



Seizure cycles

Multidien fluctuations in epileptic brain activity

Maxime Baud and Vikram Rao

Epilepsy 12 audit 2020 – Stacey | Dunkley

Risk management during COVID-19 – Ison | Angus-Leppan

ILAE COVID-19 symposium conference report

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Welcome to the winter edition of *Epilepsy Professional*. In a world that is presently dealing with a lot of uncertainty and change, *Epilepsy Professional* is still here, providing up-to-date snapshots of world leading research and clinical opinions. I hope this edition provides us all with something new which we can take into our clinical practice. I hope it gives us something extra to help people with epilepsy, in whom living with a chronic condition in the global pandemic presents its own uncertainties and challenges.

This edition provides a varied selection of articles, such as a new safety tool for living with epilepsy in the pandemic, up-to-date results from the Epilepsy12 audit and a novel insight into seizure cycles.

Rachel Ison and Heather Angus-Leppan provide an overview on risk management during COVID-19. In their article, they highlight some of the pandemic-specific challenges and disruptions people with epilepsy are now facing, such as access to healthcare and impact on safety and mental health. They illustrate the Epilepsy Risk Awareness (ERA) Scale as a remote tool which could be used to address some issues around personal safety, healthcare and quality of life. Practically you might think 'not another scale', but maybe it's about selecting the right patients to use it on, and it may prove useful for those who struggle with telephone or video consults.

Helen Stacey and Colin Dunkley give us some encouragement with

their article on the Epilepsy12 audit 2020. They highlight the increasing input of and access to epilepsy specialist nurses, the overall accuracy of diagnosis and the reduced prescribing of sodium valproate. It's great to have some positive news. However, they also report an increasing delay in accessibility of EEG during the pandemic. As an adult neurologist, a delay of 2-4 weeks is still rather envious, but I acknowledge the greater diagnostic utility in paediatrics.

And finally, allow Dr Baud and Dr Rao to fascinate you with their paper on the circadian and multidien fluctuations in epileptic brain activity. They explore the clustering of seizures and fluctuations of epileptic activity over days. They describe the role of longer-term seizure monitoring and its potential role in seizure forecasting and in the development of novel preventative, or, dare I say, prophylactic treatments for epilepsy.

So, as we cautiously dive into winter – and winter during the COVID-19 pandemic – you, like me, may probably be acutely aware of time. We've seen the clocks go back and the days getting shorter. That said, sometimes a few days in the pandemic can seem like weeks or even months! So, let me encourage you to while away a few hours reading this edition of *Epilepsy Professional*.

Ann Johnston
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Despite good news of a COVID-19 vaccine being on the precipice of availability, the pandemic still touches every aspect of our work and life. And it still forms a big part of the articles we have for you this issue. In September, the ILAE held a virtual symposium about epilepsy and COVID-19. A panel of experts discussed the paradigm shifts and discoveries the pandemic has led to, and the new challenges patients are facing. You can find our summary on page 28. Also acknowledging the challenges this year has presented, Rachel Ison and Dr Heather Angus-Leppan discuss risk management during COVID-19. They present their Epilepsy Risk Assessment (ERA) Scale on page 22.

Many healthcare services have been disrupted to some extent by the pandemic, but the latest Epilepsy12 audit looked at children's services before the pandemic hit. Helen Stacey and Dr Colin Dunkley describe the findings – some positive and some that still need work – on page 10. Looking hopefully to a future when COVID-19 is under control, these audits will help us build on existing successes and deliver the best patient care possible.

Finally, our cover feature this issue comes from Dr Maxime Baud and Dr Vikram Rao. They describe their research into cycles of epileptic brain activity and share the discovery of a multidien cycle. This has implications for clinical trials, monitoring treatment responses and seizure forecasting in the future. You can read more on page 16.

We wish everyone a happy, healthy and peaceful festive period and let's look forward to a better 2021. Enjoy!

Kami Kountcheva
Editor

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The information contained in this magazine is intended for medical professionals

Epilepsy Professional is available on subscription to non-members – £13 a year to UK residents. Please send letters or articles to the editor. We are unable to acknowledge receipt of materials, due to cost. We cannot offer payment to authors. All income generated by *Epilepsy Professional* funds the Association's work.

Epilepsy Action is a working name of British Epilepsy Association. British Epilepsy Association is a Registered Charity in England and Wales (No. 234343) and a Company Limited by Guarantee (No. 797997).

© 2020 Epilepsy Action ISSN 1750-2233

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Slightly higher risk of more severe COVID-19 symptoms in epilepsy

There may be a slightly increased risk of hospital admission and death from COVID-19 in people with epilepsy, according to a new study in the *British Medical Journal (BMJ)*.

The research, published in October 2020, looked at risk factors for hospital admissions and death from COVID-19 in 6.08 million adults across England. The data were collected between 24 January and 30 April.

Among the risk factors, were conditions for which people are advised to shield, and conditions moderately associated with increased risk of complications from COVID-19, according to current NHS guidance. Epilepsy is in the latter group.

The evidence from the research by Clift *et al* showed a small increase in risk of hospital admissions and deaths resulting from COVID-19 in both men and women with epilepsy. The risk appears to be slightly higher still in men than in women.

Until now, there was no evidence to suggest people with epilepsy were at an increased risk of more severe symptoms of COVID-19.

A FAIR Health White Paper published in November 2020 looked at risk factors for death from COVID-19 among privately insured patients in the US. The findings of this paper are in line with the *BMJ* study when it comes to epilepsy – it identified a slightly increased risk.

Dr Markus Reuber, professor of Clinical Neurology at the University of Sheffield, said: “Epilepsy emerges as a factor associated with a slightly higher risk of death or of hospital admission due to COVID-19 in this dataset. This does not mean that epilepsy is the cause of this higher risk.”

Dr Reuber explained that a diagnosis of epilepsy could be a marker of other features more directly linked to the risk of more severe COVID-19 infection. These could include more contact with professional carers, attendance of educational settings and other conditions linked to or causing the epilepsy.

He added: “This study raises the concern that people with epilepsy could be at slightly greater risk of hospitalisation during or shortly after a COVID infection, and that they could be at increased risk of death in these circumstances. This study does not prove a link between hospitalisation or death and epilepsy.”

Dr Rhys Thomas, consultant neurologist at the Newcastle upon Tyne Hospitals NHS Foundation Trust, said: “Population data have identified health features that increase the risk for COVID-19 severity. It is unclear how this contributes to an individual’s risk. People with an intellectual disability appear to be at a greater risk of COVID-19 severity, and to a much lesser extent the same appears to be the case for people with epilepsy.

“This risk is not sufficient to ask people with epilepsy to strictly shield, or to identify themselves as highly vulnerable. But it further emphasises the need for all of us to keep up our efforts to wear face-masks, keep our distance from others and wash our hands as advised.”

Dr Reuber also pointed out that further social withdrawal could be harmful for some people with epilepsy, especially in people already facing stigma or social exclusion.

The full *BMJ* study is available online at bit.ly/2UZgADg

Depression management and quality of life

A recent study from Spain suggests that depression is an independent predictor of worse quality of life in people with epilepsy. The study by Campos-Fernández *et al* also suggests that managing depression can reduce the negative effects of other factors on the quality of life of people with epilepsy.

The study authors set out to analyse the relationship between seizure frequency, irritability and depression and how they impact each other’s effect on quality of life in epilepsy. The 157 participants were recruited from an outpatient epilepsy clinic in Barcelona. Each had been evaluated for psychiatric comorbidity.

The study results showed that seizure frequency, irritability and depression all had a negative impact on quality of life. Depression appeared to be the only independent predictor of poorer quality of life. However, the results also showed that depression had a significant mediating effect on how seizure frequency and irritability affected a patient’s quality of life.

The full *Epilepsy & Behavior* study is available at: bit.ly/337U0wo



MHRA designates cenobamate Promising Innovative Medicine

A new medicine for refractory focal-onset seizures in adults, cenobamate, was given a Promising Innovative Medicine (PIM) designation by the Medicines and Healthcare products Regulatory Agency (MHRA) in August 2020.

Cenobamate is produced by Arvelle Therapeutics International. The PIM designation from the UK's MHRA is an early indication that this medicine could be a candidate for the Early Access to Medicines Scheme (EAMS), according to Arvelle Therapeutics.

Cenobamate has been approved for use in the US by the Food and Drugs Administration (FDA) as an adjunctive anti-seizure medicine. The European Medicines Agency (EMA) also approved it for use in the European Union in March 2020.

Cenobamate has undergone clinical trials for safety and effectiveness. The trials showed it was more effective than currently available medicines in achieving seizure

freedom in adults with refractory focal-onset seizures.

In an expert opinion piece, Dr James Wheless, professor and chief of the Department of Pediatric Neurology at The University of Tennessee, reviewed cenobamate as an adjunctive treatment. In the Expert Review of Neurotherapeutics article, he said cenobamate shows “a high level of efficacy” in treating refractory focal epilepsy. He said for some participants in the clinical studies carried out on this medicine, seizure frequency halved. Just under a third of people became seizure free during the trials.

Dr Wheless said: “If efficacy responses in real-world use reflect what have been observed in clinical studies, cenobamate would be a welcome new treatment option and could become a mainstay over the next five years.” If the MHRA includes cenobamate in the EAMS, it will evaluate the risk and benefit of the medicine and offer a scientific opinion on it.

EMA approves perampanel use in younger patients

The European Commission (EC) has approved the expansion of the existing prescription regulations of Fycompa, Eisai's perampanel preparation.

Perampanel can now be used as an adjunctive treatment for focal-onset seizures in children four years old or above in Europe.

It can also be used as an adjunctive treatment for primary generalised tonic-clonic seizures in people with genetic generalised epilepsy. The new regulations mean it can be prescribed to children seven years old or above.

Previously, the age for its use in both of these circumstances was 12 years old and above.

Phenytoin sodium NRIM 100mg capsules out of stock



Accord's epilepsy medicine phenytoin sodium NRIM in 100mg capsule doses is currently unavailable in the UK. It was previously reported as out of stock in January this year. Despite expecting these to be back in stock by May, it was reconfirmed in June that they were still unavailable.

The Department of Health and Social Care wrote to healthcare professionals to advise that they switch patients to Flynn Pharma's 100mg capsule formulation. However, phenytoin is a Category I medicine, according to the Medicines and Healthcare products Regulatory Agency (MHRA) and switching may not be a feasible option.

Updates can be found at epilepsy.org.uk/drugwatch

Government urged to deliver on promises around access to cannabis-based medicines

The families of children with severe epilepsy and epilepsy charities are pleading with the UK government to act on promises made two years ago around access to cannabis-based medicines.

On 1 November 2018, the UK law changed to allow specialist clinicians to prescribe cannabis-based medicines to patients with “exceptional clinical need”. This included children with severe epilepsy syndromes like Dravet and Lennox-Gastaut syndromes.

Two years on, campaign group End Our Pain and charity Epilepsy Action say that they believe only three NHS prescriptions for cannabis-based medicines containing cannabidiol (CBD) and tetrahydrocannabinol (THC) have been written.

Two of these three prescriptions have been made out to two boys at the centre of campaigns to make these products legal in the first place – Billy Caldwell and Alfie Dingley.

The organisations say that the lack of NHS prescriptions has left many families having to fund their own prescriptions at a cost of thousands of pounds a month. Many others are not able to afford these, so don’t have access at all to this medicine for their children.

Following pressure from families, Health Secretary Matt Hancock instructed the NHS to carry out a review of apparent barriers to these medicines in the health service. The review report showed many clinicians were concerned about a lack of knowledge and long-term safety data from trials on some types of cannabis-based medicines.

The review report recommended an “alternative study”, such as an observational trial, should be carried out on children already taking cannabis-based medicines. It suggested that in cases where benefits are seen, the families should be able to obtain the medicines from the NHS with appropriate monitoring and supervision.

The organisations are urging the Department of Health and Social Care and NHS England to honour their commitment to an “alternative study”, which they said seems to have been forgotten about in recent months.

There has been mention of randomised controlled trials (RCTs) instead. While the organisations have welcomed these, they added that these are not suitable for all the children who are already taking the medicines, as they would have to “wash out” the medicine from their system before starting. The trial will also involve a group taking a placebo, which is a risk many families don’t want to take.

Deputy chief executive of Epilepsy Action, Simon Wigglesworth, said: “The current situation continues to leave many families with desperately ill children in an unbearable position. The reality is that these children simply don’t have time to wait. Every seizure poses a potentially serious risk and can ultimately be fatal. Some children are having hundreds of seizures every day.

“The government needs to urgently deliver on its promise to provide a way for these children to access funding for medicines which are helping them.”

Epilepsy Action and End Our Pain have put together an open letter to parliament urging them to act.

Sleep apnoea more common in generalised epilepsy

People with generalised epilepsy are at a higher risk of obstructive sleep apnoea (OSA), according to a new study from the US.

Study author Matthew Scharf *et al* said OSA is common in people with epilepsy and treating it could improve seizure control. However, they note that this is often undiagnosed in this group.

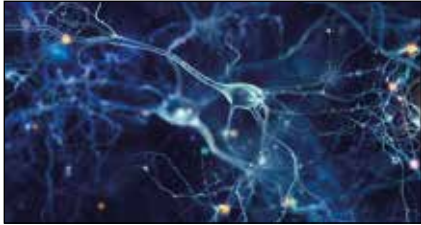
The study authors recruited 115 people with generalised and focal epilepsies. The researchers found that risk of OSA was significantly higher in people with generalised epilepsy.

Other risk factors for OSA were older age, higher body mass index and a history of high blood pressure. OSA can result in tiredness or sleepiness in the day due to poor sleep quality, which could affect seizures.

The research is published in the journal *Epilepsy & Behavior*.



Some neuronal subtypes more affected by epilepsy



A new study has identified which neuronal subtypes are most affected by epilepsy.

Researchers from the University of Copenhagen and Rigshospitalet looked at neuronal subtypes from people with and without epilepsy. They wanted to identify dysfunctional neuronal subtypes that may underly seizure activity.

The research, published in the journal *Nature Communications*, included an analysis of more than 117,000 neurons. It found that some subtypes were more likely to become affected by epilepsy than others. They belonged to several families of principle neurons (L5-6_Fezf2 and

L2-3_Cux2) and GABAergic interneurons (Sst and Pvalb).

The study also suggests that there is a change in the function of thousands of genes in affected brain cells in epilepsy, rather than hundreds as other studies have found. Previous studies have looked at a damaged area of the brain in epilepsy as a whole, rather than the individual neuronal subtypes. The current research offers a more in-depth and accurate target for future treatments.

Study author and associate professor Konstantin Khodosevich explained: "Our findings potentially allow for the development of entirely new therapeutic approaches tailored towards specific neurons, which are malfunctioning in cases of epilepsy. This could be a breakthrough in personalised medicine-based treatment of patients suffering from epileptic seizures."

The full article is available at: go.nature.com/346cvCD

Zonisamide stock issues

Some Teva zonisamide capsules are out of stock. Teva's 25mg, 50mg and 100mg capsules are all unavailable. The 100mg are expected back in January 2021, while the 25mg and 50mg capsules are expected back between January and March 2021.

These medicine doses have been in and out of stock since August 2020.

Actavis/Accord zonisamide capsules are also long-term out of stock with no resupply date given. The capsules initially went out of stock in

all strengths in August 2020.

Updates can be found at epilepsy.org.uk/drugwatch



ESNs and ongoing epilepsy care lacking in Northern Ireland

A new 2020 study from Northern Ireland suggests that people with epilepsy are not able to access vital epilepsy support. This includes not having access to epilepsy specialist nurses (ESNs) and ongoing care for their condition.

The research was carried out by Epilepsy Action Northern Ireland between July and August 2020, focusing on people's experiences of services before the COVID-19 pandemic. The study found that one in three study participants did not have access to an ESN. Of those who did, more than half did not get to see their ESN often enough. This included people who are at higher risk of harm from their condition, such as people with epilepsy who have daily seizures, learning disabilities, autism or mental health conditions.

According to Epilepsy Action Northern Ireland, there should be around 30 ESNs to provide adequate care to adults with epilepsy in the country. There are currently only three ESNs in a full-time position and one who is part-time. Three out of five health trusts do not have an ESN in employment. ESNs are a key part of the epilepsy service team can be a lifeline for people with epilepsy.

Epilepsy Action Northern Ireland is calling for more ESN posts to be created and funded in Northern Ireland. The organisation has written to Health Minister, Robin Swann, and is speaking to health trusts about their plans to increase epilepsy specialist healthcare staff.

Epilepsy | 2 audit 2020

Children and young people with epilepsy receiving better care

Helen Stacey, Epilepsy | 2 manager, and Dr Colin Dunkley, clinical lead for Epilepsy | 2, describe the improvements and problem areas in paediatric epilepsy services identified by the latest Epilepsy | 2 national audit



Epilepsy 12 is the national audit of seizures and epilepsies in children and young people, facilitated by the Royal College of Paediatrics and Child Health. In September 2020 we released a major report on the clinical and organisational aspects of epilepsies care for children and young people within England and Wales.

As part of the audit, we collect data to describe the epilepsy workforce and the services available in each Trust or Health Board. We also collect a patient level dataset which follows children and young people from their initial referral and diagnosis through their first 12 months of care.

Although published within the pandemic, the 2020 report conveys findings completely pre-dating COVID-19. It describes the organisation of the services and workforce as they were in November 2019, and 12 months of the clinical care for patients between 2018 and

2019. All eligible NHS Trusts and Health Boards are registered to take part and these results describe the quality and outcomes of care for 3,318 different children and young people.

We reported evidence of input by an ESN in the first year of care of children with epilepsy increasing to 69% – up from 43% and 55% in previous audit rounds

The good news is that there were signs of many improvements in care, particularly children having input from epilepsy specialist nurses (ESN). We reported evidence of input by an ESN in the first year of care of children with epilepsy increasing to 69% – up

from 43% and 55% in previous audit rounds. There was a total of 158.4 whole time equivalent ESNs employed in Health Boards and Trusts across England and Wales. This is compared to 147.3 in 2018 and 81.8 in the first round of the audit back in 2011.

NICE Clinical Guideline 137 [NICE.org.uk, 2012] and previous SIGN [SIGN, 2018] guidance both highlight the importance of ESNs as part of multi-disciplinary paediatric epilepsy care networks and teams. The recommendation we made is for all Health Boards and Trusts to ensure at least one whole time equivalent ESN for every 250 children and young people with epilepsy. This is so that families, alongside other roles fulfilled by ESNs, can reliably receive prompt, individualised specialist advice and input between scheduled reviews.

There was also evidence of increased input from paediatricians with expertise in epilepsies, and fewer withdrawals of epilepsy diagnoses



which acts as our proxy for misdiagnosis. The majority (82%) of children and young people diagnosed with epilepsy had input from a paediatrician with expertise in epilepsies during their first year of care. Withdrawal of diagnosis rates are very low; 97% of children with an initial diagnosis of epilepsy had the same diagnosis after one year. This had been 88.1% of children and young people in 2011, suggesting that misdiagnosis rates have declined.

The audit also found that there was very little evidence of children receiving anti-epilepsy medication unnecessarily. Less than 2% of children and young people who received anti-epilepsy medication did not have a diagnosis of epilepsy after one year. Another positive finding was that from the age of nine years old, there was a clear trend in reduced prescribing of sodium valproate for females. There was also evidence that the risks had been discussed in all cases where it had been prescribed for older girls and young women.

There were areas where the timeliness of care was a concern for children and young people with epilepsy. Around two-fifths (43%) of children with epilepsy had to wait more than four weeks for their first EEG. Most children referred to a paediatrician with expertise in epilepsy



waited longer than the recommended two weeks to see them.

There were also 70% of children who met Children's Epilepsy Surgical Service (CESS) referral criteria who had not received a referral. This suggests there may be children with surgically treatable epilepsies who are missing out on evaluation and treatment. EEG and other investigations were often available within the Trust or Health Board. However, services may need to work within their regional epilepsy

There were also 70% of children who met Children's Epilepsy Surgical Service (CESS) referral criteria who had not received a referral

network [RCPCH, OPEN UK] or Integrated Care System to establish shared care pathways to paediatric neurology and the CESS.

The audit is supported by a group of young volunteers, the Epilepsy12 Youth Advocates. The young people steered us strongly towards themes around 'contactability' of services, and



to consider mental health and wellbeing of young people with epilepsy – and not just their seizures.

Just 14% of services were able to provide mental health provision within their epilepsy clinics, and 48% of services still report a typical response time of three or more days when families seek advice in between clinics.

The Youth Advocates have been working on a quality improvement project with eight paediatric epilepsy services. They are creating a self-assessment tool for paediatric epilepsy services looking to find out what makes ‘gold standard services’ in supporting patients’ worries and anxieties. The services involved many members of their teams to complete the checklist, evaluating their own service and processes. There were many great examples of how clinics were working to support worries and anxieties. All eight clinics engaged well with the self-assessment process and some were even able to involve their patients.

The Youth Advocates reviewed each service’s submission for: things they were doing well, ideas for change, and the support offered. Each service was provided with individual feedback, suggestions based on the other services, and resources and tools. The Youth Advocates found a lot of simple ideas and changes which they felt

could make a huge difference to patients and their families. A lot of ideas the services are using were cheap, quick and easy, although others required some further thought and planning. The advocates ‘top tips’ from the feedback services gave on the checklists are below.

Cheap, quick and easy ideas

- A clear out-of-hours voice message for patients with advice and signposting where appropriate
- Linking to local support for worries and anxieties, such as: Kooth (online service), MeeTwo (online service), local counselling services, charities, school services or youth services
- Provide ‘protected time’ to discuss anxieties and worries with patients and families, including, when appropriate for their age, the patient being offered time to be seen alone

With more time and planning

- Develop new patient information packs and make these age-specific – which includes signposting to services, national charities, helplines and specific information, such as driving, exams and travel
- Ensure good timely processes between A&E and being seen in clinic
- First aid training for patients and families
- The ability to offer school or home visits especially for newly diagnosed patients

Epilepsy care provision is still not commonly embedded alongside mental health and educational provision. Unexpectedly, both issues may be helped by the rapid developments towards virtual working and different models of remote clinics prompted by the COVID-19 pandemic.

The RCPCH Epilepsy Quality Improvement Programme (EQIP) has





seen 12 local epilepsy teams work together to construct, deliver and showcase tangible improvements in a broad range of areas for their service. In 2019, 55.9% of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals. One EQIP team chose to focus on setting up a new transition service and process using 'Ready, Steady, Go' [Southampton Children's Hospital, 2020] to develop a plan for each young person. Others [RCPCH, EQIP] reduced waiting times in their clinics, improved the pathways and information for new patients and tested different ways to improve the EEG experience to increase the number of high-quality recordings. It has been heartening to see how the passion to collaborate proved so resilient through the pandemic. Teams have used their quality improvement knowledge to rapidly test, adapt and improve their new ways of working and communicating [EQIP, 2020].

Our challenges going forward are beginning to reveal themselves.

COVID-19 is clearly impacting the health and care provision for children with long-term conditions like epilepsy. But it is also challenging our ability to collect the intelligence needed to describe this impact and make the case for prioritising further provision. Ongoing audit and quality improvement programmes like Epilepsy12 are one way to make visible this impact and continue to improve outcomes.

You can find the 2020 Epilepsy12 reports at: bit.ly/321XMXK

You can also look at the results spreadsheets in the downloads section on that web page to see where you and your local service fit in.

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Further reading

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The Epilepsy Space



Learn . Share . Grow

The mobile friendly website is a helping hand for 16-25 year olds to live their best life with epilepsy

The Epilepsy Space will help young people to:

- Manage their epilepsy
- Feel less alone
- Increase their confidence
- Get the support they need

There's lots of epilepsy facts, tips and stories from young people sharing their experience.

The content is short and interactive. It's not all reading, there's video and young people can share their own quotes, stories and videos too.

It's been created with young people and reviewed by epilepsy nurses.

Take a look at:
epilepsyspace.org.uk

Get in touch:
learning@epilepsy.org.uk



Seizure cycles

Circadian and multidien fluctuations in epileptic brain activity

Dr Baud and Dr Rao discuss cycles in epileptic brain activity and their implication on clinical trials, monitoring treatment responses and seizure forecasting



The cyclical recurrence of seizures is a hallmark of epilepsy known since ancient times. Historically, seizure timing was related to cycles of natural variables, such as the lunar phase. By the early 20th century, a celestial basis for seizures fell out of favour. But striking accounts of institutionalised patients whose seizures occurred cyclically – at consistent times of the day, week, month or year – suggested the existence of a temporal structure in epileptic brain activity [Langdon-Down and Brain, 1929; Griffiths and Fox, 1938]. Yet, the fundamental question of why seizures occur when they occur remained unanswered. This knowledge gap stemmed mostly from the inability to objectively quantify seizures over long periods of time. Recently, however, this gap has been bridged by the advent of

technology for chronic electroencephalography (EEG).

The RNS System created by the company NeuroPace is a cranially-implanted pacemaker-like device

We were inspired by the prospect of seeing more than just overt seizures, the 'tip of the iceberg' in epilepsy

approved in the US for treatment of certain forms of drug-resistant focal epilepsy [Bergey *et al*, 2015; Nair *et al*, 2020]. Intracranial lead wires enable the device to detect seizures at their source(s) and to deliver responsive

electrical stimulation that promotes normalisation of brain activity [Sun and Morrell, 2014]. This approach has shown promising therapeutic results [Nair *et al*, 2020], but chronic recordings of brain activity stored by the device also have powerful diagnostic potential. For example, hourly counts of brief detections made by the device (interictal epileptiform activity, IEA) help characterise fluctuations in brain excitability. Meanwhile, counts of sustained detections help quantify electrographic seizures. Participants in clinical trials of the device also reported daily counts of seizures they experienced [Bergey *et al*, 2015]. We were inspired by the prospect of seeing more than just overt seizures, the 'tip of the iceberg' in epilepsy. So, we began investigating the relationships between IEA,

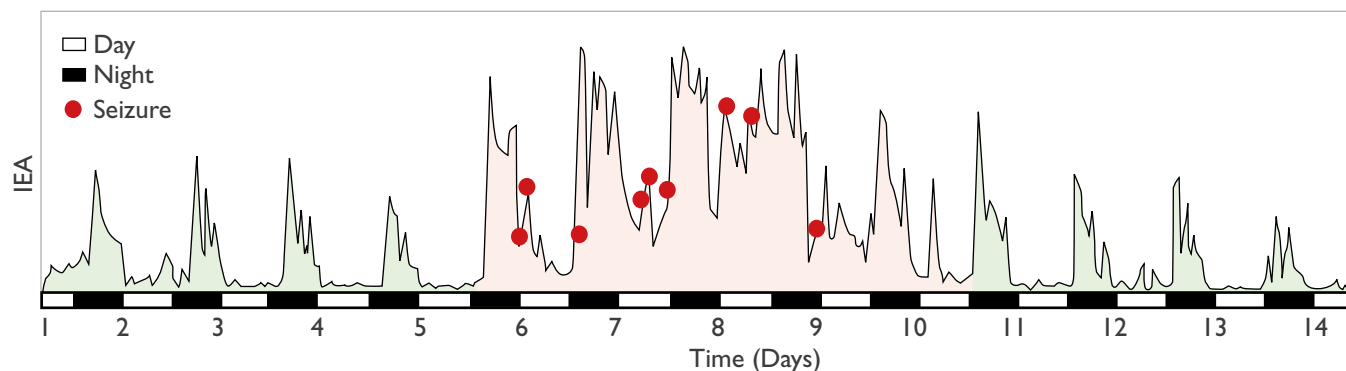


Figure: Fluctuations of epileptic brain activity. A 14-day long recording of chronic EEG in the patient's natural environment demonstrating circadian and multidien fluctuations in hourly counts of interictal epileptiform activity (IEA). Circadian cycles are evident as IEA waxes during nighttime (black rectangles) and wanes during daytime (white rectangles). Starting at day five, an underlying slow oscillation (multidien cycle) increases overall IEA for five days before returning to baseline. Seizures occur during this five-day period, indicating heightened seizure risk during these phases of the multidien cycle.



electrographic seizures and patient-reported seizures.

We anticipated that IEA would fluctuate in concert with the day-night cycle, as circadian (about-daily) influence on brain excitability has been described. But, we soon made an unexpected finding: in addition to circadian periodicity, IEA also oscillates with robust multi-day periodicity, a phenomenon that we termed “multidien” cycles [Baud *et al*, 2018]. These long cycles could be the basis for variability in IEA captured on serial routine EEGs, a frequent source of consternation for clinicians. Indeed, we found that multidien IEA cycles exist in around 60% of patients. They seemed less prevalent than ubiquitous circadian IEA cycles, but they were just as robust and occurred equally in men and women. Thus, multidien cycles cannot be explained only by catamenial effects [Herzog, 2015], and the underlying mechanisms remain elusive.

We next asked how multidien cycles of IEA relate to the occurrence of seizures. Remarkably, we found that seizures occur preferentially at certain phases of

multidien cycles. Specifically, electrographic and self-reported seizures tend to cluster on the rising phases (upslope) of these cycles [Baud *et al*, 2018], possibly reflecting a predilection of seizures for specific states of brain excitability [Baud *et al*, 2020]. Modulation of seizure timing by multidien cycles is very consistent across subjects and, on

We soon made an unexpected finding: in addition to circadian periodicity, interictal epileptiform activity also oscillates with robust multi-day periodicity

average, is as strong as circadian modulation of seizures.

The period-length of multidien cycles is variable across individuals but relatively constant over time within an individual. Gender and seizure

localisation are not major determinants of the periodicity of seizures, which, across individuals, centers around seven, 15, 20, and 30 days [Baud *et al*, 2018; Rao *et al*, 2020]. Given these periodicities, we assessed whether external fixed cycles – days of the week, month, or lunar cycles – correlate with seizure timing. In some cases, day of the week may influence seizures [Karoly *et al*, 2018], possibly secondary to systematic variation in stress and behavioral factors. However, we did not find statistical evidence that the arbitrary seven-day week plays a major role in the chronobiology of epilepsy [Rao *et al*, 2020]. Rather, multidien cycles in epilepsy seem to be generated endogenously and are free-running (that is, their periodicity is not paced by the environment).

So far, our findings can be generalised to other mammalian species. Similar multidien cycles of IEA and seizures were found in a rat model of temporal lobe epilepsy [Baud *et al*, 2019] and in dogs with naturally occurring epilepsy [Gregg *et al*, 2020]. In these models, just like in humans with epilepsy, seizures tended to occur on the rising phase of IEA over multiple days. Slow cycles of IEA were also found in another long-term human EEG dataset [Karoly *et al*, 2016], and the phasic relationship of seizures to these cycles was recently confirmed [Maturana *et al*, 2020]. These studies, employing passive EEG recordings, address concerns about confounding effects of brain stimulation on cycles of IEA measured with the RNS System.

These discoveries have tangible implications for clinical practice and research in epilepsy. Natural fluctuations in IEA limit the ability to monitor treatment response with short timescale studies, such as routine EEG. Small changes in the number of

epileptiform discharges from one routine EEG recording to the next are negligible in comparison to large fluctuations in IEA over multiple days. Cyclical variation in seizures also has implications for the design of short-term clinical trials in which seizure frequency is an endpoint. Of course, it is not feasible for all people with epilepsy to be implanted with an intracranial device for chronic EEG, and the RNS System is currently only commercially-available in the US.

Natural fluctuations in interictal epileptiform activity limit the ability to monitor treatment response with short timescale studies, such as routine EEG

Minimally-invasive (for instance, sub-scalp) devices are being developed in a number of European countries, in Australia and the US [Duun-Henriksen *et al*, 2020]. Such innovative devices have the potential to revolutionise clinical care in epilepsy by widening the temporal lens for evaluating this dynamic disorder [Baud and Rao, 2018]. Like continuous glucose monitoring in diabetes, the ability to monitor continuously epileptic brain activity paves the way for tailored, time-varying therapies in the future. For example, estimating the momentary and future risk of seizures ('seizure forecasting') may enable novel preventative treatments. Seizure forecasting is not a new concept [Litt and Echauz, 2002]. But the field has pivoted from identifying neural activity signatures in the seconds or minutes before seizure onset to leveraging





longer timescale information. Circadian [Karoly *et al*, 2017] and multidien cycles [Proix *et al*, 2020; Maturana *et al*,

With reliable seizure forecasting, dynamic risk-based treatment strategies or 'chronotherapy' will become increasingly feasible

2020] can allow to anticipate upcoming seizures. With reliable seizure forecasting, dynamic, risk-based treatment strategies or 'chronotherapy' [Sánchez Fernández

and Loddenkemper, 2018], will become increasingly feasible. Challenges for the field include elucidating the mechanistic basis for multidien cycles, developing less-invasive means for tracking these cycles, and refining seizure forecasting algorithms. Indeed, much work remains to be done, and, for patients and providers alike, time is of the essence.

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Tribute to Sue Higgins

Epilepsy specialist nurse Sue Higgins died in 2020. Mel Goodwin and Phil Tittensor pay tribute to one of the UK's most influential ESNs



We had the privilege of working closely with Sue Higgins, Epilepsy Specialist Nurse (ESN) for more than 20 years. We present a tribute to one of the UK's most influential ESNs, put together with the help of Sue's colleagues and life-long friends.

Sue worked tirelessly to improve the care of people with epilepsy for over 20 years. She started her epilepsy specialism as an ESN at the Queen Elizabeth hospital in Birmingham, honing the clinical skills that would underpin the rest of her career. In 1998, she took on a pharmaceutical company sponsored role aimed at improving access to epilepsy services in the UK by increasing the number of ESNs. This post epitomised Sue's drive to promote nursing and match enthusiastic nurses to suitable posts. I (Phil) owe Sue huge thanks for persuading an initially sceptical neurologist in Stafford that a nurse from a learning disabilities background could take on the role of an ESN, thereby launching me on the epilepsy trail.

Having supported the development of a number of new ESN posts, Sue took the opportunity to return to her first love – directly supporting patients. She set up and ran a thriving and busy epilepsy service at Gloucestershire Royal Hospital, establishing the role and ensuring its continuity and subsequent expansion. Sue continued as an ESN in

Gloucester until she took early retirement in 2016, a decision that gave her the chance to indulge her love of travel, immersing herself in new cultures and experiences.

Sue had a strong academic background. She was heavily involved with ESN education, working as a lecturer and examiner at Leeds Metropolitan University. Sue and I (Mel) were founding members of a small nursing research group. Within that group, Sue was the 'queen' of statistics and databases and went on to publish a number of research papers. These ranged from a seminal study on the role of the ESN, through to articles on nurse prescribing and sudden unexpected death in epilepsy (SUDEP). Sue's wish was to champion epilepsy research. To that end, a Just Giving page for Epilepsy Research UK has been created in her name. Visit [bit.ly/3mPjoPe](https://www.justgiving.com/epilepsyresearchuk) to make a donation.

Sue passionately wanted to help each ESN achieve their full potential. One of the ways she championed this was through her work with the Epilepsy Nurses Association (ESNA). For many years, she kept nurses apprised of the latest developments in the organisation as its membership secretary. She dealt with queries and generally ensured that nurses got the best possible experience and support from the association.

Despite her busy career, Sue placed her family at the top of her

agenda and was a devoted daughter. She nursed both her mother and father through terminal illness with enormous dignity and compassion, qualities that epitomised her nursing career.

Sue was, herself, diagnosed with epilepsy several years prior to her retirement. She dealt with this in her usual stoic manner, refusing to allow the presence of seizures to diminish her passion for life. Sue died at home in March 2020 at the age of 58. She has been a part of our lives for a quarter of a century and has touched the lives of countless people from a variety of professions during that time. She was always courteous, supportive and constructive. Above all, she has been a source of incredible support, professionalism and expertise for her patients. We were privileged and fortunate to have worked closely with her, and incredibly proud to call her a friend.

Mel Goodwin, Clinical Nurse Specialist in Epilepsy and Phil Tittensor, Consultant Nurse for the Epilepsies

The tribute was put together with input from Sue's colleagues from ESNA and from Gloucestershire (Sarah Clifford, Geraint Fuller, Penny Shewell and Janie Cowmeadow), and life-long friends and colleagues Veena Rellon-Basra and Melanie Wilcox.



Risk management during COVID-19

Keeping people with epilepsy safer with the ERA
Scale during the pandemic

Rachel Ison and Heather Angus-Leppan describe how the recently developed ERA Scale can help clinicians and people with epilepsy better manage epilepsy risks exacerbated by the COVID-19 pandemic



The Landscape

The coronavirus disease 2019 (COVID-19) pandemic has radically changed many aspects of our lives, including healthcare. While this poses challenges for everyone, it has been particularly disruptive for those with chronic conditions such as epilepsy. Our patients have had to alter how they access care, and we have had to alter how we provide it.

Routine care for epilepsy is no longer 'routine'. There has been increased difficulty in accessing care with delayed, rescheduled or even cancelled appointments due to pressured resources [Brigo *et al*, 2020]. There has also been a shift away from face-to-face contact, which has previously been a core part of treatment and management for people with epilepsy. This affects elements such as medication access and adherence, seizure management plans, risk assessments, driving licence reviews, and the identification and treatment of comorbidities [Adan, Mitchell and Marson, 2020]. Government measures aiming to control the pandemic, such as lockdown, self-isolation and social distancing, have their own fallout, one being a detrimental impact on people's

mental health. Some have experienced increases in loneliness, anxiety and panic [Torales *et al*, 2020]. This is a pressing concern to focus on in clinical practice due to the higher rates of psychological difficulties in people with epilepsy [WHO, 2019].

The Epilepsy Risk Awareness Scale is a validated, holistic risk assessment tool for people with epilepsy

As professionals working with people with epilepsy through the COVID-19 pandemic, we will already be asking questions such as: Are there new risks we need to be mindful of? How can we improve our information sharing when delivering care remotely? How do plans need to be updated to support our patients' safety? How will the required lifestyle changes affect our patients psychosocially as well as medically?

Although a medical approach is vital when assessing risk, epilepsy has complex biopsychosocial aspects, so risk must be considered holistically

and within the context of individuals' lives [Epilepsy Action, 2020].

The Epilepsy Risk Awareness (ERA) Scale

The ERA Scale is a validated, holistic risk assessment tool for people with epilepsy. In June 2020, the ERA Scale (version 3) was published and made available for clinical use [Ison *et al*, 2020]. The idea originated from an identified gap in risk-related assessment tools. There was no one standardised tool used by all healthcare professionals and people with epilepsy, or one that focused on improving both safety and quality of life. Importantly, healthcare professionals and people with epilepsy were involved throughout the multiple phases of development, supporting both the design and content [Ison *et al*, 2020; Braun *et al*, 2017; Cole *et al*, 2010]. The ERA Scale contains questions across four main sections: Your Epilepsy, Your Personal Safety, Your Physical Wellbeing, and Your Mental Wellbeing.

The ERA Scale and COVID-19

There are a number of reasons why incorporating the ERA Scale into clinical practice could help to keep



people with epilepsy safer during the COVID-19 pandemic.

Standardised approach to risk assessment

While the ERA Scale was not designed with a global pandemic in mind, it was designed to standardise risk assessment in epilepsy. Given the healthcare system's fraught 'new normal', it is even more important to have a shared and robust method to assess risk. It can be vital in order to keep our patients safer and living as well as possible within the restrictions. The NHS and other organisations are creating ways to improve information sharing to support clinicians and

The ERA Scale can be incorporated into care plans to prevent unnecessary hospital admissions and provide clear emergency plans and thresholds for seeking urgent help

patients during COVID-19. For example, NHS Digital and NHSX introduced GP Connect. This enables authorised clinical staff to access primary care records so they can provide patients with quick and appropriate care, regardless of whether they have accessed that particular service before [NHS Digital, 2020]. There can be many different healthcare professionals and services involved with each person with epilepsy, including epilepsy specialist nurses (ESNs), GPs and neurologists. If every one of them utilised the ERA Scale, it would be another method to enhance information sharing,

communication and, ultimately, care. This would also help to streamline the documentation of clinical consultations – an ongoing priority.

Care plans

In this period of change and uncertainty, robust care plans are particularly important for people with epilepsy. The ERA Scale can stimulate tailored, holistic conversations around risk. These can help fulfil NICE guidelines for comprehensive care plans, agreed by the person with epilepsy and their care team, and focused on both lifestyle and medical issues [NICE, 2012]. The process of completing the ERA Scale with a person with epilepsy encourages shared decision-making. This helps balance risk reduction with avoiding excessive restrictions, and helps to improve their quality of life.

Additionally, the recommendation for professionals working with people with epilepsy during COVID-19 is to reduce the risk of exposure where possible. This means minimising visits to outpatient clinics and hospitals [French *et al*, 2020]. The ERA Scale can be incorporated into care plans to prevent unnecessary hospital admissions and provide clear emergency plans and thresholds for seeking urgent help.

Holistic approach to risk assessment

The psychological and social impacts of COVID-19 are major and becoming ever more apparent. They include increased anxiety, loneliness, economic and employment challenges, to list a few. Irrespective of the pandemic, it is well documented that these are challenges that people with epilepsy face, so an integrated approach to risk, treatment and management is even more critical. The diverse sections of the ERA Scale aim to encourage people with epilepsy to share their

experiences beyond their medical symptoms, enabling healthcare professionals to understand them on a more personal level. It also provides an opportunity for people with epilepsy to feel listened to and be treated as experts in their own life and condition. All of this could lead to improvements in patient-clinician relationships [Ha and Longnecker, 2010], clinical outcomes and self-management [Alexander *et al*, 2012]. To gauge psychological and social risks, the ERA Scale asks questions about a wide range of topics. They include alcohol consumption, sleep patterns, employment status, strategies to manage stress, support systems and needed access to mental health care.

Future developments

Our research group is developing the ERA Scale into a free mobile app, which

will be available in 2021. This vital move towards telemedicine will increase its accessibility, which is particularly important during COVID-19. It will also allow the scale to be quantified and therefore provide risk scores. This will support people with epilepsy and healthcare professionals to monitor changes to risk over time, both in the short-term and long-term. It will enable us to look at overall risk, as well as risk in specific aspects of individuals' lives, such as mental wellbeing.

The development of the ERA Scale and app has been supported by Epilepsy Action as part of the Epilepsy-Related Deaths Project, which aims to reduce epilepsy mortality.

To view the ERA Scale, see: bit.ly/3k2SUaW

For more information about the ERA Scale, please contact Dr Heather Angus-Leppan, Consultant Neurologist,

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Acknowledgements

Our thanks to Epilepsy Action, the Royal Free Charity and the National Institute for Health Research for their support.

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Highlights

Top picks from *Seizure*

Editor of the journal *Seizure*, Professor Markus Reuber highlights his key papers from the latest editions

Like antiseizure and other medications, antibiotic drugs have a hard time getting into the brain. Orally administered preparations have to survive the acidity of the stomach, penetrate the intestinal mucosa and potential first-pass metabolism in the liver. From there, they need to get to the head and pass the blood brain barrier. It is perhaps not surprising that it was an attempt to overcome these hurdles that first led to the discovery of the seizure-provoking effects of penicillin. Very soon after this drug was first discovered, it was noted that the intraventricular injection of penicillin caused myoclonic jerking [Johnson and Walker, 1945]. This discovery has been put to good use since – when penicillin is used in animal research as a precipitant for acute seizures or (with repeated administration) for epilepsy [Kandratavicius *et al*, 2014]. However, the ictogenic and epileptogenic potential of penicillin and more recent antibiotic drugs continue to be problematic when these potentially life-saving medicines are used to treat infections in humans.

My editor's choice paper from issue 81 of *Seizure*, by Pitchaya Wanleenuwat *et al*, provides a masterly overview of the different ways in which antibiotic treatment can precipitate seizures [Wanleenuwat *et*



al, 2020]. The most commonly used antibiotic drugs, β -lactams and fluoroquinolones, are also the ones most closely associated with neurotoxic side-effects. Directly seizure-promoting mechanisms include interference with inhibitory processes and enhancement of excitatory processes (such as gamma-aminobutyric acid (GABA) antagonism, inhibition of GABA synthesis or glutamergic N-methyl-D-Aspartate (NMDA) receptor agonism). However, other mechanisms may play an additional role, and patients with hepatic and renal insufficiencies – both the rule rather than the exception in elderly patients – are at greatest risk. Directly harmful effects of antibiotics within the brain are particularly common in clinical scenarios in which the efficacy of the blood brain barrier is reduced – for instance in infections involving the meninges. Macrolide antibiotics (clarithromycin and erythromycin) can cause neurotoxic effects (including delirium and seizures) by inhibiting the hepatic metabolism of antiepileptic drugs. Carbapenem can enhance valproate breakdown, thereby increasing the risk of seizures.

There are clearly many and complex ways in which epilepsy, infections, antiseizure medications and antibiotics can interact. So, one

wonders how often a deterioration of seizure control in an individual with epilepsy was actually due to the medicine prescribed to combat an intercurrent infection rather than the infective illness itself.

Multi-directional interactions

Epilepsies are conditions not only characterised by the seizures which define them but also by their neurobiological, cognitive and psychosocial consequences. Particular 'consequences' may not be linked exclusively to epilepsy, but they are so common, and their patterns so characteristic, that they have been included in the definition of epilepsy [Fisher *et al*, 2005]. Although the word 'consequence' implies a unidirectional relationship in which seizures are the cause, in many cases, there are bidirectional relationships between certain neurobiological, cognitive or psychosocial features and epileptic seizures. For instance, individuals with uncontrolled epilepsy are more likely to experience symptoms of depression than those whose seizures are well controlled [Jacoby *et al*, 1996]. At the same time, depressed individuals are more likely to have epileptic seizures (or to develop epilepsy) than those who are not [Hesdorffer *et al*, 2012]. Having said that, the term 'bi-directional' still oversimplifies these associations. Particular features interact not only with epileptic seizures but also with each other, as well as the underlying cause of the epilepsy and its potential consequences. Therefore, the relationships between different features really need to be thought of as 'multi' rather than 'bi' directional.

All this becomes even more complicated in children and adolescents. In them, interactions are not limited to features associated with epileptic seizures and any

underlying disease, but also include features associated with neurobiological, cognitive and psychosocial brain development.

My editor's choice paper from issue 82 of *Seizure* is an original article by Tamar Silberg *et al* [2020]. It explores some of these multifactorial interactions by describing the relationship between cognitive, emotional, behavioural and seizure-related variables in a sizable group of children and adolescents. Using data from a range of sources, including clinical information, neuropsychological testing, and parent and teacher reports, they found that parents and teachers both reported high levels of emotional and behavioural problems. Teachers reported more emotional and behavioural problems than parents. However, at group level, the cognitive profile of the sample was within the normal range. The relationship of teachers' assessment of emotional and behavioural problems and epilepsy-related factors, such as the number of antiseizure medications and illness duration, was mediated by the children's cognitive performance. This mediation effect was not observed in relation to parents' reports of

emotional and behavioural problems. Perhaps this reflects the different situation in which parents and teachers observe children's behaviour or the more complex relationships between parents and their children. The findings could also have been influenced by negative attitudes towards epilepsy among teachers, leading to an increased perception of emotional and behavioural problems, especially in children with cognitive problems.

The reasons for the differences in the perceptions of parents and teachers are not clear. But the discrepancies found in this study highlight the importance of taking full account of the sources of information about patients and the context in which the information was gathered. In order to achieve an optimal understanding of an individual's epilepsy, its consequences and associations, and to provide optimal intervention, information from multiple sources needs to be carefully triangulated. A correlation between two features does not always mean that there is a causal link. Even when there is a link, causation may be mediated by a third (or multiple other) factor(s).

Further reading

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ILAE symposium



ILAE COVID-19 Symposium

Learnings from the COVID-19 pandemic from the International League Against Epilepsy

Kami Kountcheva summarises some of the main topics discussed at the virtual symposium, held in September 2020, on epilepsy care during the COVID-19 pandemic



This year has been largely dominated and underpinned by COVID-19 and the worldwide pandemic. After an initial spike in cases and subsequent lockdown back in March, we are still dealing with the predicted second spike.

The coronavirus outbreak has placed enormous pressure on the NHS and has had a detrimental effect on many different health services, including epilepsy.

The International League Against Epilepsy (ILAE) held a virtual epilepsy symposium on 8 September 2020 entitled 'Learnings from the COVID Pandemic: The New Normal'.

The symposium was moderated by Julie Hall and chaired by Prof Helen Cross, Honorary Consultant in Paediatric Neurology and The Prince of Wales' Chair of Childhood Epilepsy. They were joined by Prof Samuel Wiebe, Prof Emilio Perucca and Prof Ingmar Blümcke. Prof Wiebe is Professor at the Department of Clinical Neurosciences, Associate Dean for Clinical Research and Director of the Comprehensive Epilepsy Program at the University of Calgary (Canada). Prof Perucca is a Professor at the University of Pavia and Director of the Clinical Trial Center of the C. Mondino National Neurological Institute in Pavia (Italy).

Prof Blümcke is Director, Neuropathology Department, University Hospital Erlangen and professor at Friedrich-Alexander University School of Medicine (Germany). The symposium focused on neurological implications of COVID-19, effects on anti-seizure medications, the pathology of COVID-19, attempts to optimise patient care during a pandemic and potential lessons from COVID-19 for the future.

COVID-19 and epilepsy risks

Prof Cross stated that having epilepsy does not seem to be a risk factor for getting COVID-19 or having more

A disruption in circadian hygiene in terms of sleep, eating patterns and exercise could be contributing to an increase in seizures

severe symptoms of the disease*. She added that, generally, evidence suggests that COVID-19 seems less severe in children. However, some comorbidities

of epilepsy could result in more severe COVID-19 symptoms, such as existing respiratory problems.

Prof Wiebe pointed out that people in more deprived socio-economic areas seem to be at higher risk of more severe COVID-19 symptoms and mortality. This is something that has been reflected in the media for many months.

The panel agreed that coronavirus does not appear to exacerbate seizures any more than other common respiratory viruses. However, they said people have reported an increase in seizure frequency during the pandemic.

Prof Wiebe highlighted that the disruption to people's lives by the pandemic could be a cause for an increase in seizures. A disruption in circadian hygiene in terms of sleep, eating patterns and exercise, among other things, could be contributing to the problem. He said that the pandemic has certainly uncovered pre-existing mental health problems in some patients with epilepsy. This will be incredibly important to address and manage both now and in the future.

Mental health is equally important in children and young people with epilepsy as in older people. A complete lack of routine, being out of school and constantly



in the family environment is likely to affect many children. Prof Cross cited a survey carried out by 'Young Epilepsy' that reported an increase in seizures. She explained that possible factors for this increase could include difficulty accessing AEDs, a reluctance to go to hospital for fear of catching coronavirus and an inability to see their neurologist. She said behavioural changes, anxiety, depression and sleep disturbance were reported in the survey. The mental health of parents and carers has also been affected through economic, family dynamic, financial and employment problems, a lack of routine and stress. However, Prof Cross did highlight that there have been some positive experiences including more family time together and, in some cases, a healthier lifestyle.

Clinical practice

The COVID-19 pandemic has had a profound and lasting effect on epilepsy services. Prof Cross explained that throughout the pandemic, services have had to try to carry on. Service providers have had to ensure families have a continuous point of contact to seek advice, while keeping children out of hospital as much as possible. She added that very clear advice has had to be given about when to attend hospital and when not. Healthcare providers have also had to ensure a sustained supply of AEDs for patients through longer prescriptions. Prof Cross added that it is particularly important to ensure patients with epilepsy know where to go for advice and support for mental health problems.

Prof Wiebe said the young adult population has been affected slightly differently. Factors such as isolation, not being able to gather with others, and not being able to see friends face

to face have played a part in their wellbeing and stress levels.

When these people are seen in clinic, most of the time is spent managing psychosocial problems. He said the requirements for effective communication have increased. In this group of patients, asking the right questions is important to uncover any mental health concerns, as they can go undetected. This is key, as mental

Prof Cross said that it is particularly important to ensure patients with epilepsy know where to go for advice and support for mental health conditions

health problems can then affect things like medicine adherence and sleep.

In older people, Prof Wiebe said managing medicine interactions is a key aspect of clinical work. In this group, a lot of time is spent talking about comorbidities. In these difficult circumstances, it can be hard to be sure that a patient's comorbidities are being managed by another service. He added that it's important not to neglect their epilepsy when also managing comorbidities, and to keep an eye for more subtle changes in condition.

Prof Wiebe mentioned the high risk of COVID-19 spread in care and nursing homes. He said this is very important to consider.

The panel also highlighted that older patients sometimes stay at home with very serious conditions such as strokes and cardiac comorbidities. This is often due to fear of being in a hospital and contracting COVID-19.

Prof Wiebe added that there is a need to emphasise to this group that hospitals are fairly safe places now and that they should seek medical help for serious conditions like these.

Drug therapy management

Prof Perucca spoke about the importance of maintaining a supply of medicines for patients at a time when supply could be affected. He acknowledged that it is difficult to give advice applicable across the world, as different places are at different stages with the pandemic. However, he said ensuring that patients don't run out of medicines is vital, possibly through prescriptions that allow medications to be supplied for many, rather than just one month. He also said the threshold for using rescue medicines should be reviewed and, in specific situations, lowered to prevent or avoid prolonged seizures and the need for hospital care. He added that changes to medicines that could compromise seizure control, such as withdrawing medicines in patients who are seizure free, should be postponed.

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Regarding interactions with COVID-19 treatment, he highlighted that we do not yet have a drug to treat COVID-19. But he said the classes of drugs currently used are steroids. These may be significantly

affected by enzyme inducing agents, so care should be taken with certain AEDs. Prof Perucca suggested that intravenous rather than oral administration of COVID-19 medicine (such as steroids) could minimise any interactions. He also added that people being treated for COVID-19 will probably also be taking many other medicines, which might also interact with AEDs. He said that, wherever possible, AEDs with the lowest risk of interactions with other drugs should be prescribed.

Telemedicine

Telemedicine has also become a staple of healthcare services during the pandemic to help ensure that care is optimised during this time and disparity of care is avoided. It offers much in terms of being able to see the patient, as well as speak to them. It should be stressed that this is not ideal for everyone. Prof Cross said some patients may prefer a simple phone call. But in the absence of face-to-face consultations, it is an important tool. Prof Cross added that young people can often feel more comfortable with video calls, if only because they are much more used to this form of communication.

She added that there can be issues with video calls. People may not have access to the internet or have the bandwidth to do these types of calls. Telemedicine also requires good preparation in advance on the part of the clinician and the patient, which may be more so than would have been needed previously.

Prof Wiebe added that older patients and those with cognitive impairment or who need somebody with them could struggle with video calls. As well as this, issues with language barriers may be more challenging to solve through video conferencing and can make





communications difficult and confusing. Working out a secure and private way to share video footage of epilepsy events is also important. Clinicians must be readily available and sensitive in recognising which patients need urgent consultations and investigation. The panel agreed that in this day and age, internet access and good bandwidth is part of, and should become standard practice in, healthcare provision.

New normal

The panel were sure that the healthcare landscape looks and will continue to look very different to what it did before the pandemic. However, all were in agreement that there should be one clear, coherent and consistent message – that healthcare, research and learning must continue.

Prof Cross said that during the beginning and at the peak of the pandemic, hospitals stopped doing investigations. She argued that it is now safe to do EEGs, MRIs and video telemetry with appropriate precautions. These investigations must continue to maintain the best

levels of patient management. Prof Wiebe added that recent events have highlighted the need to empower patients to take control of their own conditions when access to specialists is difficult (although it must be acknowledged that this is often easier said than done). This includes patients and their families understanding their epilepsy and things like what medicines they are taking and at what doses. He also stressed that mental health cannot be overemphasised or neglected.

Prof Blümcke explained that online teaching may become the new normal. He also believes that there may be a change in medical competencies in case professionals need to respond to a medical emergency like this again.

Prof Perucca said COVID-19 has slowed research and he had three messages to share. Firstly, epilepsy research should not stop, as this is clearly important, particularly for those with intractable epilepsy. Secondly, he said that the pandemic has revealed extraordinary opportunities to use new technology which has been incredibly useful, and we should learn how to best integrate

it into research. Lastly, we must establish contingency plans to try and ensure research can continue.

Prof Cross closed, saying that we can't stop treating patients with epilepsy when we have an outbreak of an illness like COVID-19. She said we should all strive to advocate continuing care and deliver the service our patients need.

The symposium showed the importance of adapting services in order to continue to deliver the highest quality of care despite the crisis and chaos around us. The pandemic has also shown how common and under-managed mental health problems are in patients with epilepsy, and other chronic conditions. This must be addressed help reduce seizure frequency and optimise people's self-management of their epilepsy and overall quality of life. Clinical practice now relies more heavily than ever on very effective communication between healthcare professionals and patients, as well as on new technologies to help bridge the face-to-face gap left by COVID-19. The biggest take-home message the panel wanted to share was that patient management, teaching and research must continue even when there is a global medical emergency. The tools we have developed for patient care and teaching are here to stay and we should ensure they are improved and become an integrated part of patient care wherever possible.

To see the symposium in full, visit: bit.ly/34Y5dB4

**The symposium was held on 8 September 2020, before the publication of a large study suggesting that epilepsy is associated with a slight increase in hospitalisation or death as a result of COVID-19 (more on page 6). The study can be found at: bit.ly/2UAtDut*

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Grow your confidence managing epilepsy in your family

Your child and epilepsy is a new online course for parents and carers of children with epilepsy. It's been developed with parents, epilepsy nurses and psychologists.

This course is a helping hand to support families on their epilepsy journey. It's full of advice and stories from parents. It aims to give parents and carers the confidence, skills and knowledge to support their child to manage their epilepsy.

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Leaflets about the course to give to families can be requested by emailing nurseorders@epilepsy.org.uk

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Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust



Inspiring the next generation

The Serenity Prayer has us wishing for the “serenity to accept the things we cannot change, the courage to change the things we can, and the wisdom to know the difference.” I have written before about Brexit, about COVID, but I draw the line at writing an opinion piece about American politics and today’s broken electoral college system. (But I will say that the Presidency race remains on a knife edge as I write this!) Perhaps I’m not keen to write about it because, despite my ambitions, I am relatively powerless to change political strategy. Or even vote in the American election, at that.

But something that does worry me, and that we can influence, is how we encourage the next generation of enthusiasts to specialise and care for people with epilepsy.

There is a national dearth of epilepsy specialist nurses, of general neurologists who relish the complexity of epilepsy, researchers, neurophysiologists and psychological support. We have come so far in terms of the number of specialists, the understanding of epilepsy and risk, and the therapies that we can provide. And yet – ancient attitudes may still prevail. I am reminded of the damning and narrowminded adage of mental health services spouted around as recently as couple of generations ago: ‘second-rate doctors for third-rate patients’. This pejorative aside is clearly harmful, outdated, derogatory and very far from the truth. But it does make you wonder whether ‘UK Epilepsy PLC’, if you will, has its best foot forward from a brand management point of view. The employment market for YESTIs (young enthusiasts with sufficient time and inclination) is weighted in its favour. But are we doing enough to instil them with the life-long passion for epilepsy care that we share?

How are we best to motivate? Look at the tools at our disposal. Do we excite people by saying we have nearly 30 drugs available for epilepsy? Or does this show weakness (if any one of them was any better than the rest, we’d not need another, let alone 30)? Do we project forward to the optimistic future with individualised therapies, implantable devices, wearable technology and self-driving cars? Or is the complexity, conversely, completely off-putting? People like rules and structures –

particularly as they learn. Yes, our terminology can be obtuse (how many ways do we need to describe a brief seizure where someone goes blank?), so how can I inspire anyone to study epilepsy by listening in to my phone clinic? The nuanced human interactions and subtleties are invisible down the line.

Just as epilepsy is more than just seizures, epilepsy care is far more than rational pharmacology. Epilepsy care remains remarkably easy to do remarkably poorly. Someone at the end of a detailed patient-led discussion about mood, sleep or employment, may pull the metaphorical lever marked ‘more Tegretol’ or ‘less Tegretol’ and usher the underwhelmed patient out of the door. Someone could pay lip-service to the importance of first seizure waiting times, SUDEP discussion standards, valproate audits, non-epileptic attack disorder psychology support. But they may also tolerate a postcode lottery where the system only works well in a handful of centres. This is all very possible. If we are too busy to make these changes – is that not reason enough why we need more colleagues to join us? And we need the best of the next generation, please, we have important work to do!

And finally, I know that one cannot ask to be replenished at the resilience well too often, before coming up dry in 2020; this year has tested all of us. If a call to arms to improve epilepsy care is too much for you now, we could consider this alternative mission statement from the cartoon strip Calvin and Hobbes: ‘grant me the strength to change what I can, the inability to accept what I can’t, and the incapacity to tell the difference’.

Dates for the diary

Dates and events may be subject to change – please check on the relevant websites.

2020

5-9 July
14th European Congress on
Epileptology (ECE)
POSTPONED TO 2022
Geneva, Switzerland
epilepsycongress.org/ece

2021

6-8 January
47th Annual Meeting of the British
Paediatric Neurology Association
Held virtually
bit.ly/3nHo35U

3-5 March
Fetal and Neonatal Neurology
Congress
Paris, France
mcascientificevents.eu

1-5 June
14th European Paediatric Neurology
Society Congress
Glasgow, UK

28 August – 1 September
34th International Epilepsy Congress
Paris, France
epilepsycongress.org/iecl

1 September
British YES Masterclass: What is a
Seizure?
Cardiff, UK
www.ilaebritishconference.org.uk/

28-30 September
ILAE British Branch Annual Scientific
Meeting
Cardiff, UK
www.ilaebritishconference.org.uk/

Next issue:

Mark Atherton

Case study: biotinidase
deficiency in infancy.

David Henshall

Potential new targets for
epilepsy medicine
development.

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