

Learning for life - How children with unilateral spastic cerebral palsy learn to master bimanual activities

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i lokal Arvid Carlsson, Academicum, Medicinaregatan 3, fredagen den 28 september klockan 9.00

av Git Lidman

Fakultetsopponent:

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Avhandlingen baseras på följande delarbeten

- I. Lidman G, Peny-Dahlstrand M, Nachemson A, Himmelmann K. Botulinum toxin A injections and occupational therapy in children with unilateral spastic cerebral palsy: a randomized controlled trial. *Dev Med & Child Neurol* 2015;7:754-61.
- II. Lidman G, Peny-Dahlstrand M, Nachemson A, Himmelmann K. Long-term effects of repeated botulinum toxin A, bimanual training and splinting in young children with cerebral palsy: A four-year follow-up. *Submitted for publication*.
- III. Lidman G, Himmelmann K, Gosman-Hedström G, Peny-Dahlstrand M. How children with cerebral palsy master bimanual activities from a parental perspective. *Scand J Occup Ther* 2017;9:1-8.
- IV. Lidman G, Himmelmann K, Peny-Dahlstrand M. Managing to learn bimanual activities as life unfolds in unilateral spastic cerebral palsy – a grounded theory approach. *In manuscript*.

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Abstract

Background: For children with unilateral spastic cerebral palsy (USCP), activities in daily life pose a challenge due to reduced function in one hand.

Aim: To study the development of hand function and occupational performance in children with USCP after intervention with occupational therapy (OT) combined with botulinum neurotoxin A (BoNT-A), and describe learning of bimanual activities in everyday life from a parental perspective and from self-perceived experiences of children and adolescents with USCP.

Methods: Twenty children with USCP (inclusion median age 3y and 1 mo) participated in a randomized controlled trial to evaluate the effects of repeated BoNT-A+OT compared to OT alone over a course of one year. Annual assessments were performed the following three years. Comparisons between the two study groups, and a reference group from a national quality register were made. To capture experiences of learning of bimanual activities in daily living, focus group discussions according to Krueger were conducted with parents of children with USCP, and interviews were conducted with young people with USCP, analysed according to Grounded Theory.

Results: BoNT-A+OT appeared superior to OT alone for bimanual performance ($p<0.03$). Active supination and goal achievement improved in both groups. At final follow-up, the improved bimanual performance in the BoNT-A+OT group was maintained. The OT group increased the bimanual performance during follow-up to the same level as the BoNT-A+OT group. Active supination increased in the total group compared with the reference group ($p<0.001$). The parents described that learning took place in activities that could wake the children's inner drive, and that children developed their own way to perform an activity, sometimes with support. Other activities were not possible to learn. An overall theme emerged: *'Finding harmony between pleasure and effort is the key to learning'*. In the individual interviews, the learning of bimanual activities was described as a process taking place in interaction with the dynamics of everyday situations, summarized as: *'Managing to learn bimanual activities as life unfolds'*.

Conclusion: Learning of bimanual activities should be viewed from multiple perspectives. The impact of development with age, timing of the right interventions, evaluated in long term, and experiences from parents and people with USCP themselves, need to be considered.

Keywords: hand, bimanual performance, cerebral palsy, children, botulinum toxin.