Neurocritical Care

P.039

Informing treatment advancement and innovation in a tertiary care neurocritical care (NCC)) program

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Background: Children with neurological injuries/insults carry the highest risk of death and disability in Pediatric and Neonatal ICUs. These patients comprise 25-30% of admissions and have a myriad of diagnoses. Longitudinal outcome data is required to inform treatment effects and innovation strategies. NCC at the Alberta Children's Hospital (ACH) participates in acute, subacute, and long-term/outpatient management with an aim to use comprehensive clinical data to improve outcomes. Methods: A prospective, longitudinal, population-based observational cohort study of NCC patients from local NICUs, PICU, and a NCC follow-up program, with comprehensive data from clinical records, development scores and QoL assessments. Results: Since 2019, 929 patients have been enrolled including: 407 neonates, 167 infants, 106 preschool-age and 100 school-age children, and 152 adolescents. The most common reasons for NCC consult were paroxysmal events (36%), encephalopathy (27%) and neonatal HIE (20%). Conclusions: Our database encapsulates the diverse nature of NCC patients and has enabled cohort-specific studies (e.g., neonatal HIE and ECLS outcomes). Program evolution will further facilitate higher powered research studies through large enrollment, comprehensive data capture (with a provincial EHR), and longitudinal outcomes. Engagement with staff and families will also inform treatment and afford evidence-based counseling to families.

Neurological Implications of Covid-19

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Decreased incidence of neuro-autoimmune disorders during COVID-19 pandemic restrictions

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Background: Infections are hypothesized to trigger certain autoimmune diseases; however, data surrounding incidence trends of pediatric neuro-autoimmune disorders during the COVID-19 pandemic are lacking. Our retrospective study thus assessed the incidence of pre-defined autoimmune disorders diagnosed at the Children's Hospital of Eastern Ontario in Ottawa, Canada between October 2017 and June 2023. Methods: Inpatient and outpatient charts were queried to identify subjects with neuro-autoimmune disorders or type 1 diabetes (T1D) as a non-neurological autoimmune comparison group. Monthly incidences were calculated and grouped based on three COVID-19 pandemic restriction periods: the pre-restrictions period (October 2017-March 2020), intra-restrictions period (April 2020-June 2022), and post-restrictions period (July 2022-June 2023). Poisson regression models were fit to the incidence data. Results: New diagnoses of neuro-autoimmune disorders and T1D were identified in 86 and 591 subjects, respectively. Incidence of neuro-autoimmune disorders decreased significantly during the intra-pandemic restrictions period when compared to the pre-pandemic period (IRR=0.56, 95% CI: 0.32-0.93, P<0.05). Albeit not statistically significant, the incidence then increased to higher than pre-pandemic levels during the post-restrictions period. T1D showed no significant changes in incidence. Conclusions: Incidence of neuro-autoimmune disorders, but not T1D, decreased during COVID-19 pandemic restrictions, which may be due to reduced transmission of key infectious triggers.

Neuromuscular Disease and EMG

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3 year longitudinal health related quality of life in a spinal muscular atrophy cohort

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Background: Spinal Muscular Atrophy (SMA) is a rare, genetic disorder marked by motor neuron degeneration, causing progressive muscle weakness. SMA significantly impacts patients and their families. This study investigates HRQOL in a longitudinal SMA cohort. Methods: The study used the Canadian Neuromuscular Disease Registry to examine HRQOL in children aged 6-10 years with genetically confirmed SMA. HRQOL was evaluated using the PedsQL™ Measurement Model. This tool is validated in children and adolescents with various health conditions. The PedsQL Neuromuscular Module which has been validated in SMA was also used. Results: Eight participants completed the PedsQL generic and Neuromuscular Module at timepoint 1 (TP1) and 2 (TP2). The mean scores at TP1 were 49.66 (SD=5.05) for the generic PedsQL and 61.06 (SD=18.37) for the Neuromuscular Module. At TP2, mean scores increased to 59.32 (SD=13.08) and 74.86 (SD=9.88), respectively. The overall mean change over the two timepoints was +9.66 (SD=15.16) for the Generic PedQL and +13.80 (SD=23.03) for the Neuromuscular Module. Six participants were on disease modifying treatment. Conclusions: HRQOL scores in SMA patients improved over the study period. The enhancement in HRQOL may indicate the positive impact of diseases modifying treatments of SMA that became available during that time.