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1. Blümcke, Ingmar, et al. "Roadmap for a competency-based educational curriculum in epileptology: report of the Epilepsy Education Task Force of the International League Against Epilepsy." *Epileptic Disorders* 21.2 (2019): 129-140.

ABSTRACT

33rd international Epilepsy Congress

Bangkok, Thailand | 22–26 June 2019

SATELLITE SYMPOSIA ABSTRACTS

Saturday, 22 June 2019

Livanova

15:30–17:00

Shaping The Future Of Drug Resistant Epilepsy

Chair: Patrick Kwan (Australia)

Saturday, 22 June 2019

ucb

15:30–17:00

Treatment Gaps In Epilepsy

Chair: Raymond Edward Faught (USA)

Globally, approximately 50 million people are living with epilepsy, with nearly 80% of them in resource-limited, developing countries. A substantial proportion patients with epilepsy do not receive appropriate treatment, constituting an epilepsy 'treatment gap'. This occurs in up to 95% of patients in developing countries and in 10%–43% in developed countries such as the US and Australia.

Untreated epilepsy is a critical health issue, due to the continued risk of seizures and the associated physical injuries such as fractures and burns, as well as the psychological distress caused to patients. The epilepsy treatment gap occurs at different stages of the patient care pathway and is attributable to a combination of factors, including diagnostic delays, failure to receive treatment, limited access to tertiary care and the lack of patient engagement.

Diagnostic delays are particularly prevalent in developing countries due to the lack of awareness of epilepsy symptoms, limited diagnostic facilities, limited neurologic expertise of primary care providers and the inability to afford healthcare. In developed countries, while there is higher awareness of the symptoms of epilepsy and better access to neurologists, a large proportion of patients remain untreated or have delayed treatment initiation. Reasons from neurologists for not offering anti-epileptic drugs (AEDs) include the presence of

seizure precipitating factors, the risk-to-benefit ratio associated with AEDs and the perception that delayed AED therapy does not adversely affect the long-term potential to achieve seizure freedom. Patients may also choose not to receive treatment at first diagnosis, or even if they accept treatment, may have sub-optimal adherence for a variety of reasons.

The aim of this symposium is to discuss the challenges associated with epilepsy treatment gaps along the patient care pathway: from seizure onset to diagnosis, to treatment and referral to tertiary care; the importance of patient-physician dialogue will also be discussed.

Onset To Diagnosis

M. Tripathi*

**All India Institute of Medical Sciences, New Delhi, India*

More than 80% of people with epilepsy live in low- to middle-income countries (LMICs). Despite the availability of cost-effective anti-epileptic drugs, approximately 10%–98% of people with epilepsy remain untreated, with wider treatment gaps reported in LMICs and resource-limited regions of higher income countries. In India, the treatment gap ranges from 22% in urban middle-income populations to 90% in rural villages.

This session will focus on the gap from seizure onset to diagnosis in resource-limited settings. There are several factors contributing to poor diagnosis of epilepsy. Firstly, patients and their family members may be unaware of the symptoms of epilepsy, and hence do not seek medical attention.

Secondly, patients may avoid seeking medical attention due to the stigma associated with the disease. For example, in India, patients with epilepsy have lower marriage rates and higher divorce rates compared to the general population. Thirdly, there may be a lack of patient history, neurologic expertise among primary-care providers, healthcare facilities and diagnostic equipment, all of which are needed for an accurate diagnosis of epilepsy. Given the relative dearth of neurodiagnostics such as electroencephalogram, physicians rely

largely on patients' history to determine seizure semiology, which may lead to misdiagnoses.

Diagnosis To Treatment

R.E. Faught*

**Emory University, Atlanta, Georgia, USA*

Up to 95% of people with epilepsy in resource-limited developing countries do not receive anti-epileptic drugs (AEDs) due to limited patient awareness, social stigma and the lack of healthcare resources. In developed countries, despite higher awareness of the symptoms of epilepsy, and better access to accurate diagnostics and tertiary care, there is still a substantial treatment gap in epilepsy. In the US and Australia, the treatment gap in newly diagnosed epilepsy patients ranges from 10%–43%; in Australia, 29% are not offered treatment and 14% decline treatment. Untreated epilepsy is a critical health issue, with the risk of physical injuries such as fractures and burns in patients who experience seizures, and it contributes to greater psychological distress and mortality.

There are several factors that may explain why patients do not receive appropriate AED treatment within a short period after their diagnosis. This lecture will focus on the reasons for AED treatment delay from a physician perspective. Reasons from neurologists for not offering AEDs include: the presence of seizure precipitating factors, risk-to-benefit ratio associated with AEDs, waiting for further investigation, and the perception that delayed AED therapy does not adversely affect the long-term potential to achieve seizure freedom.

Gaps In Epilepsy Management

E. Beghi*

**University of Milan, Milan, Italy*

Patients with epilepsy are recommended to have regular follow-ups with specialists (neurologists or epileptologists) following treatment initiation for optimised clinical management. Specialists are well-placed to develop the most effective medical or surgical treatment plan, and manage the often complex needs of epilepsy patients. They allow patients to benefit from regular specialised assessments, information about their condition and treatment options, management of potential side effects and drug-drug interactions, and access to other professionals within a multidisciplinary team. Specialists have a particularly important role to play in women who wish to become pregnant, who need specific advice and management to control their disease while minimising the

risk to the foetus. Specialists are also important for timely assessment of patients' need for epilepsy surgery.

However, a large percentage of epilepsy patients are currently not accessing specialist care. In the US, 42% of patients do not see a neurologist or an epileptologist, and only 48% of qualifying patients are being referred to an epilepsy surgery specialist. Poor referral to specialist care is partly due to the limited availability of specialists, particularly in resource-limited countries: epilepsy specialists are only present in 43.5% of countries in the Western Pacific World Health Organisation region, 57.1% in Africa and 66.7% in the Eastern Mediterranean region. There may also be a lack of collaborative management between primary and specialty care or across various types of specialists.

This lecture will focus on the importance of referrals to specialist care and the challenges associated specialist care access.

Dialogue Between Physicians And Patients

F. Cendes*

**University of Campinas, São Paulo, Brazil*

Effective communication between physicians and patients is key to improving the quality of healthcare services provided to people with epilepsy, and driving optimal seizure control. Studies have reported that 14%–42% of patients decline treatment; common reasons include not recognising the necessity of treatment, fear of social implications and concerns regarding adverse events. There are also significant treatment non-adherence rates of 29%–66%. This is potentially due to limitations in physician-patient communication and the lack of patient engagement in clinical decision-making. Based on a study conducted in the US, Spain and Germany that observed neurologist-patient dialogues, it was identified that neurologists tend to focus on the adverse events of medications rather than the benefits. Neurologists also predominantly make treatment decisions without patient input and rarely clarify the meaning of 'seizure control' with patients.

Improvements in physician-patient communication and shared decision-making have a potential to improve patients' ability to effectively manage their condition. It is important that physicians use patient-friendly language to discuss seizures with patients and set treatment goals with them; patients should also be encouraged to consider the benefits and risks of treatment options, and assist in the selection of a treatment that will meet their treatment goals. This allows patients to be informed partners, and empowers them with the ability to evaluate the effectiveness of their treatment and the necessity for medication changes.

This lecture will focus on the need for effective physician-patient communication to improve the overall treatment experience and long-term outcomes of patients.

Monday, 24 June 2019
Eisai inc.
13:30–15:00

Striving For Seizure Freedom: Addressing Uncontrolled Seizures In Patients With Epilepsy

Chair: Patrick Kwan (Australia)

Tuesday, 25 June 2019
GW Pharmaceuticals
13:30–15:00

Science, Innovation And Technology In Epilepsy

Chair: Philippe Ryvlin (Switzerland)

Epilepsy is the most common chronic neurological disorder, affecting millions of people across the world. In the last decade, the interplay between science and technology has grown in importance, with the development of new innovative strategies to further improve epilepsy diagnosis, disease management and care. In this GW-sponsored parallel symposium, three expert speakers will each review one distinctive area of epilepsy research, exploring the current state of the art and highlighting some of today's research efforts and future opportunities. The first presentation will focus on seizure detection and wearable devices. This talk will explore the current state of the field and review the evidence supporting the real-world use of seizure detection devices. The second presentation will assess current invasive and implantable technology strategies, such as possible seizure prediction and drug delivery techniques, and their viability as possible disease-management initiatives. In the final presentation, the speaker will review the emergence of 'big data' analysis and deep learning as valuable techniques in epilepsy diagnosis. As modern computational power increases, researchers can analyse and review larger volumes of data in shorter periods of time. This continuing trend will bring new levels of disease understanding and has the potential to provide increasingly sophisticated approaches to epilepsy diagnosis, treatment and management. These presentations will be followed by a panel discussion (involving all of the faculty) and questions and answers with the audience, providing a unique opportunity to discuss the symposium topics in more detail.

Seizure Detection Using Wearable Devices: A Modern Possibility?

S. Beniczky*

**Danish Epilepsy Center and Aarhus University, Denmark*

Innovations in modern healthcare technology have improved the management of chronic disease and current research suggests a promising future for seizure monitoring devices in epilepsy. Automated seizure detection using wearable devices presents a number of advantages for patients with epilepsy: it allows for objective seizure documentation and monitoring over time, decreases

seizure-associated morbidity/mortality, and triggers on-demand therapy in closed-loop systems. Recent developments in the field have given rise to a large volume of research addressing seizure detection, although approaches and observed outcomes have varied greatly. Current literature shows robust evidence supporting the efficacy of non-electroencephalography (EEG)-based wearable devices for detecting generalised tonic-clonic seizures, and for detection of focal seizures using devices with intracranial EEG electrodes. This presentation by Professor Sándor Beniczky will review the current state of seizure detection and provide a clear picture of future direction, with a particular focus on the level of evidence that supports notable seizure detection devices.

Innovations In Epilepsy: Today's Science, Tomorrow's Technology

M. Cook*

**Department of Neurology, University of Melbourne*

Approaches to epilepsy disease management have long focused predominantly on the development of pharmaceuticals. More recently, there has been increasing interest in techniques that can monitor and detect seizures. While these techniques and their associated technologies offer varied benefits to patients, innovation also brings fresh perspective and the opportunity to rethink our approach to long-term epilepsy management. One of the most exciting emerging areas in epilepsy disease management is seizure prediction. The basis of seizure prediction is the use of long-term electroencephalography data (obtained from an implanted device) to build a data 'picture' unique to an individual patient; this 'picture' can be used to understand a patient's unique seizure types and patterns to such an extent that seizures can be predicted. The potential benefits of seizure prediction technologies range from providing patients with increased autonomy when living with this difficult disease, to maximising the use of current therapies. In this presentation, Professor Mark Cook will

explore the current state of the art in this cutting-edge area of epilepsy research and provide a thorough assessment of the current challenges and limitations of seizure prediction, while looking toward the opportunities for the future.

The Role Of Big Data And Deep Learning In Epilepsy Diagnosis

P. Botas*

**Foundation29, Madrid, Spain*

Epilepsy is one of the most common neurological diseases, affecting roughly 1% of the global population. Many epilepsy patients achieve adequate seizure control with management by their primary care physician and minimal neurologist contact. However, approximately 30% of patients with epilepsy have uncontrolled seizures, despite often being prescribed multi-drug therapy regimens. The diagnosis of epilepsy remains complex as, although the disease can begin to develop in early life, the onset of all symptoms can take years. It is estimated that ~40% of epilepsy patients have a genetically-associated epilepsy. This percentage is even larger in patients

showing no structural lesion in the brain. Analysis of genomic information of epilepsy patients is therefore an important step and may reduce the time to diagnosis, especially in instances where disease onset/symptoms are irregular or complex. 'Big data' analysis and machine learning techniques use artificial intelligence (AI) to emulate human processing; many modern AI approaches in epilepsy focus on the use of previous patient information to inform current diagnoses. With such methodology, patient symptoms are identified by searching electronic medical reports using clinical natural language processing. In this presentation, Dr Pablo Botas will discuss Dx29, a platform which assists healthcare professionals and patients during the disease diagnosis process. Created by Foundation29, a non-profit organisation dedicated to improving rare disease diagnosis, Dx29 enhances the capabilities of healthcare professionals by improving genetic variants analysis with public and contextual information. Symptoms outlined in electronic medical reports are automatically detected by means of AI, and used to aid patient mutation analysis. Feedback loops help the user to identify previously unnoticed symptoms, strengthening the connection between genotype and phenotype. A list of possible pathologies is then produced and prioritised, facilitating differential diagnosis.