

Life is doing

Facilitators and hindrances for occupational performance in adults with cerebral palsy - including methods of intervention

Akademisk avhandling

Som för avläggande av medicinsk doktorsexamen vid Sahlgrenska Akademien, Göteborgs Universitet kommer att offentligens försvaras i SEB-salen, Handelshögskolan, Vasagatan 1, Göteborg, den 31 januari 2020, klockan 9.00.

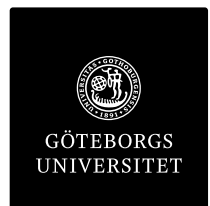
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Avhandlingen baseras på följande delarbeten

- I Bergqvist L, Öhrvall A-M, Himmelmann K, Peny-Dahlstrand M. *When I do, I become someone: experiences of occupational performance in young adults with cerebral palsy*. Disabil Rehabil. 2019;41:341-47.
- II Bergqvist L, Öhrvall A-M, Peny-Dahlstrand M. *The process of doing, a challenge for persons with cerebral palsy*. In manuscript 2019.
- III Peny-Dahlstrand M, Bergqvist L, Hofgren C, Himmelmann K, Öhrvall A-M. *Potential benefits of the Cognitive Orientation to daily Occupational Performance Approach in young adults with spina bifida or cerebral palsy: a feasibility study*. Disabil Rehabil. 2018;8:1-12.
- IV Öhrvall A-M, Bergqvist L, Hofgren C, Peny-Dahlstrand M. *"With CO-OP I'm the boss" - experiences of the Cognitive Orientation to daily Occupational Performance Approach as reported by young adults with cerebral palsy or spina bifida*. Disabil Rehabil. 2019;12:1-8.
- V Bergqvist L, Öhrvall A-M, Rönnbäck L, Johansson B, Himmelmann K, Peny-Dahlstrand M. *Evidence of construct validity for the modified Mental Fatigue Scale when used in persons with cerebral palsy*. Dev Neur Rehabil 2019;12:1-13.

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Abstract

Introduction: Occupational performance is a complex process which poses difficulties to persons with CP even where they have relatively good motor function.

Aim: To explore and describe the perception of occupational performance in everyday life in adults with cerebral palsy, to examine whether a certain intervention has the potential to improve opportunities for occupational performance, and to test an instrument that can be used to detect occupational imbalance in this target group.

Methods: Study I took a phenomenographic approach, focusing on variation in the participants' perceptions of occupational performance in everyday life. Directed content analysis was used in Study II, where the interview material from Study I was related to the Model of the Process of Doing. Studies III and IV investigated the feasibility of an intervention, the Cognitive Orientation to daily Occupational Performance (CO-OP) ApproachTM. Study III had an exploratory multiple-case design while in Study IV the semi-structured interviews about the participants' experiences were analysed using content analysis. Study V used a sequential exploratory design.

Results: The participants described it as extremely important to perform occupations independently, since by doing they formed their identity. Facilitators and hindrances for doing were described, showing difficulties in all phases of the 'process of doing' where each participant had difficulties in one or more phases. Doing often came with a high cost in terms of deterioration, pain, stress and mental and/or physical fatigue. However, the participants also strove for inclusion when performing occupations. Strategies to be able to process what happens during the performance of a task as well as knowledge about one's strengths and limitations were characterised as crucial for belief in one's capability. The participants' satisfaction with the CO-OP Approach was high and they found that it boosted them. CO-OP was deemed to support their way of thinking and doing during the various phases of the 'process of doing'. Their self-rated goal attainment as well as their measured executive functions improved. The modified Mental Fatigue Scale showed the potential to be a useful instrument for self-rating of mental fatigue and related symptoms in adults with CP.

Conclusion: Young adults with CP (MACS I–II) consider it important to perform everyday occupations themselves and to develop by doing. Hence there is a need for person-centred interventions where persons can develop their potential to solve performance problems that may arise during the various phases of the 'process of doing'. Moreover, there is a need for interventions that create good opportunities to attain occupational balance.

Keywords: Occupational performance, cerebral palsy, person-centred intervention, self-assessment, activity of daily living, participation, mental fatigue, metacognition, executive functions, self-efficacy, validity