Identifying and monitoring pain and sleep in children with cerebral palsy: Early findings from a surveillance program

P Karlsson¹, C Galea¹, A Townsend¹, M Wallen¹

Background and Objectives

Early identification and intervention are critical to the well-being of children and their families. This study examines the incidence of pain and sleep disorders from prospectively collected surveillance data of individuals with cerebral palsy.

Methods

Prospective cohort study. One-hundred-twenty children, aged 3 to 17 years, who received surveillance and services at a state-wide disability organisation in New South Wales, Australia from August 2011 to December 2015, and with complete classifications, pain and sleep data were included. Mean age was 6y 3m (SD 2y 5m); 65% males. Distribution of the children’s Gross Motor Classification System (GMFCS), Manual Ability Classification System (MACS) and Communication Function Classification System (CFCS) is presented in Figure 1.

Demographic information and parental report of the child’s pain, sleep and interventions recorded in CP Check-Up™, a surveillance database linked to the NSW/ACT* CP Register, were extracted. The Sleep Disturbance Scale for Children (SDSC) identified the incidence and nature of sleep disorders. Descriptive statistics and non-parametric correlations were used for data analysis.

Results

PAIN

At the assessment following each child’s third birthday, 51% of parents reported their child experienced pain. Pain in hips and legs were most commonly reported; impacting on sleep (26%), movement (26%), and concentration (23%).

SLEEP

The SDSC showed that 70% had a sleep disorder. Severe sleep disorder was reported in 33% of children; of those, 69% of parents also reported their child was in pain.

The proportion of children presenting with no, presence of, or severe sleep disturbance within each domain of the SDSC (initiating and maintaining sleep (DIMS), sleep breathing disorders (SBD), disorders of arousal (DA), sleep-wake transition disorders (SWTD), excessive somnolence (DOES), sleep hyperhidrosis (SHY)) is shown in Figure 2. Sleep and pain distribution according to GMFCS is presented in Figure 3.

Conclusions

Results indicate a high incidence of pain and sleep disorders in this cohort of children with cerebral palsy.

Monitoring across the spectrum of cerebral palsy is important as the findings show that pain and sleep disorders exist throughout a range of ages and classifications of cerebral palsy. Hence there is an imperative to devise strategies to ensure children who experience pain and sleep disorders are offered effective interventions.

Data continues to be collected on pain, sleep and outcomes of follow-up assessments as part of the active surveillance program CP Check-Up™.

Further research is required to monitor the implementation, and measure the impact, of sleep and pain interventions in order to ensure the well-being of children and their families.

Key messages

• There is a high incidence of sleep disturbance across all GMFCS levels
• Careful identification of pain and sleep disorders is critical
• Evidence-based interventions must be offered and monitored