



Pediatric Neurology Part I: Chapter 20. Everyday life and social consequences of cerebral palsy (Handbook of Clinical Neurology)

Peter Uldall

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The disclosure of diagnosis for a child with cerebral palsy (CP) is a highly stressful experience to the parents. The experience can be alleviated by clarity, empathy, and an emphasis on the child's resources and abilities. Despite chronic stress many families function well and manage to strengthen the child and family's resources through spousal and family support, maintenance of hope for further development, and active care taking. The caregiver burden can be divided into an objective burden (socio-structural constraints) and a subjective burden (emotional distress). The subjective burden of care seems less important, as illustrated by the quote: "We are tired, not sad." Quality of life is similar in 8- to 12-year-old European children with CP and controls, whereas participation in daily life was lower for children with CP. Participation varies significantly among countries implying that some countries can improve in this area. In a study from Denmark only 29% of adults with CP were employed (versus 88% of controls), 25% were cohabitating, and 20% had children. These long-term achievements could be predicted from development quotient, CP type, and motor impairment at age 5. The goal of habilitation is integration into society, which is not achieved for the majority.

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