C.6

Efficacy and safety of mTOR inhibitor therapy in a Canadian paediatric tuberous sclerosis complex cohort

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Background: Tuberous Sclerosis Complex (TSC) is a genetic condition marked by multisystem benign tumours. mTOR inhibitor (mTORi) therapy is indicated for subependymal giant cell astrocytomas (SEGA), renal angiomyolipomas (AML), and drug-resistant epilepsy. This study aimed to evaluate the efficacy and safety of mTORi in our paediatric TSC cohort. Methods: Data on patient demographics, clinical outcomes, and adverse events (AEs) were obtained from SickKids' prospective observational TSC Database (n=107). Results: 19 children (median age at diagnosis 0.6 years, range 0-8.3; F:M 10:9) received mTORi. Indications were SEGA (n=6), AML (n=4), seizures (n=4), prophylactic (n=2), AML/SEGA (n=1), seizures/AML (n=1), and seizures/SEGA (n=1). Median age at mTORi initiation was 8.4 years (range 2.1-15.4). 68.4% (n=13/19) received sirolimus and 31.6% (n=6/19) received everolimus. 24 months post-mTORi initiation, 50% showed stable SEGA (n=4/8), 50% reduced SEGA (n=4/8), 66.7% stable AML (n=8/12), 25% reduced AML (n=3/12), and 8.3% larger AML (n=1/12). Variability in reporting seizure frequency rendered mTORi effects on epilepsy inconclusive. mTORi was overall well tolerated, yet 100% (n=19/19) reported AEs, majority Grade 1-2. Conclusions: This study describes the efficacy and tolerability of mTORi in a Canadian paediatric TSC cohort, which demonstrates beneficial effects on SEGA and AML, with mild to moderate AEs reported.

C.7

Design and implementation of individualized Acute Seizure Action Plans (ASAP): a quality improvement study

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Background: Epilepsy affects approximately 3% of Canadian children. Despite the availability of standardized seizure abortion guidelines, many patients require personalized treatment plans due to genetic factors, medical contraindications, or a history of adverse medication reactions. This study aims to create and evaluate personalized Acute Seizure Action Plans (ASAPs) for epilepsy patients at the Children's Hospital of Eastern Ontario (CHEO). Methods: Using a Plan-Do-Check-Act (PDCA) framework, we developed electronic ASAPs for integration into participants' electronic medical records. The effectiveness and user satisfaction of these ASAPs will be evaluated through electronic surveys administered to Neurology physicians, Emergency Department (ED) physicians, and patient participants at baseline and six months post-implementation. Results: Baseline surveys were administered to ED physicians with a 70% response rate, indicating only 43% satisfaction with current generic seizure treatment practice. One hundred percent of respondents expressed interest in using an ASAP, citing challenges in selecting the appropriate anti-seizure medications and determining when to adjust treatment as priorities. These findings underscore the need for ASAP implementation. Conclusions: ED providers desire improved seizure action plans. ASAP implementation is expected to enhance emergency seizure management, reduce adverse events among epilepsy patients, and increase satisfaction of seizure management among all participants.

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D.1

Quality of life in people with epilepsy living in Canada

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Background: Epilepsy has significant implications to quality of life (QOL) beyond the seizures themselves. While research has investigated QOL among people with epilepsy (PwE) from around the globe, minimal research exists on QOL among PwE living in Canada. Methods: People with drug-resistant epilepsy admitted to the Epilepsy Monitoring Unit in London, Ontario completed the "Quality of Life in Neurological Disorders" questionnaire (Neuro-QOL), a scale evaluating 13 QOL domains. We assessed objective cognition using a battery called Creyos. Results: Participants (N=42) scored significantly worse than the reference populations on the anxiety, satisfaction with social roles and activities, and cognitive functioning Neuro-QOL domains ($p<.05$). Scores on these domains, as well as depression and positive affect/well-being were unrelated to age (mean=39.3 years, SD=16.9), sex (28 females), education level, epilepsy duration, and age of epilepsy onset ($p>.05$). There were no correlations between scores on these Neuro-QOL domains and Creyos performance in short-term memory, reasoning, and verbal processing ($p>.05$). Conclusions: PwE living in Canada experience negative QOL in anxiety, social satisfaction, and subjective cognition, unrelated to the clinical factors or cognitive domains investigated. More attention is needed in Canadian clinical care and research to assess and address these affected attributes of QOL for all PwE.