

Health conditions, functioning, and social outcomes in adults with cerebral palsy

Akademisk avhandling

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av Ulrica Jonsson

Fakultetsopponent: Professor Reidun Jahnsen, Institutt for helse og samfunn,
Universitetet i Oslo, Norge

Avhandlingen baseras på följande delarbeten

- I. Jonsson, U., Eek, M. N., Sunnerhagen, K. S., & Himmelmann, K. (2019). Cerebral palsy prevalence, subtypes, and associated impairments: A population-based comparison study of adults and children. *Developmental Medicine & Child Neurology*, 61(10), 1162-1167.
- II. Jonsson, U., Eek, M. N., Sunnerhagen, K. S., & Himmelmann, K. (2021). Changes in walking ability, intellectual disability, and epilepsy in adults with cerebral palsy over 50 years: a population-based follow-up study. *Developmental Medicine & Child Neurology*, 63(7), 839-845.
- III. Jonsson, U., Eek, M. N., Sunnerhagen, K. S., & Himmelmann, K. (2021). Health conditions in adults with cerebral palsy: the association with CP subtype and severity of impairments. *Frontiers in Neurology*, 12:732939.
- IV. Jonsson, U., Himmelmann, K. Social outcomes in middle-aged adults with cerebral palsy compared to the general population - a register study. *In Manuscript*.

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Health conditions, functioning, and social outcomes in adults with cerebral palsy

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Abstract

Background: A majority of individuals with cerebral palsy (CP) are adults, and yet healthcare and research are focused on children. In comparison to the consequences in childhood, little is known about the long-term consequences of CP.

Aims: To explore the health, functioning, and social outcomes in a population-based cohort of middle-aged adults with CP in western Sweden.

Methods: The total cohort of individuals with CP born between 1959-1978 in the CP Register of western Sweden formed the basis for this thesis. Childhood data from the CP Register was used to compare survivors from the total cohort with the total cohort. Register data on the survivors' social outcomes and of sex and age matched controls in the general population were gathered from Statistics Sweden and compared. All survivors still residing in the region were invited to a follow-up assessment of impairments and health conditions. The presence of impairments at the follow-up assessment in adulthood were compared to childhood data from the CP Register.

Results: The survivors differed from children with CP in the distribution of CP subtypes and had less severe associated impairments. Among the survivors, there was a decline in walking ability from childhood to adulthood and an increase in individuals with intellectual disability and epilepsy. In adulthood, pain and gastrointestinal, respiratory, and psychiatric disorders were common, and social outcomes, such as education, living arrangements, employment, and income differed greatly from the general population.

Conclusions: CP has serious long-term consequences for health and social outcomes. From childhood to adulthood, the presence and severity of CP-related impairments may change, and other health conditions may develop. In order to improve health and functioning and provide equal opportunities for adults with CP so that they can fully participate in society, it is recommended that specialized services and follow-up be extended into adulthood.

Keywords: cerebral palsy, prevalence, adults, CP subtypes, associated impairments, health conditions, social outcomes

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