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**Quality of life and scoliosis in cerebral palsy**

**Background**
Cerebral palsy (CP) is the most common cause of motor disability in children. The motor impairment is classified according to the Gross Motor Function Classification System (GMFCS) I-V. Scoliosis is frequent and affects quality of life and overall function. The aim was to validate the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire for children with CP (I), examine the use of spinal orthoses (II), the incidence of scoliosis (III) and protective factors for scoliosis (IV) in individuals with CP.

**Method/Results**
In study I, CPCHILD was distributed to 123 families and evaluated for known-groups validity (n=106), and test–retest reliability (n=64). CPCHILD showed good construct validity and ability to discriminate between GMFCS-levels for the total score and all domain scores (p<0.05). Test-retest reliability was high for total score (ICC 0.92) and for domain scores (0.72–0.92).

CPCHILD is a valid and reliable proxy measure for health related quality of life.

Study II was a cross-sectional study of spinal orthosis in 2800 children 1-14 years, reported to the Swedish cerebral palsy registry (CPUP). Data were analyzed relative to age, sex, GMFCS, degree of scoliosis, goal and goal attainment. Overall, 251 children, used spinal orthoses. The use increased with age and GMFCS level. Functional goals was most common and only one third of the children used spinal orthoses to prevent deformity. Goal attainment was 78–87% for the functional outcomes and 57% for prevention of deformity. There seems to be functional benefits with spinal orthoses.

Study III was a prospective register study of the incidence of scoliosis related to age, gender and the GMFCS, of all 962 individuals, born 1990-2012 in southern Sweden, participating in CPUP. The number of people with scoliosis increased up to 20-25 years of age. The incidence was related to age and GMFCS. In individuals at GMFCS V, 75% had a Cobb angle >40 degrees at 20 years of age. Surveillance programs for scoliosis in CP should be based on age and GMFCS-level and should be initiated at a young age and continued into adulthood.

Study IV will investigate protective factors that may reduce the risk of scoliosis in children with CP.

**Published papers**