

Life is doing

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

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*'Occupation is a curious thing
It pervades our lives and marks our days
It defines us and is defined by us
It both shapes the world and is shaped by the world
It can be known by the tools it uses and the wake it leaves in its path
It is intangible and invisible until a person engages in it
It is a performing art
It can only be seen when a person performs it and only understood
when a person tells you its meaning'*

By Helene J. Polatajko

Abstract

Introduction: It is through being engaged in doing things across the life span that people develop. People exist in an environment in which they do things, i.e. perform occupations. Occupational performance is a complex process, which is more complicated for some people than for others. Studies have shown difficulties performing occupations in persons with CP, even where they have relatively good motor function.

Aim: The overall aim of this thesis was 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: Three of the studies included (I, II, IV) had a qualitative design and two (III, V) used mixed 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 to search for evidence of construct validity for a modified version of the Mental Fatigue Scale (m-MFS).

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. With CO-OP, the participants' self-rated goal attainment as well as their measured executive functions improved. The participants' satisfaction with the CO-OP approach was high. It was deemed to support their way of thinking and doing and to boost them. Also, it was highly compatible with the core values of the Swedish Habilitation services. The m-MFS was easy to read and understand; the opportunity to identify with a rating option facilitated self-assessment. Very good agreement was seen between the respondents' self-ratings and the designers' intended meaning of the m-MFS. Evidence of construct validity based on response processes and content was shown for the m-MFS 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, social participation, mental fatigue, metacognition, executive functions, self-efficacy, validity

Sammanfattning på svenska

Inledning: Det är genom att vara engagerad i att göra olika aktiviteter som människor utvecklas under sin levnad. Utvecklingen sker i interaktion mellan personen, det personen gör och den miljö som görandet utförs i. Själva görandet av en aktivitet är en komplex process som för vissa människor är mer komplicerad än för andra. Studier har visat att personer med cerebral pares (CP) kan ha stora svårigheter att utföra vardagliga aktiviteter även om de har relativt god motorisk förmåga.

Syfte: Avhandlingens syfte var att utforska och beskriva hur unga vuxna med CP uppfattar sitt utförande av vardagliga aktiviteter, att undersöka om en viss typ av behandling har potential att förbättra aktivitetsutförande och att testa ett självskattningsinstrument som kan användas för att upptäcka mental trötthet hos personer med CP.

Metoder: Deltagare i denna avhandlings studier var personer med CP som inte hade någon intellektuell funktionsnedsättning och hade relativt god motorisk förmåga (MACS I-II). I Studie III och IV deltog även personer med ryggmärgsbråck, men i denna avhandling har fokus lagts på resultaten gällande deltagarna med CP. Tre av studierna (I, II, IV) i avhandlingen hade en kvalitativ design och i två (III, V) användes mixad design. I Studie I användes fenomenografisk ansats för att kunna fånga deltagarnas variationer av uppfattningar om sitt aktivitetsutförande i vardagen. Riktad kvalitativ innehållsanalys användes i Studie II då intervjumaterialet från Studie I relaterades till görandeprocessen, som beskrivs i modellen ”The Model of the Process of Doing”. I Studie III och IV prövades behandlingsformen Cognitive Orientation to daily Occupational Performance (CO-OP) Approach™ i Svenskt kontext. Studie III, en utforskande multipel fallstudie, utvärderade behandlingsmetoden CO-OP utifrån olika perspektiv, med olika utfallsmått och inom olika analysområden. Semi-strukturerade intervjuer där deltagarna beskrev sina erfarenheter av CO-OP analyserade i Studie IV med kvalitativ innehållsanalys. Sekventiell utforskande design användes i Studie V för att undersöka om konstruktionen av en modifierad version av självskattningsinstrumentet Mental Fatigue Scale (m-MFS) fångar mental fatigue hos gruppen vuxna med CP.

Resultat: Deltagarna beskrev det som mycket viktigt för dem att själva utföra vardagliga aktiviteter, genom att *göra* formade de sin identitet. Dessvärre medförde görandet ofta att deltagarna fick betala ett högt pris i form av fysisk försämring, smärta, stress och svår fysisk och/eller mental trötthet. Både möjligheter och hinder vid görandet beskrevs. Deltagarna uppfattade svårigheter i alla görandeprocessens faser men där de enskilda deltagarna beskrev svårigheter i en eller flera faser. Kunskap om sina styrkor och begränsningar såväl som strategier för att kunna bearbeta vad som händer under utförandet av en aktivitet beskrevs som avgörande för att våga tro på sin förmåga att själv göra. Resultaten från behandling med CO-OP Approach visade att deltagarnas självskattade måluppfyllelse såväl som deras planeringsförmåga förbättrades. Deltagarna var mycket nöjda med behandlingsperioden med CO-OP. De beskrev att CO-OP Approach hade gjort det möjligt för dem att utveckla kognitiva strategier vilka kunde användas för att tänka ut hur aktiviteten skulle utföras. Deltagarnas tilltro till sin egen förmåga ökade då de kunde lösa svårigheter som uppstod under utförandet av aktiviteter. CO-OP Approach överensstämde väl med den värdegrund som beskrivs i officiella dokument för Svensk habilitering. Självskattningsformuläret m-MFS beskrevs av deltagarna som lätt att läsa och förstå. Deltagarna hade lätt att identifiera sig med de beskrivande svarsalternativen, vilket underlättade självskattningen. Överensstämmelsen mellan respondenternas självskattningar och designers avsedda mening med m-MFS var mycket god. Detta visar att det finns validitet utifrån både innehåll och svarsprocesser för konstruktionen av m-MFS för målgruppen vuxna personer med CP.

Slutsats: Unga vuxna med CP (MACS I-II) anser att det är viktigt att själva göra vardagliga aktiviteter för det är genom att *göra* de upplever att de är någon. För att kunna möta detta behov krävs personcentrerade behandlingsmetoder där personen kan utveckla sin förmåga att lösa utförandeproblem som kan uppstå i de olika faserna under görandeprocessen. Dessutom finns behov av att skapa goda förutsättningar för aktivitetsbalans hos personer med CP.

List of papers

This thesis is based on papers describing the following studies, referred to in the text by their Roman numerals. The published papers are reprinted with permission from Disability and Rehabilitation for Studies I, III and IV and from Developmental Neurorehabilitation for Study V. Study II is in manuscript.

- 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. doi: 10.1080/09638288.2017.1390696
- 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. doi: 10.1080/09638288.2018.1496152
- 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. doi: 10.1080/09638288.2019.1607911
- 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. doi: 10.1080/17518423.2019.1645227

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Abbreviations

ACP	Ataxic cerebral palsy
ADL	Activity of Daily Living
AMPS	Assessment of Motor and Process Skills
BSCP	Bilateral spastic cerebral palsy
CFCS	Communication Function Classification System
COPM	Canadian Occupational Performance Measure
CMOP-E	Canadian Model of Occupational Performance and Engagement
CO-OP	Cognitive Orientation to daily Occupational Performance
CP	Cerebral palsy
DEX	Dysexecutive Questionnaire
DCP	Dyskinetic cerebral palsy
EF	Executive function
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
IMOD	Interactional Model of Occupational Development
MACS	Manual Ability Classification System
MFS	Mental Fatigue Scale
m-MFS	modified Mental Fatigue Scale
MPoD	Model of the Process of Doing
OSA	Occupational Self Assessment
OSA-S	Occupational Self Assessment, Swedish version
SB	Spina bifida
USCP	Unilateral spastic cerebral palsy

Preface

Working for more than three decades as an occupational therapist at a centre for adults with congenital or early acquired disabilities, I have primarily focused on making it possible for people to perform the occupations that they need, want or have to be able to perform, based on their own wishes. I have seen people with a broad spectrum of different disabilities, who in most cases had no intellectual disability and had received their education in the mainstream school system, although there was a great deal of variation in cognitive ability. Some of them had only mild physical impairments (and no identified intellectual ones) but still experienced major difficulties performing various tasks. This was often found in one particular group: persons with cerebral palsy (CP). Those persons often did not receive any interventions or resources because of their relatively good motor ability. This challenged me and set me thinking about what might be the reason for these persons' difficulties performing activities of everyday life. I wondered how the persons themselves experienced this and whether there were any interventions that could make their life situation better.

My work on this doctoral thesis has given me an opportunity to go to the primary sources and learn from the persons themselves. They have openly shared their experiences as participants in the various studies which have formed the basis for the ongoing research efforts in which I have been involved. I am genuinely grateful to have had the opportunity to work on this thesis in this way. It is my sincere hope that this thesis will help to spread knowledge about the difficulties that persons with CP often face when performing tasks of everyday life despite having a good motor ability.

Thesis at a glance

Study	Aim	Design/Method	Results	Conclusion
I	To obtain deeper knowledge of how young adults with CP (having relatively good motor function) perceive their occupational performance in everyday activities.	Qualitative. Individual semi-structured interviews. 10 participants with CP. Phenomenographic approach.	Categories of the participants' perceptions: 'Important to do', 'Demanding but can be facilitated', 'Excludes or includes', 'Diminishes me or makes me grow', 'Comes at a price'.	Young adults with CP (MACS I-II) consider that, despite the high price, it is important to perform everyday occupations themselves, because by doing they strive to become someone.
II	To describe how young adults with CP (having relatively good motor ability) perceive challenges in their occupational performance in relation to the different phases of the 'process of doing'.	Qualitative. Deductive analysis of individual semi-structured interviews. 10 participants with CP from Study I. Directed content analysis using MPoD as a frame of reference.	Difficulties were described by the participants in all phases of the 'process of doing'. No participants had difficulties in all phases but all had difficulties in one or more.	There is a need to broaden the scope of occupational therapy intervention methods for adults with CP (MACS I-II) to all phases of the 'process of doing', even the more invisible phases of the process.
III	To investigate whether the CO-OP Approach™ is feasible for and potentially beneficial to adolescents and young adults with CP or SB in Sweden.	Mixed method. Exploratory multiple-case feasibility study. 5 participants with CP, 5 participants with SB. Triangulation of results from measurement, field notes, interviews and policy documents from different perspectives.	Self-rated goal attainment and executive function improved. The participants' satisfaction with the CO-OP Approach was high. The approach is highly compatible with the core values of the Swedish Habilitation services.	The CO-OP Approach is a promising approach for enabling adolescents and young adults with CP (MACS I-II) (or SB) to enhance occupational performance and achieve personal goals, in a Swedish context.
IV	To explore and describe experiences of the CO-OP Approach™ as reported by the young adults with CP or SB.	Qualitative. Individual semi-structured interviews. 5 participants with CP, 5 participants with SB. Conventional content analysis.	The participants' experiences categorised: CO-OP - 'is a different way of learning', - 'sometimes put a strain on me', - 'supports my way of thinking and doing', - 'boosts me'.	The CO-OP Approach provides opportunities to master problem-solving during performance of everyday occupations and enhances self-efficacy.
V	To gather evidence of construct validity for a slightly modified version of the MFS (m-MFS) by investigating whether it captures experiences of mental fatigue and related symptoms in adults with CP, of less motor severity.	Mixed method. Sequential exploratory validation study. 10 participants with CP. Think-aloud interviews and retrospective questions analysed in accordance with Fonteyn. Descriptive and comparative statistics.	The m-MFS was easy to read and understand and the feeling of identification with a rating option facilitated self-assessment. Very good agreement was seen between the respondents' self-ratings and the designers' intended meaning of the m-MFS.	Evidence of construct validity based on response processes and content was shown for the m-MFS in adults with CP. The m-MFS has the potential to be a useful instrument for self-rating of mental fatigue and related symptoms in adults with CP (MACS I-II).

Introduction

It is through being engaged in doing things across the lifespan that people develop and maintain their health (1). People exist in an environment in which they do things, i.e. perform occupations. An occupation here refers to any activity that is constructed personally in a unique context. It is a one-time subjective experience, which will never again be repeated in exactly the same way. Occupations have a certain meaning in life and include things that a person needs to, wants to or is expected to do (2, 3). The three components of person, environment and occupation interplay during occupational performance throughout the lifespan, creating positive or negative circumstances for development (4). People are unique, and so are the occupations and the environments that they interact with. Thus, the development of a person's occupational repertoire also becomes unique. If a person has difficulties performing or engaging in activities and/or the environment is a hindrance, this will affect the person's opportunities for occupational development. The outcome may be reduced occupational competence, which may negatively affect the person's sense of ability and self-identity (4).

The 'process of doing' describes the phases that anyone must go through when performing an occupation (5, 6). However, this is more complicated for some people than for others. Previous studies have shown that persons with CP have difficulties performing occupations (7-11) and have lower levels of participation and independence in doing tasks than their peers (12), even where they have relatively good motor ability and no intellectual disability. Therefore, the focus of this thesis is on the doing and the participation of persons with mild CP (i.e. having relatively good motor function and no intellectual disability). The work on the thesis has been underpinned by three assumptions:

First, *engagement in occupations in everyday life has an impact on people's well-being and health* (13, 14). Whenever a person is engaged in an occupation within a certain environment, occupational performance takes place. The result of that occupational performance is influenced by the quality of the interaction between the person, the occupation and the environment (15). In addition, opportunities to attend and be involved in various occupations affect opportunities to participate in occupations (16, 17). Consequently, the perception of well-being and health is affected by opportunities to participate in occupations and by the result of occupational

performance (17, 18). This thesis describes different aspects of how persons with CP perceived their occupational performance and participation in occupations.

Second, *throughout a person's life there is a gradual change in his or her occupational behaviour* as a result of growth and maturation as well as interaction (based on the person's abilities and volition) with the environment; this can be referred to as occupational development (4). Depending on the result of the dynamic interaction between the person's abilities, the occupation and the environmental opportunities, occupational development can be hindered or facilitated. In addition, the number of different occupations performed and their variety are important for how a person will perceive his or her occupational balance (19, 20). An occupational imbalance can affect occupational development (4). This thesis explores ways to facilitate a positive occupational development and occupational balance in persons with CP by investigating an intervention approach that promotes problem-solving during occupational performance and by testing a modified self-rating scale to assess mental fatigue, one of the factors that may have a negative effect on occupational balance.

Third, *every unique person and his or her lived world experiences have to be respectfully acknowledged* (21, 22). For this reason, all studies included in this thesis take a person-centred approach, focusing on how the persons with CP perceive doing and participation in everyday life and on what enables their own problem-solving. This person-centred approach was the starting point for the choice of research theories and methods as well as intervention methods.

Cerebral palsy

The most recent definition of CP as proposed by the International Executive Committee for the Definition and Classification of Cerebral Palsy is the following:

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developmental fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems (23).

By choosing this definition, the leading authorities in the field emphasise that the concept of CP involves numerous developmental functions which vary across persons and may be more problematic at different stages of life (23, 24). CP is a life-long disability which is the most common motor disability of childhood. In the Western world, its prevalence is reported as about 2–2.5 cases per 1,000 live births (24–28). The size and location of the brain lesion causing the disorder as well as the stage of brain development where it occurs are vital for how CP is manifested (28, 29). The reason why a child is affected by CP is often a combination of factors (23, 24). Preterm birth and low birth weight, maternal infections and multiple birth are strongly associated with an increased risk of CP (30). A small group of children with CP acquire the brain lesion after the neonatal period, usually as a result of bacterial infection, inflammation or trauma (24, 31).

Classification of CP

As seen above, the definition of CP covers a heterogeneous group of people with a broad range of clinical presentations and activity limitations (23). For this reason, various classifications are used to specify a person's functional and activity limitations. To begin with, CP is classified based on the dominant neurological findings into three sub-types: spastic, dyskinetic and ataxic. Common to all three sub-types is an abnormal pattern of movement and posture. In addition to this, spastic CP is characterised by increased muscle tone and pathological reflexes (32, 33). Based on the distribution of the clinical presentation, spastic CP is subdivided into unilateral, where only the limbs on one side of the body are involved, and bilateral, where limbs on both sides of the body are involved (26, 33). Dyskinetic CP is dominated by involuntary, uncontrolled, recurring and occasionally stereotyped movements (33). It is subdivided into dystonia and choreaathetosis (31). Finally, ataxic CP presents a loss of orderly muscular co-ordination leading, for example, to abnormal force and rhythm during movement (33). Of those diagnosed with CP, the majority have spastic CP (80%) while dyskinetic CP (7–15%) and ataxic CP (3–5%) are less common (28, 34, 35).

There is also a recommendation to use classification systems with a focus on functioning in everyday life, i.e. on what a person is able to do. In this thesis, three such classification systems for which there is evidence of good validity and reliability have been used: the Gross Motor Function

Classification System (GMFCS) (36, 37), the Manual Ability Classification System (MACS) (38, 39) and the Communication Function Classification System (CFCS) (40, 41). All three cover the whole CP spectrum and share a similar design with five levels (I–V) and verbal descriptions of the differences between the levels. The GMFCS targets gross motor function, the MACS describes how a person uses his or her hands to handle objects in daily life, and the CFCS classifies a person’s ability as a sender and receiver in everyday communication.

The ability to use the hands is of great importance when it comes to performing activities in everyday life. Hence MACS levels were used as inclusion criterion in all studies in this thesis. The different levels of the MACS are presented below (38, 42):

- Level I: Handles objects easily and successfully.
- Level II: Handles most objects but with somewhat reduced quality and/or speed of achievement.
- Level III: Handles objects with difficulty; needs help to prepare and/or modify activities.
- Level IV: Handles a limited selection of easily managed objects in adapted situations.
- Level V: Does not handle objects and has severely limited ability to perform even simple actions.

The participants in the studies included in this thesis have a gross motor function, a manual ability and a communication ability corresponding to GMFCS levels I–IV, MACS levels I–II and CFCS levels I–II, respectively. The term ‘mild CP’ is used to describe those participants; this refers to persons classified at MACS levels I–II and having no intellectual disability.

Accompanying cognitive disturbances

The second sentence of the definition of CP quoted above refers to disturbances which accompany the motor disorders, and researchers have stated that such associated disturbances may have a great impact on everyday life in persons with CP (23). The disturbances listed include those affecting cognitive functions. Children with brain lesions are at risk of cognitive, including executive, dysfunction (10). The definition of ‘executive function’ (EF) differs between researchers (43). In this thesis, EF is seen as an umbrella term for the set of cognitive skills that are involved in a person’s independent, purposeful and goal-directed activity (10, 44). It has been

found that it is not unusual for persons with CP to have impaired EF in general and difficulties with the inhibition of impressions in particular, causing their focus to shift easily and hence making it difficult for them to sustain or divide their attention (8, 45, 46). According to Bodimeade (9), children with CP have significantly more difficulties with attention control, cognitive flexibility, information processing and goal-setting than their peers. Further, children with CP, even those with fairly good motor functions and no intellectual disability, have reduced social-dominance behaviour in activities when it comes to problem-solving together with peers (47). The development of executive ability is affected not only by the brain disturbance as such but also by the outcome of the interplay between the person with CP and the social environment in which he or she interacts with others (7), meaning that a person's difficulties may increase if the environment is not a supportive one.

Theoretical perspectives

To capture the rationale for this thesis, there was a need to take various conceptual considerations into account. In order to do so, different perspectives on theoretical concepts had to be studied. The perspectives taken in the thesis and its definitions of the concepts of 'occupation', 'occupational performance', 'occupational development', 'occupational balance', 'participation' and 'person-centredness' are presented below.

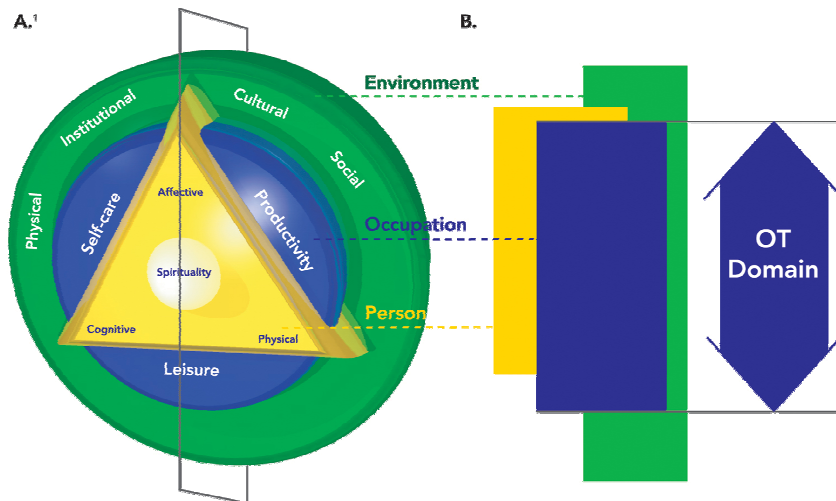
Occupation

An occupational perspective has been defined by Njelesani as 'a way of looking at or thinking about human doing' (48 p. 233). To better understand the concept of occupation, Wilcock (49, 50) presented it as a synthesis of *doing*, *being*, *belonging* and *becoming*, highlighting how a dynamic balance between *doing* on the one hand and *being* and *belonging* on the other is central for a person's experience of *becoming*. *Doing* is 'a generic term for the continual active engagement of humans in occupation' (51) or, in other words, 'taking action' (52). *Being* is to have time to think and reflect (on one's doing, among other things) and to exist in order to discover oneself (49). *Being* helps someone to become the person that he or she wishes to be (1). It is the 'process in which humans discover themselves, their goals, and priorities that makes them unique' (51). Everything that happens in a person's life is integrated in that person's becoming (1).

Becoming can be described as the constant transformation of the person by him- or herself throughout the lifespan (49, 50) – transformation into the person that he or she strives to be, is best suited to be and hopes to be (49). The process of becoming, through a balance between doing and being, is seen as essential for well-being and health (49, 53). Social well-being is dependent on belonging and becoming, and on carrying out occupations together with others (50). Finally, *belonging* is a contextual element, defined by Mahar et al. (54 p. 1031) as ‘a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics’. The prerequisites for experiencing belonging include social interaction with mutual support as well as a sense of being included in occupational performance (55). In the present thesis, Wilcock’s views on occupation have been used to deepen the understanding of the participants’ experiences of everyday occupations (49, 50).

Occupational performance

Occupational performance has been described as ‘the experience and act of *doing* occupations’ (51). Through engagement in occupations, a person interacts with his or her environment during occupational performance. This dynamic interplay between the three components (person, environment and occupation) was described by Law (15) and has been a cornerstone in the development of various models of occupational performance, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (56); see Figure 1.



A.¹ Referred to as the CMOP in *Enabling Occupation* (1997a, 2002) and CMOP-E as of this edition
 B. Trans-sectional view

Polatajko, H. J., Townsend, E. A., Craik, J. (2007). *Canadian Model of Occupational Performance and Engagement (CMOP-E)*. In E. A. Townsend and H. J. Polatajko, *Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being, & Justice through Occupation*. p.23 Ottawa, ON: CAOT Publications ACE.

Figure 1. Canadian Model of Occupational Performance and Engagement (CMOP-E) (56).

OT Domain: Occupational Therapist Domain.

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The CMOP-E draws upon humanistic, developmental and environmental theories. It is person-centred, meaning that it places the person at the centre of the model. The person is represented by a yellow triangle with three performance components: cognitive, physical and affective, all of which are essential during occupational performance. At the middle of the triangle is the person's spirituality, which is closely related to being: an experience of an inner sense of meaning and peace. The person exists within an environment (the green circle in the figure), in which occupational opportunities occur (the blue circle). The physical, the cultural, the institutional and the social environments all influence and are influenced by the person and the occupation performed by the person. During occupational performance, the occupation is the link between the person and the environment. Limitations in any of the components (person, environment, occupation) can adversely affect occupational performance or engagement (4). On the other hand, a good fit between the components will improve the person's potentials to perform the occupation and to experience participation during performance (18).

However, regardless of the result of the performance, the doing in and of itself represents a complex process consisting of several phases, from when a person generates an idea of what to perform until the task is completed. This ‘process of doing’ is illustrated in the Model of the Process of Doing (MPoD) (5, 6); see Figure 2.

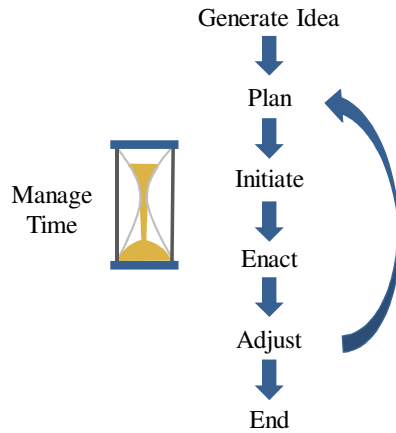


Figure 2. The Model of the Process of Doing (MPoD) (5, 6).
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The MPoD is a generic model in the sense that it describes the phases that anybody goes through during the ‘process of doing’ in relation to any occupation. This model can be used to establish a person’s individual general profile with respect to the ability to carry out any task, which can be seen as his or her point of departure in terms of the ability to perform a specific occupation in a specific environment.

In this thesis, it was essential to place the participants at the centre of attention and examine their unique subjective experience of performing occupations in everyday life, i.e. their perception of their doing. Consequently, it was also important to study their ‘process of doing’ and how this process can be facilitated. Further, it was of interest how a person, with his or her unique abilities and personal views, experienced the interplay between the environment in which an occupation was performed. Based on this perspective, the CMOP-E (56) and the MPoD (5, 6, 57) were used as references in this thesis when describing occupation performance, or doing.

Occupational development

Occupational development is often highlighted as a topic for children, but rarely for adults. However, occupational development does not end with childhood but is a continual, complex process throughout the lifespan (4, 58). During this development people create knowledge through their interactional relationship with the environment and through doing (59). Occupational development can be defined as ‘the gradual change in occupational behaviour over time, resulting from growth and maturation of the person in interaction with the environment’ (59 p. 40). This means that no single factor – neither the personal, the occupational or the environmental one – determines development on its own (4). One theoretical model which can be used to approach the issue of occupational development is the Interactional Model of Occupational Development (IMOD) (4, 60). In the IMOD, the key mechanism for occupational development is the interaction between occupational behaviour and time; occupational behaviour is defined as the outcome of the person’s interaction with his or her occupation in the context of the environment, and time refers to the lifespan of a person (4, 60).

The basic assumption made in this thesis was that occupational development continues during adulthood and is a process throughout a person’s lifespan. Additionally, occupational development was seen as a result of the ongoing interaction between the person, the environment and the occupation, with no single factor determining development on its own. Given this perspective on occupational development, the IMOD was chosen as a frame of reference.

Occupational balance

The issues of occupational balance and life balance have been increasingly highlighted in recent decades as important aspects of people’s well-being and health (61-64), but the difference between these two concepts has not been made clear. Wagman has discussed the differences between them and ended up describing occupational balance as part of life balance (65). Concretely, according to Wagman, having life balance means ‘perceiving life as including: activity balance; balance in body and mind; balance in relation to others; and time balance’, whereas having occupational balance means ‘perceiving life as having the right amount and variation of occupations in relation to occupational categories; occupations with different characteristics; and time spent in occupations’ (65 p. 48). Based on these

definitions, it appears that the different parts of occupational balance can be seen as equal as or components of the different parts of life balance (65). Further, there is a strong link between occupational balance and the perceived fit between the three factors of person, occupation and environment, which interplay during occupational performance, in the sense that occupational balance reflects the person's subjective perception of his or her occupational performance (65).

Some of the studies in this thesis highlight issues addressing occupational balance and life balance. When these concepts are described and discussed, Wagman's definitions of them are used.

Participation

Ever since participation was identified in the 1990's as one of the main concepts of the International Classification of Functioning, Disability and Health (ICF), participation has increasingly been advocated as a human right. In Sweden, the right to participate in different activities and in social contexts is governed by law (66), and the national government has ratified the United Nations Convention on the Rights of Persons with Disabilities (67). The concept of participation has also been subject to interpretation and discussion by researchers ever since it was included in the ICF. Although it has proved difficult to agree on a single definition, there is a consensus that participation is a multi-dimensional concept (16, 68, 69) and also that participation in occupation is a complex issue (17). One important point made by Hemmingsson and Jonsson (68) is that it can be questioned whether it is at all possible to talk about 'participation' unless the individual's own experiences of participating are included. In this context, it has been claimed that important factors for experiencing participation in occupation are self-determination and autonomy (68). To remedy the lack of an accepted definition, Imms et al. (16) conducted a systematic review of the multi-dimensional concept of participation and produced a model of this concept. That model described the interplay within and between the concept of participation, participation-related constructs and the environment. Further development of the model then yielded the description of the person-focused and environment-focused processes provided in the 'Family of participation-related constructs' (17) (Figure 3).

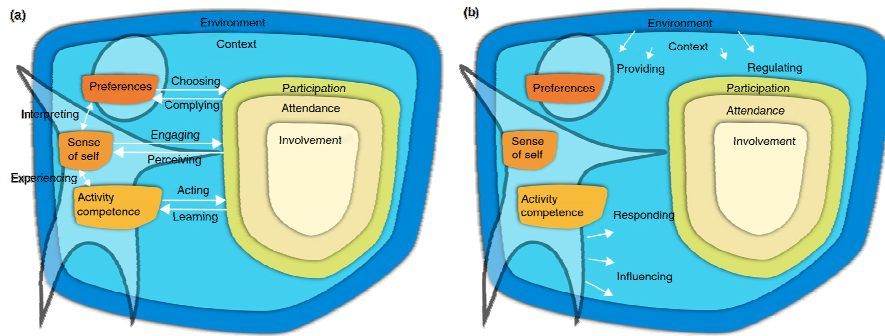


Figure 3. Family of participation-related constructs: (a) person-focused processes, (b) environment-focused processes (17)

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According to Imms et al. (16, 17), the participation construct consists of two parts: attendance and involvement. Attendance is described as ‘being there’ and involvement as the subjective ‘in-the-moment’ experience of participation. While attendance is a prerequisite for involvement, the opportunity to be involved is probably more essential for participation. Imms et al. suggest that individuals’ participation is influenced by what they prefer, how they see themselves and what they are able to do (16, 17). In addition, there is a strong interplay between the participation construct (attendance and involvement) and the environment (16, 17). Consequently, the opportunity to participate is strongly influenced by the environmental context, which can either support or hinder participation in occupation (16, 17, 58), but it is also influenced by the person’s preferences, sense of self and activity competence (16, 17).

The perspective on participation chosen for this thesis included the person’s own experience of participating, not only the person’s mere attendance. It was also deemed important to emphasise that participation during occupational performance is influenced by the interplay between the person’s abilities, the occupation and the environment. The model of Imms et al. (17) was used when describing participation in this thesis, because it is a good fit with the other theoretical frameworks used.

Person-centredness

In this thesis, it was deemed essential to highlight the participants’ unique perceptions, to respectfully acknowledge their points of view and to iden-

tify person-centred methods. Consequently, a person-centred approach was a main focus both when choosing theories and research methods and when searching for appropriate interventions to explore.

The development of person-centred approaches in occupational therapy began as long ago as the early 20th century, when the occupational therapist Eleanor Clark Slage described the importance of an approach based on the occupational therapist's ability to imagine the person's life and to see the world from his or her point of view (70). This idea has been fundamental to later developments which began as a 'client-centred' approach – a term introduced in the late 1930s by Carl Rogers (1, 21, 71). Being the 'centre' can be defined as being 'the point from which an activity or process is directed, or on which it is focused' (72), meaning that the client or person is supposed to be the mid-point during the intervention. The core of the client-centred approach has been described as a respectful and listening partnership between the client and the therapist where the client is always in the centre, while the client and the therapist work towards achieving the client's own goals (73, 74). Other key elements highlighted relate to what the therapist says and how he or she says it, to relevant information for decision-making and to the empowerment of the client by showing that he or she is the expert on his or her unique circumstances (21, 74). However, it has also been questioned whether occupational therapists and researchers really are client-centred in their actions and not only in their talk (75, 76). Moreover, the use of the word 'client' has been criticised (73). A 'client' can be defined as 'someone who is paying for service' or 'one who employs a professional person' (77). This word also implies that the professional occupies a position of power relative to the client, with the client being reliant on the professional as possessor of expert knowledge (73). The term 'person-centred' has been suggested as more appropriate and more in line with the views of the whole occupational therapy profession (73). The content of the person-centred approach is very similar to that of the client-centred one, but the term 'person-centred' emphasises the therapist's view of the person as an individual and suggests that the therapist's essential tasks are to get to know the person as a unique individual and to recognise and maintain his or her personhood. There should be a partnership between the person and the therapist which is characterised by respect and sharing of power and responsibility throughout the intervention process. The person's lived world should be acknowledged and the person should feel that his or her strengths are reinforced (73).

Rational for this thesis

We cannot understand how persons with mild CP perceive their life situation, based on their opportunities to perform and participate in everyday activities, unless their own experiences are taken into account. There was also felt to be a need to explore whether there were any appropriate interventions or instruments for this target group that might improve their opportunities for occupational performance and occupational balance. Against this background, there emerged three main questions which form the basis of this thesis:

- i) How do persons with mild CP perceive their occupational performance in everyday life?
- ii) Can a person-centred intervention that enhances strategy use enable occupational development in persons with mild CP?
- iii) Can a self-rating scale that examines mental fatigue be useful for persons with CP?

It is hoped that the results relating to these questions which are presented in this thesis will add knowledge about how to promote occupational performance and participation in occupation in persons with mild CP.

Aim

The overall aim of this thesis was to explore and describe the perception of occupational performance in everyday life in adults with cerebral palsy, to examine whether certain interventions have the potential to improve opportunities for occupational performance, and to investigate whether a self-rating instrument can be used to detect occupational imbalance in this target group.

SPECIFIC AIMS

- Study I To obtain deeper knowledge of how young adults with cerebral palsy (having relatively good motor function) perceive their occupational performance in everyday activities.
- Study II To describe how young adults with cerebral palsy (having relatively good motor ability) perceive challenges in their occupational performance in relation to the different phases of the ‘process of doing’.
- Study III To investigate whether the Cognitive Orientation to daily Occupational Performance ApproachTM is feasible for and potentially beneficial to adolescents and young adults with cerebral palsy or spina bifida in Sweden.
- Study IV To explore and describe experiences of the Cognitive Orientation to daily Occupational Performance ApproachTM as reported by the young adults with cerebral palsy or spina bifida.
- Study V To gather evidence of construct validity for a slightly modified version of the Mental Fatigue Scale (m-MFS) by investigating whether it captures experiences of mental fatigue and related symptoms in adults with cerebral palsy, of less motor severity.

Participants and methods

Participants

The participants in the studies included in this thesis were young adults and adults with CP. (The participants in Studies III and IV also included adolescents and young adults with spina bifida (SB), but the main focus of this thesis is on persons with CP, (MACS I–II). None of the participants had a diagnosis of intellectual disability. All of them were recruited through different Habilitation centres, mainly in the western region of Sweden (but in Studies III and IV also from the eastern part of Sweden). In addition to the fact that some studies used the same sample, some participants were part of several samples, as shown by the arrows in Figure 4 but no person participated in all five studies.

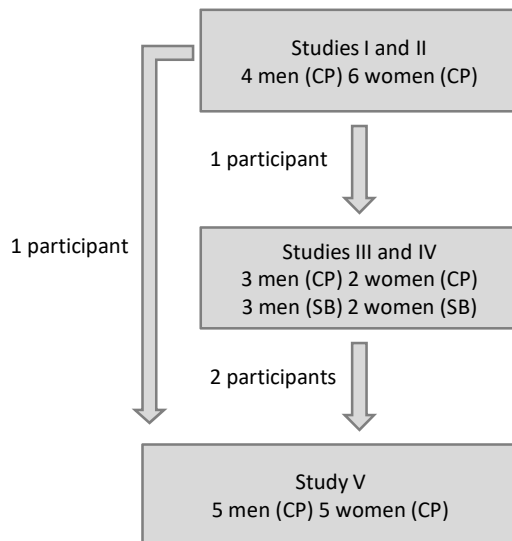


Figure 4. Distribution of participants/respondents in Studies I–V
CP=cerebral palsy, SB=spina bifida.

Studies I and II

The same young adults participated in Studies I and II. They were ten persons aged 19–30 years, four men and six women. Seven of them had a sub-

diagnosis of BSCP, two had USCP and one had ACP. They were classified at MACS levels I–II, GMFCS levels I–III and CFCS levels I–II. All had completed at least the nine years of compulsory schooling. Both urban and rural residential areas were represented in the sample. Some of the participants lived with their parents, others lived alone or with a partner. A range of employment status was represented: there were students, trainees, unemployed and employed persons among the participants. This breadth and variation in living conditions was made possible through strategic selection of participants via four Swedish Habilitation centres. The first participant took part in a pilot interview, which was subsequently included in Studies I and II owing to its rich content.

Studies III and IV

A sample of ten adolescents and young adults, aged 16–28 years, participated in Studies III and IV. Five of them were persons with CP at MACS level II and GMFCS levels I–III. Different sub-groups of CP were represented: two persons with BSCP, two with USCP and one with DCP. The remaining five participants were persons with SB, of whom four out of five used a wheelchair. All the participants were able to communicate verbally in Swedish, had nine years of compulsory education in the mainstream school system and reported difficulties with occupational performance in everyday life. Again there was a mix of participants living alone, with a partner or with their parents. Two of the participants with CP were students and three were employed. Convenience sampling was used to recruit the participants through the Habilitation centres of two Swedish regions. In fact, a total of thirteen persons originally agreed to participate in Studies III and IV, but three of them (two persons with CP and one person with SB) withdrew their participation owing to health conditions and personal circumstances before all CO-OP intervention sessions had been completed.

Study V

The participants in Study V were ten respondents with CP, five women and five men aged 22–56 years. Eight of them had BSCP and two had USCP. They were classified at MACS levels I–II, GMFCS levels I–IV and CFCS level I. Purposive sampling was used to invite potential participants to the study through two Swedish Habilitation centres. The decisive criterion for participation was willingness to share one's experiences and thoughts

while filling in the m-MFS; experience of fatigue was not an explicit requirement for participation. The first respondent participated in a pilot interview, which was subsequently included in the study because it yielded important content.

Design

This thesis is based on both qualitative and quantitative research. The ambition has been to highlight the research issues from different perspectives, but always with the participants in focus. Three of the studies included have a qualitative design and two use mixed methods. Although the main focus of all studies was to capture the participants' or respondents' perceptions and experiences of the phenomenon explored, varying designs were used to best achieve the purpose of each study. Study I focused on variation in the participants' perceptions of occupational performance in everyday life, which is why a phenomenographic approach was used (78-80). In Study II, directed content analysis (81) was used in order to make it possible to relate the interview material from Study I to the MPoD (5, 6). Studies III and IV were both part of a project investigating the feasibility of an intervention, the Cognitive Orientation to daily Occupational Performance (CO-OP) ApproachTM (82). Both Study III and Study IV had two embedded groups consisting of adolescents and young adults with CP and SB, respectively; this thesis focuses on the group with CP. Study III had an exploratory multiple-case design, mixed methods were used, and the qualitative and quantitative materials were combined to shed light on the research questions from several angles (83, 84). In the qualitative Study IV, the semi-structured interview material was analysed using content analysis (81). Finally, in Study V a sequential exploratory design was used (83, 85) when searching for evidence of construct validity for the modified version of the Mental Fatigue Scale (m-MFS). Cognitive interviews, retrospective questions and descriptive and comparative statistics were used to capture both qualitative and quantitative aspects of the self-rating scale examined. An overview of the studies, including their designs, samples and data-collection and data-analysis methods, is presented in Table 1

Table 1. Overview of the studies

Study	Design	Participants	Data collection	Data analysis
I	Qualitative Interview study	Persons with CP Age 19–30 N=10	Individual semi-structured interviews	Phenomenographic approach
II	Qualitative Interview study	Persons with CP Age 19–30 N=10	Individual semi-structured interviews	Directed content analysis
III	Mixed methods Exploratory multiple-case feasibility study	Persons with CP or SB Age 16–28 N=5 (CP) N=5 (SB)	Measurements; Field notes; Policy documents; Individual structured interviews	Descriptive statistics; Non-parametric comparative statistics; Linking goals to ICF; Conventional content analysis; Triangulation
IV	Qualitative Interview study	Persons with CP or SB Age 16–28 N=5 (CP) N=5 (SB)	Individual semi-structured interviews	Conventional content analysis
V	Mixed methods Sequential exploratory validation study	Persons with CP Age 22–56 N=10	Individual think-aloud interviews; Retrospective questions; Participants' and designers' ratings	Analysis in accordance with Fonteyn; Descriptive statistics; Comparative statistics: percentage agreement and weighted kappa

ICF: International Classification of Functioning, Disability and Health.

Methodological approaches

Qualitative approach

Phenomenography

Phenomenography, which was used in Study I, is one of the newest qualitative methodological approaches (and because of its novelty it is sometimes mistaken for phenomenology). With phenomenography, the researcher explores the different ways in which people experience a phenomenon, both with regard to how the experiences of a specific phenomenon differ between people and with regard to how a person may have different experiences of a specific phenomenon (86). Phenomenography is intended to capture variations in concepts, perceptions, understandings and ways of experiencing a phenomenon (78-80, 86) in order to provide a holistic view of that phenomenon (79, 80, 86). The main approach used in phenomenography is to highlight the 'second-order perspective', i.e. the

study participants' perceptions of the phenomenon experienced (79, 86). The intention is not to identify the 'essence' of the phenomenon but to capture its variety (79, 86). In Study I, a phenomenographic approach was appropriate because the research aimed precisely to explore the variety of experiences of how occupational performance is perceived in persons with cerebral palsy (having relatively good motor ability), and also to establish how the experiences were logically related to one another (79, 80, 86). The overall result in terms of the different identified ways to perceive the phenomenon of occupational performance formed an 'outcome space', i.e. a holistic picture of how different ways of perceiving occupational performance are related to each other in the target group (79, 80, 86).

Content analysis

Content analysis can be seen as an umbrella term for three types of content analysis using different analytic approaches ranging from strict and systematic to intuitive and interpretative text analysis (81). The types of content analysis used in this thesis are 'directed' (where the coding categories are pre-determined) and 'conventional' (where the categories are derived from the data). In Study II, directed content analysis was used (81) to make it possible to relate the interview material from Study I to the theoretical framework of the MPoD (5, 6) describing the 'process of doing'. The use of directed content analysis made it possible to identify the phases of that process in which the participants had difficulties and also to establish whether certain experiences described by them could not be categorised as pertaining to any one of the phases of that model (81). In Studies III and IV, conventional content analysis according to Graneheim and Lundman (87, 88) was chosen to generate knowledge from structured and semi-structured interviews about how the participants perceived the use of the CO-OP Approach. Conventional content analysis was used because the interview material had both structured and semi-structured parts, meaning that there was a need to analyse both what the text said (the manifest content) and what the text was about (the latent content or underlying meaning of the text) (87). The participants' answers to the structured questions were presented in Study III, about the feasibility of the CO-OP Approach, and the semi-structured parts of the interviews were presented in Study IV, whose purpose was to remedy the lack of knowledge about how the participants themselves perceived the intervention period using the CO-OP Approach.

Cognitive interviews

As the purpose of Study V was to gather evidence of construct validity for the m-MFS based on response processes and content, it was important to gain access to the respondents' spontaneous thoughts, reflections and feelings about that instrument. This is why cognitive interviews based on the think-aloud method (89) were used along with retrospective questions (89, 90). The think-aloud method made it possible to capture the participants' inner thoughts about the m-MFS. The participants were asked to fill in the self-rating scale while verbalising their thoughts and feelings about the self-rating, meaning that any individual differences in the performance of the m-MFS could be studied (89). Retrospective questions were used to shed additional light on the material from the think-aloud interviews. In addition, triangulation of data was used to provide more in-depth insights into the participants' described experiences (89, 90). The interview material was analysed in accordance with the method described by Fonteyn (91) because that method takes into account not only what thoughts the respondents expressed but also how they expressed those thoughts – for example, whether they seemed to attach great importance to them or only mentioned them in passing (91).

Quantitative approach

Non-parametric statistical methods were used because all tests used produced ordinal data and the studies were all based on small samples of participants with data that were not normally distributed (92).

Mixed approach

In this thesis, 'mixed-methods research' is defined, in accordance with Johnsson et al. (93 p. 123) as 'research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration'. To the potential advantages of a mixed approach should be added that using different perspectives and sources in a feasibility study will make it stronger (83). This is why mixed methods, involving quantitative and qualitative data from different perspectives and sources, were used in Study III. The quantitative aspects of the methods included calculation of proportions of change for the answers

to the structured questions and calculation of differences between occasions for different assessments. The qualitative aspects included evaluation to identify differences and instances of adaptation of the intervention compared with the CO-OP manual and the CO-OP fidelity scale, as well as a qualitative evaluation of how well the intervention matched the core organisational values of the Swedish Habilitation services. In Study V, where the aim was to gather evidence of validity for the m-MFS, using a mixed approach was appropriate because, to provide evidence of validity, a research process has to involve accumulation of various evidence resources (94). For this reason Study V consisted of a descriptive phase followed by a comparative one which was based on the descriptive material collected. The descriptive phase included both the qualitative interviews and the quantitative calculations relating to participants' self-ratings at the individual and item levels, while the comparative phase consisted in calculation of agreement between ratings.

Intervention method and instrument investigated

This thesis includes two studies (III and IV) to test the feasibility of an intervention method, the Cognitive Orientation to daily Occupational Performance Approach, and one study (V) to assess the construct validity of an instrument, a modified version of the Mental Fatigue Scale. The intervention method and the original self-rating scale are briefly described below.

The Cognitive Orientation to daily Occupational Performance (CO-OP) Approach™

CO-OP is a top-down, client-centred, performance-based approach which uses an interactive guiding process to enable the person to identify cognitive strategies for problem-solving during occupational performance. The approach is based on theories of motor learning and meta-cognitive learning and contains several interacting elements (82). It is a complex intervention design (95) in the sense that it contains multiple active ingredients, and the person is deeply involved. Through the therapist's use of reflective questions, the person is involved in all stages of the intervention process (82). The person identifies and sets his or her own goals and analyses his or her performance skills and breakdowns during performance to discover

strategies for problem-solving. The approach has four objectives: skill acquisition, strategy use, generalisation of performance of a task to a new situation, and the transfer of strategies to solve new performance problems. Five of its seven key features are deemed essential: client-centred occupation-focused goals, dynamic performance analysis, cognitive strategy use, guided discovery and enabling principles. Those are the active ingredients that must interplay during the intervention to achieve consistency with the theoretical foundation of the approach. The other two key features – involvement of a significant other and the intervention format – are structural elements and can be varied to fit the person's need or the context (95). In this thesis, a format encompassing 11 intervention sessions across 10–12 weeks formed the basis both for Study III and for the interviews in Study IV. The expected outcome of the CO-OP intervention is that the person will acquire the ability to analyse his or her own performance, to identify problems and to use strategies (global and domain-specific) during performance in order to reach skill-acquisition. In addition, it is expected that the person will reflect on his or her own thinking and cognitive processes during occupational performance and will acquire the ability to adjust his or her performance, which may in the longer term enhance confidence in his or her own ability to perform tasks (95). Studies have reported that the CO-OP intervention reduces impairment (95) and that improvement is seen in occupational performance and participation for persons with various disabilities (95).

The Mental Fatigue Scale (MFS)

The MFS is a multi-dimensional self-rating scale for mental fatigue and related symptoms occurring after brain injury. It includes 14 items each consisting of a question and descriptive rating options as well as a final 15th item concerning variation in fatigue. The first 14 items concern fatigue in general, lack of initiative, mental fatigue, mental recovery, concentration difficulties, memory problems, slowness of thinking, sensitivity to stress, increased tendency to become emotional, irritability, sensitivity to light and noise, and decreased or increased sleep. The rating options are based on intensity, frequency and duration. Items 1–14 have rating scales with seven options including 'half points' (0, 0.5, 1, 1.5, 2, 2.5, 3). The integer options are associated with statements describing a real-life situation which the user may identify with. A higher score reflects more severe symptoms: 0 = no problem, 1 = slight problems, 2 = fairly serious problems and 3 = serious problems (96, 97). The items have been found to have

adequate internal consistency for the group of people with brain injury, with a Cronbach's alpha of 0.944. A score of 10.5 (out of 42; the 15th item is not included as it has a range of 0–2) on the MFS has been suggested by Johansson and Rönnbäck (97) as a cut-off indicating the presence of mental fatigue and related symptoms.

The MFS is thus intended to compare the situation 'before' and 'after' brain injury. In this thesis (Study V), the MFS was modified to fit persons with congenital or early-acquired brain injury, where the information sought will refer to the present state rather than to such a difference. As few changes as possible were made. The questions and rating options were slightly modified to refer to the situation 'in the past four weeks'. Item 15 was removed and two examples illustrating rating options were changed. The rating options in Items 13 and 14 were changed so that respondents would choose among numbers of hours of sleep instead of comparing their earlier and present situation. Further information can be found in the paper describing Study V.

Data collection and procedure

Studies I and II

Individual qualitative semi-structured interviews were conducted as part of Study I. The material from those interviews was used both in Study I and in Study II. The interviews lasted for approximately 90 minutes and typically took place in the participant's home or on another location convenient for the participant. After the initial collection of demographic data, the interviews focused on how the participants themselves perceived the phenomenon; occupational performance in everyday life. A few initial questions were asked, such as, 'Please tell me about your experiences of performing everyday activities during an ordinary day'. Different techniques were used to encourage the participants to elaborate on their descriptions, such as showing interest during silence and using follow-up questions beginning with a pronoun. The interviews were recorded and transcribed verbatim.

Study III

To investigate the feasibility of the CO-OP Approach, both qualitative and quantitative data were collected from different perspectives and sources: measurements, structured interviews, field notes and policy documents. The assessments using different measurements and the interviews were carried out on different occasions: baseline (T1), post-intervention (T2) and follow-up six months after the intervention (T3) (Figure 5).

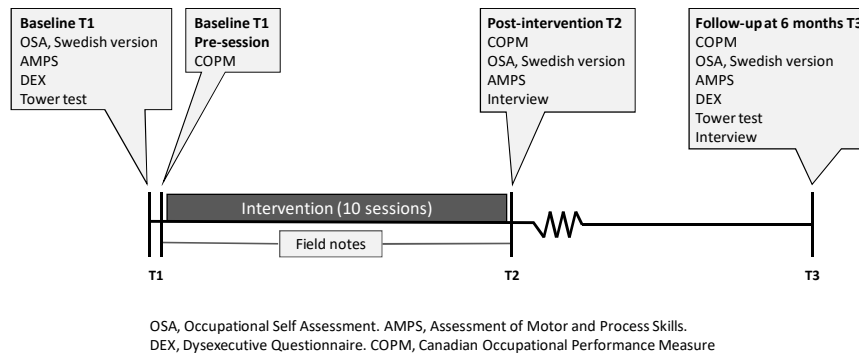


Figure 5. Timeline of Study III

The measurements were chosen to capture various aspects of the two components – Activity/Participation and Body function – of the ICF (98).

Canadian Occupational Performance Measure (COPM)

In Study III, the Swedish version of the COPM (99, 100) was used in accordance with the CO-OP protocol to identify occupation-based goals that the person was motivated to achieve. The COPM is a person-centred and occupation-focused interview-based tool designed to enable persons to identify and prioritise everyday issues in all areas of life that affect their occupational performance. The CO-OP instructor conducting the CO-OP intervention was the same person as the interviewer. The interviews started from the perspective of the person's own circumstances and focused on the person's self-perception of self-care, leisure and productivity. The interview yielded a set of occupations which the person considered highly important and meaningful. The person's self-perceived occupational performance and satisfaction with performance were rated on a ten-point scale. The outcome of the interview provided the basis for setting goals, and the COPM outcome measure was used to detect changes over time.

Differences amounting to two points on the ten-point scale are deemed to represent clinically relevant change (99-101).

Occupational Self Assessment (OSA)

The Swedish version of the OSA (102, 103) was one of the measurements used in Study III to capture changes in the ICF component of Activity/Participation. The OSA is a person-centred self-reporting tool where the person assesses self-perceived occupational performance competence and the value to him or her of specific occupations. The self-reporting scale was administered by an occupational therapist not involved in the CO-OP intervention. The OSA captures a wide range of everyday activities – it includes 21 items that deal with subjects such as handling responsibilities, managing finances and relaxing. Those items are rated on a four-point Likert scale. The OSA key form was used to transform the raw ordinal scores into interval-level scores. According to the manual, a change is clinically relevant when there is no overlap between values obtained on two occasions (102, 103). The OSA has been shown to have good stability over time for both competence and value (104).

Assessment of Motor and Process Skills (AMPS)

The AMPS was used in Study III with regard to Activity/Participation. The assessments were conducted by an occupational therapist who was not involved in the CO-OP intervention. The AMPS is a client-centred and observation-based tool designed to be used to evaluate the quality of a person's performance of activities of daily living (ADL) (105). The person chooses a task which he or she deems to be meaningful and relevant and carries it out in a natural environment. Two domains of occupational performance are evaluated: ADL motor skills and ADL process skills. ADL motor skills are defined as skills pertaining to the actions undertaken by the person to move him- or herself or the object which are necessary for the performance of the ADL task. ADL process skills relate to the person's logical sequencing of those actions over time in order to bring the task from A to Z by selecting and using appropriate tools and materials and by adjusting and adapting performance if problems occur. In Study III, measurements of ADL motor skills and ADL process skills are presented as logits (105, 106). A change is deemed statistically significant when the difference between two data points exceeds two standard errors (SE) (105).

The AMPS has been found to be valid and reliable for use in people with congenital developmental disabilities (105, 106).

The Dysexecutive Questionnaire (DEX) and the Tower test from the Delis–Kaplan Executive Function System

Both the DEX and the Tower test are measurements which relate to the ICF component of Body function. The measurements were administered by a neuropsychologist. The DEX is a self-reporting measurement of the person's own perceived everyday problems in connection with executive dysfunctions. The person self-assesses 20 items on a five-point Likert-scale ranging from 0 (never) to 4 (very often). The items sample four domains: emotional, motivational, behavioural and cognitive. The total score range is 0 to 80, where a higher score indicates greater problems. The DEX has been shown to have good validity and reliability (107). The Tower test was used by the neuropsychologist to measure the participant's planning ability. This test, which has been found to have sufficiently good psychometric properties, measures spatial planning, inhibition of impulsive or perseverative behaviour, rule learning and the ability to follow instructions (108). Changes in scores are deemed to represent a clinically significant improvement where there is a shift upwards from one ability level to another as described by Wechsler (109), where the levels are the following: low 1–3, borderline 4–6, low average 7–8, average 9–11, high average 12–13, superior 14–16 and very superior 17–19.

Field notes

All therapists conducting the CO-OP training wrote field notes about their use of the CO-OP Approach. They noted what dynamic specific strategies had been used, what plan the participant had used between sessions, whether significant others had been involved and whether any adaptations had been made to the approach. The field notes were compared with the CO-OP fidelity scale (110).

Policy documents

In Study III, to assess whether the CO-OP Approach was compatible with the principles underpinning Swedish Habilitation services, the CO-OP protocol was compared with five policy documents of relevance to the regula-

tion of those services: the Swedish Patients Act (111), the United Nations Convention on the Rights of Persons with Disabilities (67) and the ‘core values’ statements of three organisations: the Habilitation Services of the Västra Götaland Region (112), the Habilitation Services of Stockholm County Council (113) and the National Network of Swedish Habilitation Services (114).

Interviews

During data collection for Study III, structured interviews were conducted by three occupational therapists who were also CO-OP instructors. The interviewer was in no case the person who had conducted the CO-OP intervention with the participant interviewed. Five structured questions were asked, four of which were yes-or-no questions: ‘Was CO-OP meaningful to you?’, ‘Were the results worth the effort?’, ‘Have you continued using the global strategy?’ and ‘Was there a significant other who supported your continued use of the global strategy?’ (that fourth question was only asked at the six month follow-up). The fifth question was, ‘How would you rate the effort involved in the training on a ten-point scale from one (least effort) to ten (most effort)?’ When asking that question, the interviewer offered the participant a ten-point scale which was used when rating. The interviews were recorded and transcribed verbatim.

Study IV

To add further knowledge about the feasibility of CO-OP, semi-structured interviews were conducted in Study IV to obtain information from the participants themselves about how they perceived the use of the CO-OP Approach. The interviewer was one of the CO-OP therapists, but in no case the same therapist who had conducted the intervention. The interviews, which lasted for approximately 15–30 minutes, were recorded and transcribed. A few open-ended questions were used: ‘Could you please tell me a little about your experiences of the CO-OP Approach?’, ‘Are there any differences or similarities between the CO-OP Approach and other therapy that you have received?’ and ‘Could you please tell me a little about your experiences of using the CO-OP Global Strategy: “Goal–Plan–Do–Check”?’ The interviewer also used open-ended probes to show interest in obtaining a more elaborate description of the participants’ perceptions. In the second interview (at the six-month follow-up), additional questions

were asked about the participants' use of the 'Goal-Plan-Do-Check strategy' and about whether there had been any major changes in the participants' lives since the first interview.

Study V

In Study V, which had a mixed-methods design, the data collected were both qualitative and quantitative. The study consisted of a descriptive phase followed by a comparative phase. During the descriptive phase, cognitive interviews using think-aloud methodology, retrospective questions, field notes and descriptive statistics were used. In the think-aloud interviews, the respondents were asked to verbalise their thoughts and feelings while they were filling in the m-MFS. Those interviews were conducted one m-MFS item at a time, with each item followed by retrospective questions. Field notes were taken about thoughts and situations that required retrospective questions to be asked. The interviews lasted between 35 and 85 minutes and were recorded and transcribed verbatim. The descriptive phase thus generated both interview material and self-ratings from ten respondents. During the comparative phase, the designers of the original MFS chose rating options in the m-MFS based on the respondents' verbalised reasons for why they had chosen a specific rating option as well as the designers' own intended meaning for the various options. Then the designers' and the respondents' choices of rating options were compared.

Data analysis

Study I

In Study I, data analysis was carried out according to a phenomenographic seven-step analysis described by Sjöström and Dahlgren (79). Special software (NVivo 10) (115) was used to handle the material during the analysis. Familiarisation with the material was achieved during transcription. After listening to the recordings and reading the transcriptions several times, the first author of the article (i.e. the author of this thesis) identified an overall impression of the material and then discussed this with the last author of the article. The key elements of the transcribed text were identified and compiled, and condensation was made of long answers to identify the central part of the description. Variation in how the participants had

perceived the phenomenon was identified. The first author made a preliminary grouping of the material and then compared it with the last author's corresponding grouping. A good level of consistency was seen between the authors' preliminary groupings. Then similarities and differences between how the persons perceived their occupational performance were identified and categorised. The first author established the boundaries between the categories during this preliminary comparison by revising the categories several times and by discussing their content with the last author. The categories were then revised again and named to emphasise their essence. The preliminary result was discussed in a session with all authors. Finally, when the contrastive comparison of categories was made, an overall picture emerged of how the different ways of perceiving occupational performance were related to each other (79).

Study II

The transcribed material from Study I was analysed again in Study II. The use of directed content analysis made it possible to link the participants' experiences of occupational performance to the various phases of the MPoD (5, 6). The NVivo 10 software (115) was again used to handle the material. All meaning units which described how the participants perceived occupational performance were highlighted and coded with predetermined codes reflecting the phases of the MPoD. Then all categorised material was reviewed several times between the categories and between the excerpts in each category. Content that seemed not to fit in any category was also reviewed several times with regard to whether it related to any of the phases of the MPoD. All authors of the article were already familiar with the interview material from their work on Study I. The content of the categories was discussed by the three authors, after which some of the categories were revised. The final categories showed good consistency between the authors (81).

Study III

During the analysis of the material in Study III, an interactive process was used in which material from different data sources was analysed in several steps from the perspective of four focus areas: acceptability, efficacy, adaptation and expansion (116). Acceptability (i.e., how meaningful, laborious, useful over time and worthwhile the participants perceived the method

to be) was evaluated by calculating the proportion of changes in the structured questions asked on different follow-up occasions. Efficacy (i.e., goal attainment and functional changes in the participants' skill levels, societal participation and executive functions) was evaluated in terms of the differences between the scores on the COPM, the Swedish version of the OSA, the AMPS, the DEX and the Tower test on different follow-up occasions. Calculations were carried out with regard to each participant's results, to clinically relevant changes in the combined group and to proportions of clinically relevant changes in each embedded group, but this thesis only reports the proportions of clinically relevant changes in the group of persons with CP. Adaptation (i.e., adherence to the CO-OP manual and adaptations needed for use in these new groups of patients) was evaluated by comparing the therapists' field notes and the analysed content of the participants' goals with the CO-OP manual and the CO-OP fidelity scale. This analysis process included linking each participant's goals to the ICF in accordance with the linking rules described by Cieza et al. (117). Finally, expansion (i.e., how well the intervention matches organisational goals and culture) was evaluated by comparing the core values expressed in official documents about habilitation in Sweden with the CO-OP core values.

The data analysed were then triangulated to obtain an overall picture of the feasibility of the CO-OP Approach in a Swedish context. According to Johnson et al. (83), triangulation of analysed data may show that data from different perspectives and sources confirm each other.

Study IV

In study IV, content analysis was carried out in accordance with Graneheim and Lundman to describe the participants' experiences of the CO-OP Approach (87). Three of the authors conducted the analysis of the interview material. After obtaining an overall impression of the material, they identified meaning units which were related to each other. Revision and condensation were carried out and the comparison showed good consistency between the authors. Codes were created for all condensed meaning units, and categories and sub-categories progressively emerged and were discussed. Then the authors went back to the data and compared the content from the two different occasions on which each participant had been interviewed, noting any differences. From the work on the categories and the comparison of the interviews, the overall theme emerged. The trustworthiness of the categories and the overall theme were discussed in a ses-

sion with all authors. Finally, the quotations representing the content of the various categories were chosen. A good level of consensus was seen between all authors' descriptions of the categories and the overall theme.

Study V

The analysis in Study V was divided into two phases: a descriptive and a comparative one. During the initial descriptive phase, an analysis of the material from the cognitive interviews was performed in accordance with the three steps described by Fonteyn et al. (91): referring phrase analysis, assertional analysis and script analysis. Referring phrase analysis began even during transcription, in the form of marking of the respondents' reading errors and familiarisation with the material. The NVivo software was used to sort the content of each interview line by line based on the different items of the m-MFS. Phrases of data from each item which were related to each other and had the same central meaning were identified, coded and revised several times. Revision of the codes was performed again after the last author had analysed a random subset of the transcription, and a good level of consistency between the authors' coding was seen. During assertional analysis, the respondents' ways of expressing their thoughts were analysed by means of a second analysis of the transcribed meaning units, interview recordings and field notes. It was noted whether a meaning unit was expressed with strong emotion or just mentioned in passing. During script analysis, both the material from the referring phrase analysis and that from the assertional analysis were used to produce an overall description of the respondents' thoughts about the m-MFS and their reasons for the decisions they made during self-rating. All authors were involved in the discussion about the final categories describing the respondents' reasoning process. Besides the analysis of the interviews, the descriptive phase also included an analysis of the distribution of the respondents' self-rating options to see, among other things, which items had received the highest ratings. The group-level median of the self-ratings for each item was calculated.

During the subsequent comparative phase of Study V, the participants' and designers' rating options for each item were analysed using comparative statistics (92, 118). Excel for Microsoft Office 365 was used to calculate the percentage agreement (PA) and weighted kappa (k_w). A PA above 80% was deemed satisfactory, in line with Katzin (118). For k_w , Altman's interpretation (92) was used: <0.20 = poor; $0.21-0.40$ = fair; $0.41-0.60$ = moderate; $0.61-0.80$ = good; and $0.81-1.00$ = very good.

Ethical considerations

As the person-centred view influenced all of the studies included in this thesis, it was of great importance to ensure that the participants themselves were listened to in all five studies.

The five studies were approved by the Regional Ethical Review Board of Gothenburg, Sweden (Studies I and II: Ref. No. 477-13; Studies III and IV: Ref. No. 736-13; Study V: Ref. No. 128-17). Before data collection, all participants received detailed spoken and written information about the procedure and the purpose of the study. Risks and advantages of participating were described. Information was given to the effect that confidentiality was ensured, that participation was voluntary, that participants could withdraw at any time without having to give an explanation and that withdrawal would have no impact on future treatment.

Two main domains of ethical concern were identified. First, it was deemed essential not to disclose the participants' identities. Second, it was considered that participation in the studies could bring up sensitive issues for the participants. The participants in the studies included in this thesis belong to a relatively small group of people in Sweden. For this reason, great efforts were made to present the results without revealing anyone's identity. The compilation of information about the participants' sub-diagnoses and their demographic information was carefully evaluated before publication. Further, in all studies the participants were offered an opportunity to see a therapist to process issues that came up during the study, but no participant took this offer.

Results

What will be presented here represents a synthesis of the five studies included in this thesis (in the case of Studies III and IV, focusing on the participants with CP). Detailed results of the individual studies are presented in the respective papers.

The participants with CP considered it extremely important to perform occupations independently, regardless of the price, since doing in the sense of performing occupations is a way for them to build their identity. Further, the CO-OP ApproachTM turned out to be beneficial for supporting the performance of occupations and the m-MFS showed the potential to be a useful instrument for self-rating of mental fatigue and related symptoms in persons with CP.

Facilitators and hindrances for doing were described, showing that the participants had difficulties in at least one of the phases of the 'process of doing'. However, despite their difficulties, the participants aimed to feel involved with the people around them when performing occupations. It was also clear that, regardless of whether the participants' occupational performance had a positive or negative outcome, they paid a high price for their performance in terms of deterioration, pain, stress and mental and/or physical fatigue. The CO-OP offered the participants an opportunity to enhance their planning skills and find their own way of performing specific tasks. Two factors identified by participants as crucial for believing in their ability to perform tasks was having strategies enabling them to process what happens during the performance of a task and having knowledge about their own limitations.

The importance of doing

The young adults with mild CP in this thesis consider it extremely important to perform occupations in everyday life, preferably in the same way as others. Occupational performance, including doing and being, is described as what makes you develop as person (Study I). The driving forces for occupational performance identified by the participants are a desire to become better at doing along with curiosity and a positive attitude (Studies I and II). The participants expressed their hope of maintaining or developing

their ability by doing (Studies I and IV). They also pointed out the importance of feeling a sense of belonging through doing together with others in a social environment (Study I). In addition, the importance of doing by yourself and finding your own plan for how to perform occupations was strongly emphasised (Studies I–IV).

Hindrances when doing

Many situations involving occupational performance were characterised by the participants as demanding, both physically and cognitively (Studies I and II). They explained how difficulties were more frequent in some phases of the ‘process of doing’ than in others. Hindrances were described mainly in the more invisible phases of that process. For example, the participants described having difficulties planning the sequencing order of a task and figuring out how to adjust their plan in the moment if the enacting does not work out well (Study II). They also expressed that their actions during the enacting phase did not happen automatically but required strong concentration, meaning that they could not focus on anything other than the different steps while acting. Their difficulties not only induced problems but also caused complete breakdowns, especially if occupational performance required simultaneous use of motor and cognitive ability (Studies I and II). The participants explained that they had to pay a high price in terms of physical deterioration, pain, stress and mental and physical fatigue when performing occupations, which in the long term affected their whole life situation. The participants highlighted how fatigue, especially mental fatigue, sometimes made them unable to perform occupations, describing how it was difficult to make decisions when the brain had ‘shut down’ owing to fatigue (Study I).

The participants pointed out that occupational performance was often more time-consuming for them than for their peers and that they also needed more time to learn how to perform a task. When people around them did not give them as much time as they needed, they had problems with occupational performance. Also, their difficulties managing time during the different phases of the ‘process of doing’ sometimes induced total task breakdowns. Society’s high expectations of the participants’ ability to take initiative and act independently increased the pressure on them (Studies I and II). What is more, as the participants often lacked knowledge about their disability, especially about the ‘invisible’ parts of it, they were misunderstood by people around them because they were unable to explain the

reasons for their difficulties. As a result, the participants were either excluded from participation in occupational performance or were invited to perform tasks which were too vaguely described. The participants stressed how such exclusion made it difficult for them to find their role in the social environment (Study I).

Ways to facilitate doing

The participants described how they endeavoured in different ways to facilitate their own occupational performance and to achieve a feeling of inclusion. For example, they made fun of themselves and tried to ignore people's stares in order to become part of a social environment when performing a task (Study I). They searched for knowledge about their diagnosis, especially the cognitive parts, so that they could inform people around them and hopefully make those people understand their limitations better (Studies I and II). Further, although this was a difficult task in today's stressed-out society, the participants tried to use reasonable timeframes, routines, rest and help from others to deal with the fact that they needed more time than their peers when performing occupations (Study I). When the participants had experienced breakdowns during the 'process of doing', they tried to adapt the task the next time they had to perform it in order to improve their occupational performance. They noted that it was easier for them to adapt tasks if people around them understood their situation. One example given was how markings on a washing machine helped them to perform each sequence in the right order. However, such adaptations can only be used for tasks already learned or in adapted environments, not be created ad hoc. Also, the participants expressed how they saw using assistive devices as a last resort, because they preferred to perform their occupations in the same way as others if at all possible (Studies I and II).

The CO-OP Approach was shown to have the potential to enable adolescents and young adults with CP to enhance their planning skills, their ability to find the right strategy for performing a task and their success in reaching their goals (Studies III and IV). In addition, the CO-OP Approach proved to be compatible with the core values of Swedish society in terms of the individual's right to be involved in the social environment on the basis of his or her own ability. Six months after the CO-OP intervention, all participants with CP deemed participation in the intervention to have been highly meaningful and worth the effort (Study III). They characterised the approach as a different way of learning to perform occupations,

and they felt that the occupational therapist had trusted their ability throughout the intervention process. Instead of acting as an instructor and telling them what to do, the occupational therapist had used reflective questions to guide them in finding their own plan for the doing. The participants had used the occupational therapist as a sounding board for their thoughts and ideas in order to find their own way of doing that suited them and in order to reach their occupational performance goals. The participants described how this reflective process had made them think analytically, and they felt that they now had the ability to solve problems during occupational performance. CO-OP supported the participants' way of thinking and doing, and use of the 'global strategy' of the approach enabled them both to do in new environments and to perform entirely new activities. The participants described how they understood the importance of working towards a goal by making and testing plans, by doing and analysing their doing, and by changing their plan if necessary. The checking part was seen as essential for obtaining a useful plan leading to the goal (Study IV).

Even though two out of four participants with CP (data are missing for one participant) perceived the CO-OP approach as both physically and mentally challenging when asked immediately after the intervention, all of them also expressed that having participated was worth the effort because it had helped them to achieve their goals (Study III). The COPM showed improved performance and greater satisfaction with performance for all fifteen goals set by participants with CP, with a median difference of ≥ 2 points between the baseline (T1) and the six-month follow-up (T3). Self-rating of participation using the OSA-S showed that, of four persons with CP (data are missing for one), one had a higher rating at T3 than at T1 while one had a lower rating at T3 than at T1. For activity-performance skills as measured by the AMPS, there were in most cases no differences in logits between T1 and T3. For motor skills, there was one case where the score decreased by more than 2 SE, and for process skills there was one case where the score increased by more than 2 SE.

The Tower test of executive functions showed improved planning ability in four out of five participants with CP and no change in the fifth. At T1, the median scaled score was 7.0 (IQR 6.0–13.5) for the participants with CP. At T3, they had improved to a median scaled score of 13 (IQR 7.5–16.0). The results from the self-rating of executive problems using the DEX showed that three out of five participants with CP perceived there to be less problems at T3 while the other two participants perceived a higher

level of executive problems. In addition, all participants with CP used the global strategy at T3 to enable the performance of tasks both in new environments and in new situations (Study III). Taken together, the results showed that the CO-OP Approach is beneficial for persons with CP and addresses the need to enable occupational performance in persons with CP in the way they desire (Studies III and IV).

The m-MFS self-rating scale proved to have the potential to be a useful instrument for self-rating of mental fatigue and related symptoms in adults with mild CP. It showed evidence of construct validity, based on response processes and content, for use in this target group. The questions, rating options and rating scale were understood and interpreted as intended. The participants identified themselves with the life situations described in the rating options, and they found the design of the scale to be easy to understand and use. Comparison of the respondents' self-ratings with the ratings made by the designers of the original MFS scale based on the intended meanings of the items showed a very good level of agreement ($k_w=0.92$ and $PA=89\%$). In 124 out of 140 instances, the participants and the designers selected the same rating, and in most of the 16 cases where there was disagreement between the participants and the designers, the difference was only a single level (0.5 points). Finally, median scores for the individual items showed that the participants self-rated themselves as having the most severe fatigue-related problems (≥ 1.25 out of 3) for five items: mental fatigue, mental recovery, concentration difficulties, slowness of thinking and sensitivity to stress. The participants' individual total scores showed that eight out of ten scored above the cut-off of 10.5 (indicating the presence of fatigue-related problems) even though the presence of fatigue was not an inclusion criterion for participation in the study (Study V).

Self-efficacy as a result of appropriate support

The participants described how they felt diminished as human beings when occupations proved too demanding and when they felt excluded (Study I). In such situations, they became a person who they did not want to be. On the other hand, if their performance was facilitated and/or their social environment invited them to be involved in occupations, this promoted participants' personal growth, making them feel that they became the person who they wanted to be (Study I).

Knowledge about one's own abilities and limitations was highlighted by the participants as important for personal development. The participants

described that knowing how their disability affected their ability when performing a task generated self-confidence to perform tasks and to inform others (Study I). Doing things by yourself was described as extremely important, despite the risk of an defective occupational balance in life and the attendant fatigue (Study I). The m-MFS self-rating scale showed evidence of construct validity, based on response processes and test content, in adults with CP, meaning that it can be used to acquire knowledge about the risks of mental fatigue and related symptoms (Study V).

The participants described how the CO-OP Approach had boosted them and made them trust their own ability (Studies III and IV). They pointed out that reflecting on their own thinking during doing had helped them handle new situations in everyday life and in new environments. They had a feeling of knowing what to do and how to move on to the next step, and they described how they now began to see themselves as better problem-solvers. Their conscious reflecting upon and processing of what was happening during doing had improved their ability to solve problems during the ‘process of doing’. When this happened, the participants’ confidence in their ability increased, which in turn enhanced their belief in their own capabilities and improved their self-efficacy (Study IV).

*It has made a difference in my personality somehow, I believe in myself.
(Participant 7, Study IV)*

The participants’ self-confidence was boosted when they found that it was possible to facilitate demanding situations during occupational performance. The fact that the occupational therapist trusted the ability of the participant and supported him or her while at the same time handing over responsibility for the intervention process to the participant encouraged the participants’ self-efficacy and made them feel that they were ‘the boss’ (Study IV).

Discussion

The results of this thesis highlight the demanding life situation that persons with CP have to face, even when they have a relatively good motor ability. Their descriptions attest to their difficulties with occupational performance in everyday life. However, although the participants' life situation is so demanding, they still aim to perform occupations by themselves, preferably in the same way as others – because life is about doing. The thesis also presents two different methods of intervention which can enhance occupational performance and detect occupational imbalance.

Knowledge about one's own abilities and limitations

The participants in this thesis had fairly good motor function (MACS level I–II) and no intellectual disability. Even so, they expressed how hard it could be to perform occupations and to go through the different phases of the 'process of doing'. While the participants are characterised as persons with mild CP, the results of Studies I, II and V show that their difficulties in everyday life can hardly be described as 'mild'. The participants' descriptions highlighted that the most crucial issue was their cognitive – mainly executive – impairments, not their motor impairments (Studies I and II). This is consistent with the findings of previous studies, which have stated that persons with CP who have no intellectual disability and fairly good motor functions often have difficulties which are due to executive dysfunctions (7-9, 45). The participants in this thesis pointed out that some such 'hidden' difficulties could be hard to understand, both for themselves and for others (Study IV). It is likely that a lack of knowledge about cognitive difficulties associated with CP can lead to misunderstandings and to overly high expectations on the part of other people. The participants believed that better knowledge about CP would bring about a positive change in their lives, so they searched for knowledge to be able to inform people in their environment and to understand themselves (Study I).

In order to support people with CP in their endeavour to perform occupations in everyday life, it is essential for them, and for others, to gain knowledge about where in the 'process of doing' there occur problems. First, the MPoD could be used as a tool to understand and communicate

about the complex ‘process of doing’ as well as each individual’s point of departure for the ability to perform occupations (Study II). If a person with CP obtains such knowledge, it can be used when informing other people, and this, in turn, can enhance opportunities to obtain appropriate support. Second, use of the CO-OP Approach makes the person with CP involved in the analysis of what happens during doing and ensures that he or she gains knowledge about what works well and what has to be adjusted. This may result in a growing awareness of one’s own strengths and limitations. In fact, such a shift in the awareness of oneself, referred to as a ‘response shift’ by Schwartz et al. and Baracaly-Goddard et al. (119, 120), may be one of the reasons why two of the participants with CP in Study III rated themselves as having greater executive difficulties at T3 than at T1. Third, if discussions about the outcome of a person’s occupational performance draw upon his or her self-rating using the m-MFS, this may yield additional insights about the reasons for the difficulties experienced, since the m-MFS highlights the links between cognitive, sensory and affective symptoms and fatigue (Study V). According to Brunton et al. (121), professionals have a responsibility to offer opportunities for people to gain knowledge about their abilities and disabilities as a part of the process towards self-awareness. It seems that the use of the MPoD, the CO-OP Approach and/or the m-MFS could help persons with CP to obtain more knowledge about their own disability. This can make them better able to explain the reasons for their difficulties and might thus elicit more appropriate support from the social environment, and it is well known that a good ‘fit’ between the person, the occupation and the environment enhances opportunities for doing (4, 18).

Capturing the person’s unique experience of occupational balance

Knowledge about one’s own ability and capabilities is needed to achieve a balance between doing and being (1). A person’s well-being and health depend on his or her opportunities to achieve a good balance in life when developing his or her potential (49); in this context, the amount of occupation, its variedness and the time devoted to it are essential (20). In addition, stress-related conditions may occur if there is a lack of understanding of the need for a balance between doing and time for reflection (49). In this thesis, the participants described how an imbalance between doing and being affected both the amount and variety of their occupations and the time

they devoted to occupations. Since they needed more time during the ‘process of doing’ than peers did, and since they also needed time to rest, they had difficulties keeping up with everyday occupations and experienced negative stress for that reason (Studies I and II). What is more, if they chose to reduce their work hours in order to have more time for everyday occupations, their finances became weaker as a result, and this sometimes increased the stress they experienced even more (Study V). Negative stress was noted to be one of the causes of mental fatigue (Studies I and V). A noteworthy finding in this context was that eight of the ten participants who self-rated their fatigue using the m-MFS scored above the cut-off for fatigue-related problems even though presence of mental fatigue was not an inclusion criterion (Study V). It seems clear that this reflects a challenging life situation on the part of persons with CP, with both occupational and life imbalances, and this is something that has to be taken into account. In order to achieve an occupational and life balance that matches the needs of the person, people around him or her must listen to and try to understand his or her view of the situation (65). Sienko et al. (122) highlighted the importance of offering persons with CP the opportunity to undergo assessment of fatigue at an early stage of their lives. Use of the m-MFS in early adulthood can yield a fatigue baseline built on a person’s experiences until that point, making it possible to identify cases of increased fatigue through reassessment later in life. In the context of preventing occupational imbalance in the everyday life of adults with CP, the m-MFS may be a good tool to predict the need for interventions (Study V).

Learning by doing does not always work

The participants in Study I described how negative stress could also arise when they had difficulties figuring out how to perform and learn an occupation. According to John Dewey (123), experiences from the interaction between doing and reflection represent a fundamental asset in any educational situation. Real experiences are not created either from reflection that lacks action or from action that lacks reflection. Dewey described this as intelligent action (123) or as learning to do by knowing and to know by doing (124), which is usually shortened to ‘learning by doing’. Traditionally, the main focus when offering interventions to persons with CP has been to give them opportunities for learning-by-doing of life-skills (125), mainly by attempting to enhance their ability in the enacting phase of the doing (126). However, in this thesis, the group of ten participants collectively identified difficulties in all phases of the MPoD, and they high-

lighted the planning and adjusting phases as particularly prone to create major difficulties (Study II). Indeed, life-skill training based on learning by doing and on trial and error does not always seem to work for persons with CP. It sometimes turns out that they cannot figure out how to do something by means of their own reflection, meaning that they will instead repeat the same mistake over and over again or just give up doing (Studies I, III and IV). Other studies have shown that one way to help bring about occupational development in this situation is to offer interventions where, under the guidance of an occupational therapist, the person learns to use strategies of thinking when doing (127). The therapist, by asking questions, guides the person to reflect and to build knowledge about when and how different strategies can be used. In other words, the person uses meta-cognitive thinking for problem-solving to master occupations in everyday life (128). Flavell has described meta-cognitive thinking as the 'thinking about the thinking' (128). Cognitive-behavioural theories of this type underpin the CO-OP Approach (82). In Study IV, the participants described how use of strategies had made them aware of the different phases that they had to go through when performing an occupation, and how this had helped them to figure out how to perform occupations and had also helped them complete occupations. The key factor for problem-solving here seems not to be just doing, but having the therapist guide the person to reflect on what is happening during doing and to put this into words (Study IV). Cognitive processing of what is happening and reflection upon why it is important to analyse the outcome – the knowledge created by thinking about the thinking – seems to give the person tools that can be used in new situations as well. With the CO-OP Approach, the therapist situates the person at the centre and focuses on all of his or her performance components – that is, not only on the motor components but also on the cognitive and affective components. This seems useful considering that, to broaden the scope of occupational therapy beyond the enacting phase during interventions in persons with CP (MACS I–II), it would seem necessary to ensure that the intervention methods used encompass all phases of the 'process of doing' and involve the full range of the person's performance components.

The importance of being involved in the intervention process

The participants experienced that in the CO-OP Approach, the therapist had a very special role, something that they had never encountered before. They noted that in other types of treatment, the occupational therapist would mostly give or propose solutions when problem-solving difficulties arose, whereas the CO-OP Approach was instead built upon collaboration between the person and the therapist (Study III). By using reflective questions, the therapist handed over agency to the person. The fact that the participants worked towards their own goals and were involved by the therapist's reflective questions throughout the intervention session increased their engagement, which is consistent with results from other studies (129, 130). In CO-OP, with its person-centred approach, it is fundamental for the person to choose his or her own goals, to be highly involved in the purpose of the treatment and to experience the treatment as meaningful. Those three issues – choice, purpose and meaning – have also been highlighted as important factors for experiencing life as worth living in general (55). This indicates that one of the major success factors of the CO-OP Approach is that it is person-centred throughout the intervention process. However, although the format of the CO-OP Approach can be adjusted to suit a person's needs (95), it cannot be used with everyone. Whatever intervention method is used, it is always important to create optimum conditions for involving the person in as many phases and aspects of the intervention as possible.

Trusting one's own capability to solve problems during occupational performance

A person's sense of control over his or her occupational performance is essential for the experience of well-being (55). It is therefore understandable that the participants in Studies I and II who described difficulties completing the 'process of doing' experienced a loss of faith in their capability. When people lose faith in their capability, they are slower to achieve a sense of self-efficacy (131). Bandura has defined self-efficacy as 'the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations' (131 p. 3). On the other hand, the participants in Study I also described that, if occupational performance was facilitated and/or yielded a sense of inclusion, it promoted personal growth, helping the participants to become the persons they wanted to be

(Study I). This description is supported by the results of Study IV showing that the participants' belief in their own capability promoted both their occupational performance and their occupational development. The CO-OP Approach was described as giving the participants an increased sense of autonomy when problem-solving (Study IV), which is consistent with the findings of McEwen et al. (132). Concretely, during occupational performance the participants found the courage to try to solve problems that they had not previously seen themselves as capable of dealing with. The fact that the participants were involved right from the start in the analysis of their performance caused them to obtain knowledge about their strengths and limitations as well as making them start to reflect on why breakdowns occurred. This way of thinking – cognitively processing what is happening during doing – gave them knowledge and insights about how to solve problems during occupational performance. They progressively strengthened their faith in their own capability and developed their self-efficacy (Study IV), as is also described by Bandura (131). Based on the results of Studies III and IV and the format of the CO-OP Approach, it could be hypothesised that occupational and self-efficacy development may evolve over time as described in Figure 6. However, this assumption needs to be studied further.



Figure 6. Interplay between CO-OP therapist and person in the process towards self-efficacy

Time is an important component both in occupational development (4) and in the development of self-efficacy (131). The participants in Study I clearly pointed out that doing was essential in their life and important for their perception of themselves. They explained how their self-esteem and self-efficacy were influenced by the outcome of their doing. To achieve positive occupational development and self-efficacy in a clinical context, it would thus appear essential to offer enough time and a sufficient number of intervention sessions.

The importance of involvement during participation

Self-efficacy has also been identified as a key factor when it comes to enabling participation in occupation (133). This was clearly described by the participants in Study I. They expressed that if they were excluded from occupational performance they felt diminished, but if they were given the opportunity to do and to share experiences with others, they felt a sense of belonging and involvement, becoming the persons that they wanted to be. Being involved increases a person's motivation and opportunities to affect his or her situation, and it provides opportunities for social interaction (16). Hence there is reason to believe that without involvement, a person is not likely to experience inclusion and 'real' participation, even though he or she is able to attend in the sense of being physically present. In addition, Hanes et al. (134) have shown that persons with CP strive to achieve 'normality' by searching for meaningful participation in different life situations, which is in line with the findings of Study I. Consequently, although society, in Sweden and elsewhere, is increasingly accessible from the perspective of being able to attend, there is a need for further education to change the attitudes of the general public in order to create greater opportunities for people with invisible disabilities to feel involved when participating. Appropriate support from the social environment enhances a person's opportunities to participate (135) and positively affects the person's well-being and identity (134). This is one of the crucial factors for achieving positive occupational development (4).

Overcoming the hindrances

This thesis highlights both facilitators and hindrances for doing, being, belonging and becoming in adults with CP. Wilcock (136) related these con-

ceptual elements to survival and health by stating that if the various elements develop negatively, health is negatively affected. In this thesis, doing was found to be associated with unwanted physical and mental impacts, such as deterioration, pain, stress and fatigue, and the participants described an occupational imbalance. They also described occupational exclusion and pointed out that losing abilities, roles and social contexts affected their sense of self negatively, meaning that there was a risk of occupational deprivation. It has been found that people with a mild or moderate chronic disability are at increased risk of experiencing deterioration as a threat, since it would mean that they would no longer be able to hide their disability or would have to accept being members of the group of 'people with disabilities' (137). The participants in this thesis confirmed that when their occupational performance was negatively affected by the deterioration of their condition, they experienced this as threatening and as exerting a negative impact on their self-esteem and identity (Study I). However, besides highlighting hindrances and risks, this thesis also gives examples of how they can be reduced using person-centred intervention methods. It is to be hoped that the results of this thesis will be used to reduce the risk of occupational imbalance, exclusion and deprivation in persons with CP (MACS I–II) and to create opportunities for doing, because *life is doing*.

Society in Sweden expects persons with mild CP to cope with integration without any special support. They are supposed to be enrolled in the mainstream school system, to live in their own homes and to find work on the open labour market. The findings of this thesis show that persons with mild CP: they really want to perform everyday occupations by themselves, like everybody else in society. However, those findings also show that they have difficulties with doing and that this leads to unwanted physical and mental impacts (Study I). What is more, many of the persons with mild CP do not receive any support from the Habilitation services, and those who do have a low priority when it comes to interventions because they have a seemingly mild disability. To address this problem, the Habilitation services should focus more on this group. It would seem that, with relatively small resources, interventions using tools such as the CO-OP Approach and the m-MFS could considerably improve the living conditions of a large group of people.

Methodological considerations and limitations

The methodological choices made in the studies included in this thesis were based on considerations of suitability for the research question asked in each study, financial constraints, time limitations and curiosity about new methods. To a large extent, this thesis focuses on creating knowledge about how people with CP perceive certain phenomena, interventions and instruments. In Studies III and V, qualitative data were studied alongside data from quantitative sources. Qualitative research is an important tool to build knowledge, but the research has to be trustworthy. There are a number of important aspects to trustworthiness in this context, including credibility, dependability, confirmability, reflexivity and transferability (138, 139).

Credibility is roughly equivalent to internal validity in quantitative research. Various strategies can be used to ensure that the findings of a study are credible in the sense that they reflect reality. The strategies used here include prolonged engagement, persistent observation and triangulation (138). In all studies, the participants were encouraged to give examples of the situations that they described, and efforts were made to create opportunities for them to share their experiences of the phenomenon, intervention or instrument in question through the use of non-threatening language and the provision of ample time to think. In Study V, the think-aloud method was complemented with retrospective questions to prolong the participants' engagement with the self-rating questions. To attain persistent observation, the researchers carefully followed the chosen methodology when collecting, analysing and systematising data. Further, different types of triangulation were used in the studies to strengthen their trustworthiness. In all studies, investigator triangulation was used by involving the whole research team in the different phases of the studies (138, 140). In Study III, triangulation of data was carried out from different perspectives, using different data sources and within different areas of analysis (140). Methodological triangulation was used to strengthen the findings in Studies III and V.

To ensure dependability and confirmability, Korstjens and Moser (138) consider it necessary to have an audit process for checking whether the

analysis process follows the steps of the methodological design chosen and whether the interpretation of the data is grounded in data from the participants. The audit process used in this thesis involved parallel analyses made by the co-authors and negotiations until a consensus was reached. During their discussions, the co-authors constantly reviewed the interviewer's interpretation of the material and verified that the methodological design was adhered to in all steps. However, the trustworthiness of the studies could have been strengthened even more if one of the auditors had been an external expert on the methodological design used. In Study II, the interview material from Study I was investigated using directed content analysis. According to Hsieh, the use of directed content analysis entails a risk that researchers will inadvertently search for evidence that supports the framework used, in this case the MPoD, by giving cues during the interviews (81). However, here there was no such risk because the interviews were conducted before the decision was made to use the MPoD as a framework during directed content analysis.

As an interviewer or therapist in a research study, it is important to reflect on one's own pre-understanding and on how it may affect study results (138). This is what is referred to as reflexivity in trustworthiness contexts. The author of this thesis has long clinical experience of working with people with CP. This may have exerted both negative and positive effects on the study results. On the one hand, the author's experiences may have helped her familiarise herself with the participants' life situation and may have made it easier for her to understand what the participants with speech difficulties said. On the other hand, these same experiences may have caused her to over-interpret the results. To address this issue, reflexive notes and discussions with co-authors were used. In Study III, all assessments and the introduction of the self-assessments, except the COPM, were performed by a therapist who was not a CO-OP instructor. This eliminated the risk of influence from the CO-OP instructor during the assessments. The COPM is part of the CO-OP concept and was therefore conducted by the CO-OP instructor. In Studies III and IV, the interviewer was a CO-OP instructor, but not the same person who conducted the CO-OP intervention. This may have increased opportunities for the participants to openly describe both negative and positive experiences of the CO-OP Approach, but the fact that the interviewer was a CO-OP instructor could still have represented a hindrance.

One weakness of this thesis is that the study material was not checked by the participants, for example after transcription. It is likely that the credi-

bility of the studies would have been greater if the transcripts of the interviews had been sent to the participants for feedback and if meetings had been held to discuss the preliminary study results with the participants (138).

Another limitation is that all five studies are based on small samples. This means that the results should be interpreted with caution when it comes to drawing general conclusions. Even so, the results can provide a knowledge platform for further studies. One issue of decisive importance when determining the number of participants to be included in each study was interview-material saturation. In Study I, which used a phenomenographic approach, saturation was deemed to have been attained when the interviewer saw a structure in the different perceptions of the group of participants (80). In Study II, the interview material from Study I was structured according to a frame of reference, meaning that the material used in both studies came from the same sample of participants. Since Study III was a pilot study preceding a randomised controlled trial, it was decided not to have a control group. A total of thirteen persons (seven with CP and six with SB) participated, but three of them (two with CP and one with SB) withdrew their participation owing to health and personal circumstances. The sample of participants in Study IV was dependent on that decision taken in Study III, so both studies had ten participants (five with CP and five with SB). However, despite the small sample size in Study IV, content analysis clearly showed that the interview findings strengthened each other. The results from Study III and Study IV confirmed each other, which strengthened both of them (140). Finally, in Study V saturation was achieved after eight interviews, but two more interviews were conducted to obtain a wider age distribution in the group of participants. Since the studies were all based on a small sample, it was particularly important to provide detailed descriptions of the participants, their life situation and the research process, so that readers will be able to judge whether their results can be transferred to other fields. This relates to the final aspect of trustworthiness, namely transferability. In this context, careful consideration was also given to the risk of divulging information about the participants that might make them possible to identify.

Conclusions

This thesis has demonstrated that the participants with CP (MACS I–II) characterised occupational performance – i.e. doing – as extremely important in everyday life. Through doing in everyday life, they strive to develop, to show who they are and to form their identity. Despite difficulties in one or more of the phases of the ‘process of doing’, the participants endeavour to find their role in society through doing. Where this driving force takes them can affect their self-esteem and health both positively and negatively. There is a high risk that adults with CP (MACS I–II) will push themselves too hard and suffer negative consequences in the form of physical deterioration, stress, pain and fatigue, meaning that they will not find an occupational balance in their lives. Knowledge about CP and awareness of the difficulties it causes, especially the non-visible aspects such as executive difficulties, are crucial to attaining occupational balance. The m-MFS has the potential to be a useful instrument for self-rating of mental fatigue. Persons with CP could use it to obtain knowledge about how mental fatigue and related symptoms manifest themselves and affect their everyday lives. Knowledge about where in the ‘process of doing’ problems tend to arise may help them understand themselves better and may also give them tools for explaining this to other people. When it comes to the need for interventions to facilitate occupational performance, the CO-OP ApproachTM has proved to be a beneficial and feasible approach enabling young adults with CP (MACS I–II) to enhance their occupational performance and planning ability, so that they can reach their personal goals.

Future Perspective

There is a need to continue investigating how the conditions for occupational development and occupational balance can be improved for persons with CP. New research questions have already emerged.

Study V yielded evidence of construct validity, based on response processes and test content, for the m-MFS. Only a few changes to the text of the self-rating scale were proposed. As the validation of a new instrument is an ongoing process, further research is needed into other sources of construct validity. In addition, there is a need to evaluate other psychometric properties of the m-MFS as well as its use in people with other congenital or early-acquired disabilities. Further, once the psychometric properties of the m-MFS have been fully examined, it would be of interest to investigate how mental fatigue and related symptoms are manifested in adults with CP in a larger sample. This would contribute new knowledge about the different challenges that persons living with CP have to master in daily life

Although Study III showed the CO-OP Approach to be a beneficial approach for adolescents and young adults with SB or CP (MACS levels I–II) and the participants in Study IV described how CO-OP boosted them as individuals, there remain many interesting questions to be answered. First, those two studies were pilot studies which should be followed by randomised controlled trials to evaluate the effectiveness of the CO-OP Approach for the target group. Second, further research is needed to deepen our knowledge about how the CO-OP Approach affects executive difficulties and a person's ability to generalise and transfer strategies or plans when performing occupations, as well as our knowledge about how the components of the CO-OP Approach are related to self-efficacy. Third, the fact that the CO-OP Approach is not manual-based may entail challenges when it comes to its implementation in clinical work. For this reason, it would be interesting to develop and test a model for the clinical implementation of the CO-OP Approach.

Finally, to deepen our knowledge about the life situation of adults with CP, there is a need to go on carrying out research which involves listening to their own voices, both as participants in research and as experts in the research team. Further research should include adults with CP in both capacities.

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