

## ABSTRACT

**POSTER TITLE:** Optimizing the management of pain and irritability in children with severe neurological impairments: a quantitative study

**AUTHOR(S)** Sara Rizakos, BSc<sup>3</sup> Arpita Parmar, MSc<sup>3</sup> Hal Siden, MD, MHS<sup>4,5</sup> Julia Orkin, MD, MSc<sup>1,2,3</sup>

**INSTITUTION/AFFILIATION(S)** <sup>1</sup>Division of Pediatric Medicine, Complex Care Program, Department of Pediatrics, The Hospital for Sick Children, Toronto, Canada; <sup>2</sup>University of Toronto, Department of Pediatrics, Toronto, Canada; <sup>3</sup>SickKids Research Institute, The Hospital for Sick Children, Toronto, Canada; <sup>4</sup>Department of Pediatrics, University of British Columbia, British Columbia, Canada; <sup>5</sup>Child and Family Research Institute, BC Children's Hospital

**FUNDING SOURCE(S)** CHILD-BRIGHT Network

### ABSTRACT

**Background:** Pain and irritability of unknown origin (PIUO) is reported to affect 73% of children with severe neurological impairments (SNI). Currently, there is no consensus among clinicians for managing PIUO, and determining the pain source is often difficult. Limited research exists on the effect of PIUO on children with SNI and their families.

**Objective:** To explore and characterize the overall experience of PIUO for children with SNI and their families.

**Methods:** Semi-structured interviews were conducted with parental caregivers of children with SNI who experience PIUO and are followed by the Complex Care Program at SickKids. Interview guide topics included pain expression and management, healthcare-team support and family coping. Interviews were conducted until saturation was reached. Interviews were audio-recorded, transcribed verbatim, coded and analyzed by two independent reviewers using an inductive six-step thematic analysis process on NVivo software.

**Results:** Fifteen caregivers were interviewed, with 93% being mothers and 33% being a visible minority. Interviews revealed two major themes and associated subthemes (in parentheses): 1) Day-to-day life with PIUO (pain expression, management, and quality of life) and, 2) Areas for improvement (diagnostic process, resources and support, healthcare-team interactions).

**Significance:** Characterizing the PIUO experience is an important area of research as findings can be used to guide clinical teams in providing holistic family-centered care to children with SNI. The findings support the need for clinical innovation by adjusting practice guidelines through the creation and implementation of an integrated clinical pathway to identify treatable causes of pain and irritability in children with SNI.

**Conclusion:** Diagnostic tests for PIUO are often inconclusive and stressful for patient-families. Limited pharmacological and non-pharmacological treatments exist for PIUO. Parental caregivers describe the experience as emotionally challenging and requested support for coping. Future research should focus on interventions for PIUO in children with SNI and reducing caregiver stress and burden.