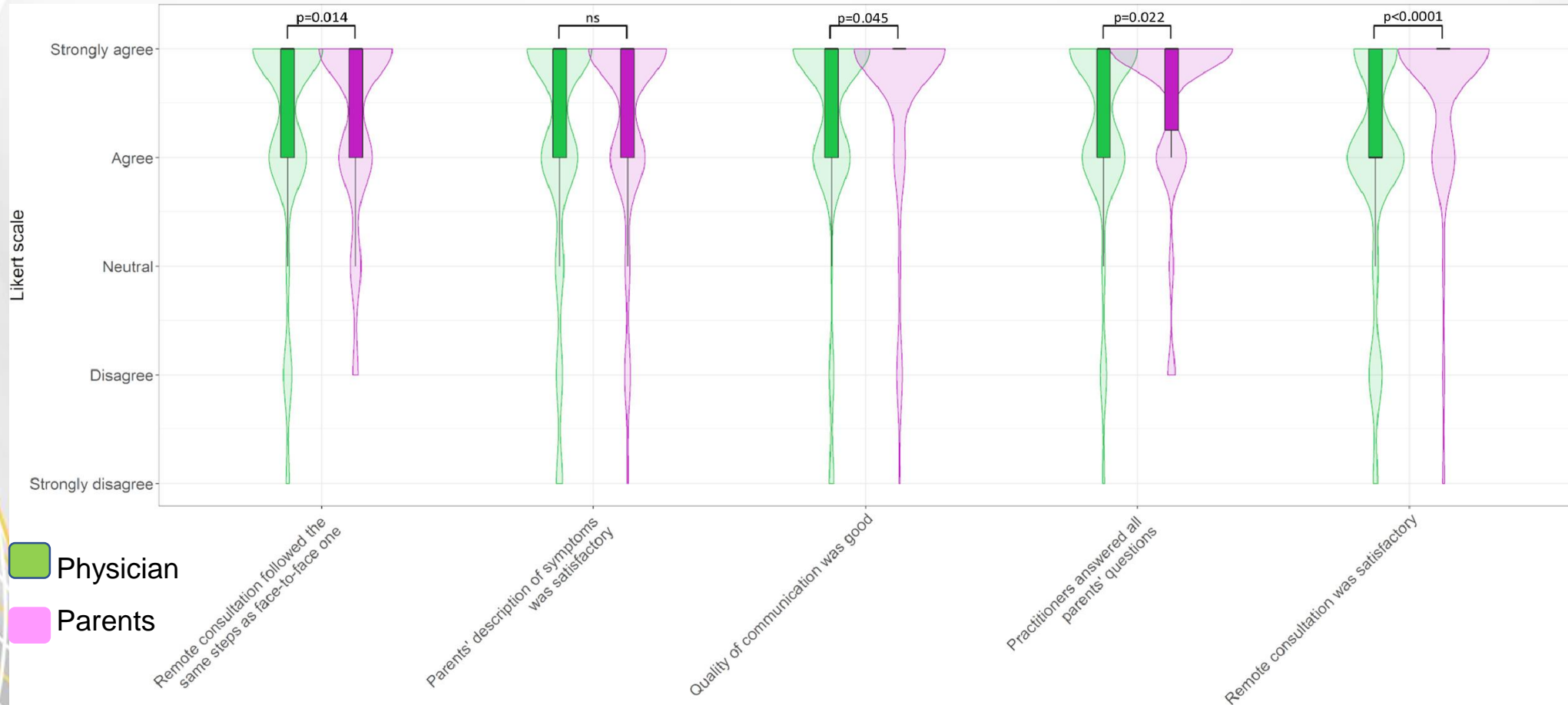
Physicians' impression on their remote encounters



Teng T, et al. *Seizure*. 2021;91:60-65.

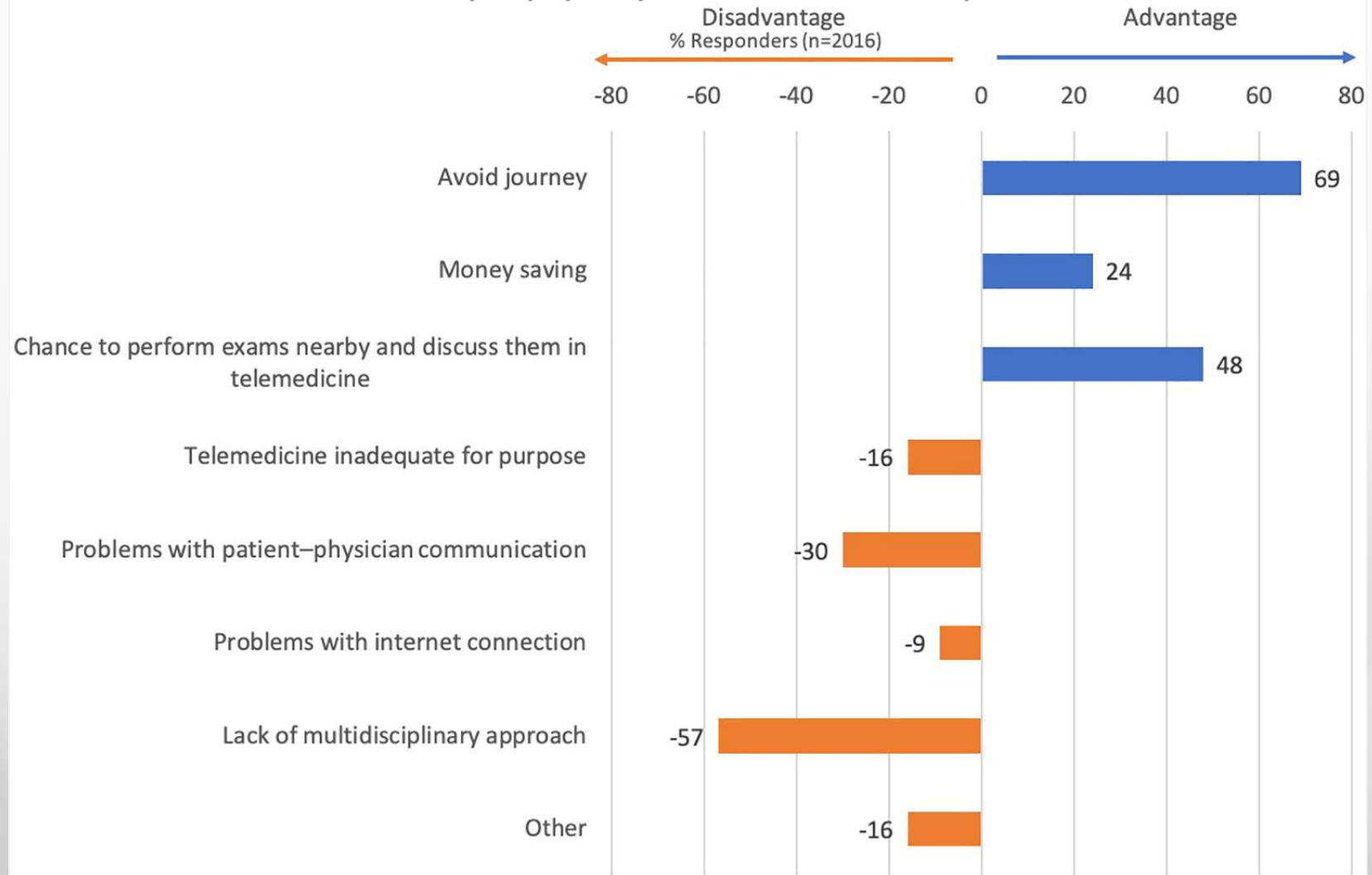


Physician and patient satisfaction with the switch to remote outpatient encounters in epilepsy clinics





Responder-perceived advantages/disadvantages of telemedicine for the care of epilepsy beyond the COVID-19 pandemic



Trivisano M, et al. Epilepsy Behav. 2020 Dec;113:107527.

Feasibility and effectiveness of teleconsultation in children with epilepsy amidst the ongoing COVID-19 pandemic in a resource-limited country

Prateek Kumar Panda^{a,1}, Lesa Dawman^{b,1}, Pragnya Panda^{c,1}, Indar Kumar Sharawat^{a,*,1}

- 153 children, 95 males [62 %], 9.45 ± 3.24 years, 140 lower/middle socioeconomic status, Uttarakhand, India.
- A total of 278 telephone consultations performed, 1-5 telephone calls per patient.
- Voice call, text message, picture/video message, and all other possible measures were employed to accumulate maximum clinical information in real-time.
- Overall, 147 (96%) caregivers were satisfied with the quality of medical advice.

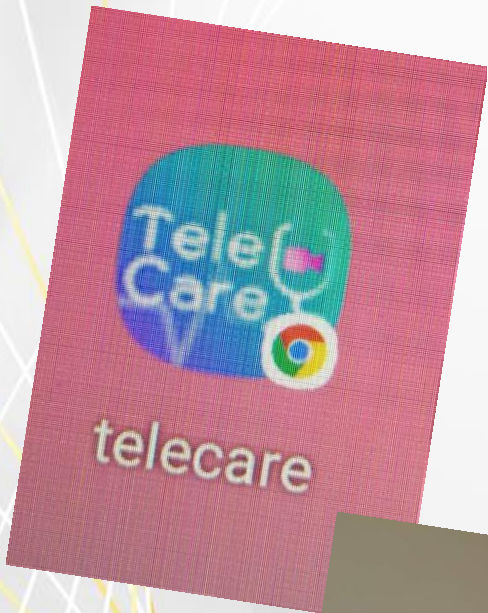


Experience during COVID-19 lockdown and self-managing strategies among caregivers of children with epilepsy(CWE): A study from low middle income country

- The caregivers indicated readiness for a similar lockdown.
 - Name of medication (88.6%)
 - Knowing the doses (84.3%)
 - Having adequate supply of medications (72.5%)
 - Maintaining one month of extra supplies (70.7%)
 - Feeling confident of having access to medications (82.9%)
 - How to contact their child's doctor (87.1%)
 - **Feeling confident about having help made available (90.7%)**



TeleCare @ Ramathibodi



มหาวิทยาลัยมหิดล
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี

เรียน ผู้รับบริการทุกท่าน
ขอความร่วมมือผู้ป่วยที่
อาการคงที่เลือกใช้บริการ
การตรวจทางไกล (Telecare)

1. แจ้งความประสงค์ยืนยันเมื่อเจ้าหน้าที่ติดต่อไป
ก่อนวันนัด หรือ
2. โทรแจ้งความประสงค์ก่อนวันนัด
ที่หมายเลข 0 2201 1000 (กด 3)
หรือ 0 2200 3000 (กด 3)
ในวันราชการ (วันจันทร์ - วันศุกร์)
เวลา 08.00 - 16.00 น.
ยกเว้น วันเสาร์ อาทิตย์ และวันหยุดนักขัตฤกษ์

โรงพยาบาล จะติดต่อ
ให้ท่านทราบหากได้รับการพิจารณาให้ตรวจทางไกล
หลังจากนั้นโรงพยาบาลจะจัดส่งยา
ให้ท่านทางไปรษณีย์

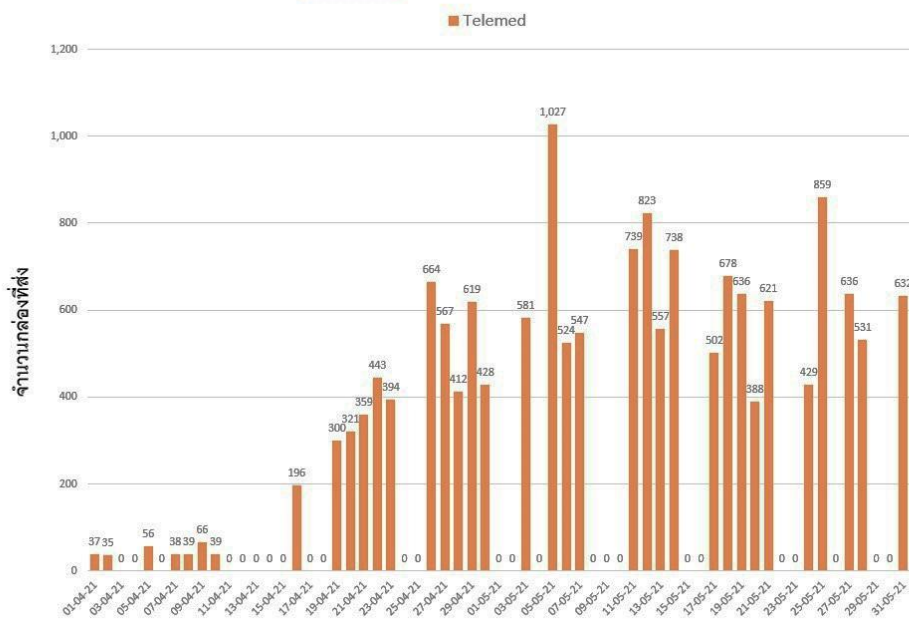
รักษาระยะห่างจากโควิด-19 ด้วย
การตรวจทางไกลผ่าน Rama App

เนอพรไทย งานสื่อสารองค์กร คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

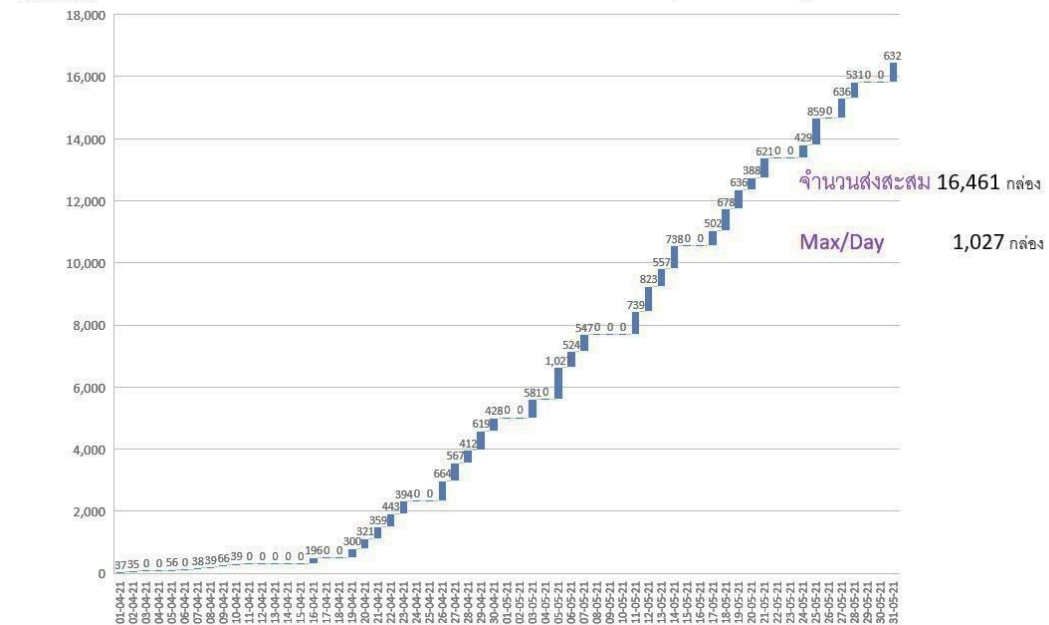


Telecare @ Ramathibodi

ปริมาณการส่ง Telemed ปณ รายวัน SDMC ระลอกที่ 3 (เม.ย.-พ.ค.64)



จำนวนกล่อง ปริมาณการส่ง Telemed ปณ สะสม SDMC ระลอกที่ 3 (เม.ย.-พ.ค.64)





Concerns for Telecare in CWE

- Liquid formulation of AEDs
- Adjust dosage of medication by body weight
- Clinical examination by virtual visit
- Laboratory monitoring e.g. CBC, AST/ALT, drug level
- Some AEDs not allowed to deliver by sending parcel
- No internet or smart phone
- Take the help of text messages, picture messages, and videos to collect additional details
- Elderly caregivers
- In patients with unresolved clinical issues, a follow-up telephone call is essential.
- Multidisciplinary team is very important.

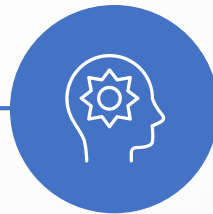




Take Home Message



Keep standard of care for children with epilepsy and support their family.



COVID-19 pandemic changed the usual healthcare assistance in children with epilepsy especially with neuropsychiatric comorbidities.



Seizure burden remained stable for most patients during the lockdown period.



The psychological burden related to the disease might worsen children and their families.



Telemedicine can be an effective option in children with epilepsy during pandemic situations.



Questions & Discussion