

Assessments of pain in children and adolescents with cerebral palsy: a retrospective population-based registry study.

[Westbom L](#)^{1,2}, [Rimstedt A](#)³, [Nordmark E](#)⁴.

Author information

1 Faculty of Medicine, Department of Clinical Sciences Lund, Paediatrics, Lund University, Lund, Sweden.

2 Department of Paediatrics, Skåne University Hospital, Lund, Sweden.

3 Faculty of Medicine, Lund University, Malmö, Sweden.

4 Faculty of Medicine, Department of Health Sciences, Lund University, Lund, Sweden.

Abstract

AIM: To explore pain screening in CPUP, a follow-up surveillance programme for people with cerebral palsy (CP), specifically to describe reported pain prevalence, localizations, patterns of distribution; to compare with studies using psychometrically sound assessment instruments; and to assess agreement between pain documented in CPUP and medical records.

METHOD: Registry study of a population with CP, born 1993 to 2008, living in Skåne, Sweden in 2013. Descriptive data, cross-tabulations, and chi-square tests to characterize and compare the study groups. Kappa analysis to test the concordance between register and medical record reports on pain.

RESULTS: Pain was reported by 185 out of 497 children (37%; females 40%, males 35%). Level V in both Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) was associated with highest prevalence of pain (50% and 54%), and level I with lowest prevalence of pain (30% and 32%). Pain was most frequent in dyskinetic CP (46%) and least frequent in unilateral spastic CP (33%). Feet and knees were the dominant localizations. Fair-moderate agreement (kappa 0.37, prevalence-adjusted bias-adjusted kappa [PABAK] 0.44) was found between documented pain in CPUP and medical records, although more seldom recognized in medical records.

INTERPRETATION: The distribution of pain between CP subtypes, functional levels, sex, and age in CPUP is concordant with previous population-based studies, indicating the validity of the CPUP pain screening. Despite this, further clinical evaluation with extended pain assessments and pain management were largely neglected in children reporting chronic pain.

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