Posture, postural ability and mobility in cerebral palsy

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Posture, postural ability and mobility in cerebral palsy

Elisabet Rodby Bousquet
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Abstract

Cerebral palsy (CP) is the most common cause of motor disability in children and adolescents with a prevalence of 2-3/1000. CP is characterized by disorders of posture and movement with impairments ranging from mild to severe. The ability to control posture is an important prerequisite for all voluntary movements. A sustained asymmetric posture predisposes to progressive deformities in people with CP, such as scoliosis, hip dislocations and contractures.

The aim of this thesis was to enhance knowledge of posture, postural ability and mobility in people with CP, their use of assistive devices and also to evaluate a clinical tool for assessment of posture and postural ability.

Study I-III were cross-sectional studies of 562 children with CP, aged 3-18 years, describing sitting, standing, sit-to-stand and the use of assistive devices, wheeled mobility, and walking performance according to the Functional Mobility Scale. The results were analyzed relative to the expanded and revised version of the Gross Motor Function Classification System (GMFCS), neurological subtype and age. Study IV was a cross-sectional study describing postural asymmetries and ability to change position in 102 young adults with CP aged 19-23 years; and the relation of posture to pain, range of motion, hip dislocation, scoliosis and ability to change position. Study V evaluated the psychometric properties of the Posture and Postural Ability Scale for adults with CP at GMFCS I-V.

The GMFCS is a good predictor of sitting and standing performance. Powered wheelchairs provided independent mobility in most cases while few self-propelled their manual wheelchairs. To achieve a high level of independent mobility, powered wheelchairs should be considered at an early age for children with impaired walking ability. The number of children who walked without aids increased up to 7 years, but the proportion of children walking independently on uneven surfaces was incrementally higher in each age group up to 18 years. Postural asymmetries were associated with scoliosis, hip dislocation, hip and knee contractures, and inability to change position. The Posture and Postural Ability scale showed an excellent interrater reliability for experienced raters, a high internal consistency and construct validity. It can detect postural asymmetries in adults with CP at all levels of gross motor function.
Abbreviations

CP         Cerebral Palsy
CPUP       Cerebral Palsy follow-up Programme and National Quality Register
FMS        Functional Mobility Scale
GMFCS      Gross Motor Function Classification System
ICF        International Classification of Functioning, Disability and Health
PAS        Postural Ability Scale
PPAS       Posture and Postural Ability Scale
ROM        Joint Range of Motion
SCPE       Surveillance of Cerebral Palsy in Europe
# Definitions

<table>
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<th>Term</th>
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<tr>
<td>Assistive devices</td>
<td>Any product, instrument, equipment or technology adapted or specially designed for improving the functioning of a disabled person.</td>
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<td>Cerebral palsy</td>
<td>A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, epilepsy, and secondary musculoskeletal problems.</td>
</tr>
<tr>
<td>Environment</td>
<td>The physical, social and attitudinal conditions which are present in an individual’s life.</td>
</tr>
<tr>
<td>Hip dislocation</td>
<td>Reimers’s migration percentage of 100%&lt;sup&gt;1&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Transferring from one place to another, by walking, or by using various forms of transportation.</td>
</tr>
<tr>
<td>Performance</td>
<td>What a person actually “does do” in a daily life situation, and differs from what a person “can do”.</td>
</tr>
<tr>
<td>Posture</td>
<td>The shape of the body i.e. the anatomical alignment of the body segments in relation to each other and the supporting surface and also the relationship between the body and the environment.</td>
</tr>
<tr>
<td>Postural ability</td>
<td>The ability to stabilize the body segments relative to each other and to the supporting surface; to get into the most appropriate body configuration for the performance of the particular task and environment. This means control of the center of gravity relative to the base of support during both static and dynamic conditions.</td>
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Original papers

This thesis is based on the following original papers referred to in the text by their Roman numerals:


IV Rodby-Bousquet E, Hägglund G, Westbom L. Postural asymmetries in young adults with cerebral palsy (Submitted)

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<th>Questions</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusions</th>
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<td>I  How do children with CP usually sit, stand, and move between sitting and standing position? What is their use of assistive devices or external support?</td>
<td>Cross sectional study of a total population of 562 children with CP 3-18 years. Use of support or assistive devices to sit, stand, stand up and sit down was analyzed relative to GMFCS, CP subtype and age.</td>
<td>Standard chairs were used by 57%, 62-63% could stand and move between sitting and standing without support. Adaptive seating was used by 42%, support to stand by 31%, and to move from sit-to-stand and back by 18-19%.</td>
<td>Sitting, standing performance and the ability to move between these positions were highly correlated to GMFCS level. The GMFCS is age-related and seems to be a good predictor of sitting and standing performance.</td>
</tr>
<tr>
<td>II What is the use of manual and powered wheelchairs and the degree of independent wheeled mobility in children with CP?</td>
<td>Cross sectional study based on data from the CPUP register of 562 children with CP, 3-18 years. Wheeled mobility was analyzed in relation to GMFCS, subtype and age.</td>
<td>Wheelchairs were used by 165 (29%) indoors, 61 for independent mobility and 104 were pushed by an adult. Wheelchairs were used by 228 children (41%) outdoors; 66 for independent mobility and 162 were pushed.</td>
<td>Powered wheelchairs provided independent mobility in most cases (86%) while manual wheelchairs only did in 14%. To achieve independent mobility powered wheelchairs should be considered at an early age for children with impaired walking ability.</td>
</tr>
<tr>
<td>III How does walking performance differ at different distances and environments, in children with CP?</td>
<td>Cross sectional study of 562 children with CP, 3-18 years. The Functional Mobility Scale (FMS) was used to rate mobility in relation to GMFCS, CP subtype, and age.</td>
<td>FMS correlated to GMFCS and varied between the subtypes. An increased proportion of children walked independently on all surfaces in each successive age group. 57-63% walked without and 4-8% with walking aids.</td>
<td>The number of children who walked without walking aids increased up to 7 years, but the proportion of children walking independently on uneven surfaces was higher in each age group up to 18 years.</td>
</tr>
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<td>IV What is the relationship between posture and the ability to change position, pain, contractures, hip dislocation and scoliosis in adults with CP?</td>
<td>Cross-sectional study of a total population of 102 adults with CP, 19-23 years. Analysis of the relationship between posture and joint range of motion, hip dislocation, scoliosis and pain.</td>
<td>Postural asymmetries were present at all GMFCS levels but more frequent at lower levels of motor function. Hip dislocation and scoliosis increase the odds ratio for an asymmetric posture.</td>
<td>Postural asymmetries were associated with scoliosis, hip dislocation, hip and knee contractures, and inability to change position.</td>
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<tr>
<td>V How are the psychometric properties of the Posture and Postural Ability Scale for adults with CP?</td>
<td>Posture and postural ability was rated from photos and videos of 30 adults with CP, by three independent raters. Construct validity was evaluated based on known groups, GMFCS I-V.</td>
<td>Excellent interrater reliability (kappa=0.85-0.99), high internal consistency (alpha=0.96-0.97, item-total correlation=0.60-0.91). Median values differed (p&lt;0.02) between known groups.</td>
<td>The Posture and Postural Ability Scale showed an excellent interrater reliability for experienced raters, a high internal consistency and construct validity. It can detect postural asymmetries in adults with CP at all levels of gross motor function.</td>
</tr>
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Introduction

Cerebral palsy

Cerebral palsy (CP) is a lifelong heterogeneous disorder affecting posture and movement. It is the most common cause of motor disability in children and adolescents with a prevalence of 2-3 children per 1000\textsuperscript{2-8}. The children grow into adults and the expected survival rate for people with CP is almost the same as for the general population\textsuperscript{9}. The severity of impairments varies greatly and the mobility ranges from independent walking to totally dependent wheelchair mobility\textsuperscript{4}. The motor disorder is often combined with associated impairments such as learning disability, epilepsy and visual impairment\textsuperscript{3;10;11}. CP was first described by an orthopaedic surgeon in England, William Little 150 years ago (1862)\textsuperscript{12;13}. He described contractures and deformities resulting from spasticity and paralysis due to brain damage during infancy, especially in children born pre-term or with complicated births causing perinatal asphyxia. The condition was sometimes accompanied by epilepsy and behavioral disorders. Little classified cerebral palsy in children according to clinical symptoms into hemiplegia (one side more affected than the other), paraplegia (legs more affected than arms) and generalized rigidity\textsuperscript{12}.

Definitions

There have been several attempts to define CP throughout the years. In 1959 Mac Keith et al\textsuperscript{14} defined CP as ‘a persisting qualitative motor disorder appearing before the age of three years, due to a non-progressive interference with development of the brain.’ Some years later Bax et al (1964)\textsuperscript{15} proposed the following definition of CP; ‘a disorder of movement and posture due to a defect or lesion of the immature brain.’ In 1992 Mutch et al\textsuperscript{16} defined CP as ‘an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development’. The most recent definition and the one used in this thesis was presented by Rosenbaum et al in 2006\textsuperscript{17} where CP is described as ‘a group of permanent disorders of the development of movement and posture, causing
activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, epilepsy, and secondary musculoskeletal problems.

Prevalence

The prevalence of cerebral palsy in the western world, about 2-3/1000\(^2-8\), has not decreased during the last decades in spite of improvements in maternal health and neonatal care\(^2; 18\). This could be explained by a decrease in perinatal mortality and at the same time an increase in survival for children born preterm\(^2; 18\).

The live birth prevalence of CP for the period of 1980 to 1990 was 2.08/1000 in a study by the Surveillance of Cerebral Palsy in Europe network (SCPE) in 2002\(^4\). The prevalence of CP in southern Sweden (Skåne, Blekinge) was 2.4/1000 at 4-7 years of age and 2.8/1000 at 8-11 years of age in children born 1990-1993, including children born abroad, and the mortality rate was low before 20 years of age\(^3; 6; 9\). The CP prevalence in adults is less well studied. Young people 17-20 years born 1988-1991 and living in Skåne, Blekinge the 1\(^{st}\) of Jan 2009 had a CP prevalence of 2.3/1000 and formed the basis of study IV.

Classifications

There have been different classifications of CP since the first was proposed by Little in 1862\(^12; 13\) (Table I). Mac Keith et al\(^14\) suggested a more detailed classification based on clinical signs into; spastic CP divided into hemiplegia (unilateral, upper limb more affected than lower limb), diplegia (bilateral, lower limbs more affected than upper limbs) and double hemiplegia (bilateral, upper limbs more affected than lower limbs); dystonic CP (fluctuating tone, disorders of static and dynamic postural control), choreoathetoid CP (presence of unwanted movements), mixed forms of CP, ataxic CP (incoordination not due to dystonia, weakness or choreic movements) and atonic diplegia (bilateral distribution of weakness and hypotonia).

The Swedish classification of CP subtypes by Hagberg\(^16; 19\) has been widely used and is based on clinical signs into spastic hemiplegia (involving one side of the body), spastic diplegia (bilateral, lower limbs more affected than upper limbs), spastic tetraplegia (bilateral involvement of upper more or equal to lower limbs), ataxic CP (divided into ataxic diplegia and congenital ataxia), dyskinetic CP (divided into dystonic CP and choreoathetotic CP) and mixed form. In
epidemiologic studies ataxic diplegia and spastic diplegia are usually grouped together. The classification by Hagberg form the basis of the less detailed classification of the Surveillance of Cerebral Palsy in Europe network (SCPE). The classification of subtypes according to SCPE is divided into unilateral spastic 29%, bilateral spastic 55%, ataxic 4%, dyskinetic CP 7% and non-classifiable 4%. The dyskinetic subtype can be further divided into dystonic and choreoathetotic CP. The SCPE classification of subtypes shows substantial interrater reliability.

Table I: Classifications of neurological subtypes in CP. *In italics; subtypes further divided into subgroups.*

<table>
<thead>
<tr>
<th>Subtype Description</th>
<th>Little 1862</th>
<th>Mac Keith 1959</th>
<th>Hagberg 1975</th>
<th>SCPE 2000</th>
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<tr>
<td>Spastic</td>
<td></td>
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<tr>
<td>Unilateral involvement</td>
<td>Hemiplegia</td>
<td>Hemiplegia</td>
<td>Spastic hemiplegia</td>
<td>Unilateral spastic CP</td>
</tr>
<tr>
<td>Bilateral involvement, Legs more affected</td>
<td>Paraplegia</td>
<td>Diplegia</td>
<td>Spastic diplegia</td>
<td>Bilateral spastic CP</td>
</tr>
<tr>
<td>Bilateral involvement, Arms more or equally affected</td>
<td>General rigidity</td>
<td>Double hemiplegia</td>
<td>Spastic tetraplegia</td>
<td></td>
</tr>
<tr>
<td>Ataxic</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Dystonic tone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased activity, Unwanted movements</td>
<td>Dystonic CP</td>
<td>Dystonic CP</td>
<td>Dyskinetic CP -Dystonic CP -Choreoathetotic CP</td>
<td></td>
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<tr>
<td>Hypotonic</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mixed</td>
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To describe CP in children the neurological subtype is usually combined with a classification of gross motor function. The Gross Motor Function Classification System (GMFCS) is a 5 level classification system describing gross motor function of children and youth with CP on the basis of their self-initiated movement with particular emphasis on sitting, transfers, and mobility. Although developed for children, the original version of the GMFCS for children aged 2 to 12 years has been evaluated for use in adults with CP. The expanded and revised version of the GMFCS covers five age-bands from less than 2 years up to 18 years and has been used for all studies in this thesis (Figure 1).
GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations

**GMFCS Level I**
Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

**GMFCS Level II**
Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

**GMFCS Level III**
Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

**GMFCS Level IV**
Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

**GMFCS Level V**
Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

Figure 1 Illustration of the expanded and revised version of the GMFCS, age-band 12-18 years, reprinted with permission from professor Kerr Graham.
Musculoskeletal problems

Children with CP are not usually born with deformities, and although the lesion of the brain is non-progressive, many secondarily acquired clinical problems are progressive, and musculoskeletal abnormalities tend to develop during childhood\(^{27}\). In both children with CP\(^{28}\) and typically developing children\(^{29}\) there is a decline in joint range of motion as they grow older. Several studies\(^{24; 30-35}\) show a decline in gross motor function in adults with CP such as reduced balance, walking ability, range of motion together with increasing pain, physical fatigue, and problems related to spasticity. A crouched standing posture leads to a reduced hip and knee extension that worsens over time, due to gravity and the altered position of the body segments in relation to each other\(^{36}\). Contractures, bone and joint deformities most commonly affect the spine and the lower extremities leading to scoliosis, pelvic obliquity, hip dislocation, windswept deformity, contractures of hips and knees, and foot deformities\(^{37; 38}\). An asymmetric posture increases the risk of tissue adaptation leading to these contractures and progressive deformities\(^{39-42}\). The time aspect is crucial for the development of contractures making posture relative to time spent in these positions clinically important\(^{41; 43}\).

Hip dislocations usually occur at an early age\(^{44}\). In order to detect lateral migration and prevent dislocation, children with CP should be followed with radiographs from an early age\(^{45; 46}\). Scoliosis is more frequent at lower levels of gross motor function and the curve magnitude tends to increase with age even after bone maturity\(^{47-49}\). Severe scoliosis is associated with pelvic obliquity, windsweeping, and hip dislocations\(^{50-52}\) affecting the sitting ability, but also to pain, pressure ulcers, cardiopulmonary and gastrointestinal dysfunction\(^{51; 53}\). A review of risk factors for scoliosis by Loethers in 2010\(^{54}\) revealed difficulties in interpreting data since the cut-off for scoliosis on radiographs varied in different studies. In addition, lateral migration of the hips ranging from 33-60 degrees was sometimes defined as hip dislocation\(^{54}\). However, contractures, scoliosis, hip dislocations, and other fixed deformities can be reduced by early detection and preventive treatment\(^{45; 46; 50; 51; 55; 56}\).

The word “Orthopaedics” originates from the Greek words “orthos” (straight) and “paideia” (children) and was introduced by the pediatrician Nicolas Andry de Boisregard in 1741. His book “Orthopedia or the art of correcting and preventing deformities in Children” (Figure 2) was published in English 1743\(^{57}\). Andry suggested treatment that is still in use today such as early non-surgical treatment with brace, bandages and shoes. He illustrated this as tying a tree to a pole to straighten it out (Figure 2).
During the 19th century in Sweden, physiotherapy was a scientific treatment called “mechanical medicine”, sanctioned by the Government\textsuperscript{58}. Physiotherapy was complementary to the chemical treatment provided by the doctors. Today, physiotherapy and orthopaedic interventions designed to prevent contractures and deformities in people with CP are still focused on early detection and prevention.

**CPUP - Cerebral Palsy follow up programme**

CPUP is a National healthcare programme for people with CP in Sweden\textsuperscript{45, 55}. It was initiated in southern Sweden in 1994 as a collaboration by the Orthopaedic departments and the Habilitation Centres as an attempt to detect and prevent hip dislocations, scoliosis and contractures in children with CP. The idea was to improve and standardize the clinical assessment and the radiographic follow up of the children’s hips and spine from an early age. Since 2005, CPUP is a National healthcare programme approved by the National Board of Health and Welfare in Sweden.

The associated registry includes all children with CP born after January 1, 1990, living in the counties of Skåne and Blekinge, which have a total population of approximately 1.3 million. The number of children with CP in the area corresponds to a prevalence of 2.4/1000\textsuperscript{3, 6}. A search is made regularly to identify all children with cerebral palsy in the area and invite them to participate in CPUP, and almost all families (98%) have agreed to participate\textsuperscript{6}. The CPUP health care programme includes a continuing standardized follow up with assessment of gross and fine motor function, mobility, joint range of motion, clinical findings, and treatment. The children are examined by their local physiotherapist and
occupational therapist twice a year until six years of age, then once a year. The CPUP has been successful in reducing the incidence of hip dislocations in Sweden to <1% compared to 15% in Norway before Norway implemented the CPUP, without increasing the number of operations. There has also been a reduction in the number of severe contractures, scoliosis and windswept deformity. Since 2009 CPUP is a National healthcare programme in Norway and the CPUP programme is currently expanding to parts of Denmark and Iceland.

In 2009 a project was started to expand CPUP to include adults with cerebral palsy. All people with CP born 1988-1991 living in the area of Skåne and Blekinge were invited to participate in CPUP for adults. The place of living on 1st of January 2009 was ascertained through the Swedish population register (Statistics Sweden). Adults born 1988-1989 were included in the inventory 2009. The CP-prevalence was 2.3/1000 at the age of 17-20 years. Adults born 1990-1991 were previously followed by the CPUP program for children, but before the hip screening started. In order to assess the adults a form was developed which included; clinical assessment of joint range of motion, scoliosis, posture, mobility, gross and fine motor function, tone, and reports about pain, treatment, fractures, use of orthosis, brace and assistive devices (www.cpup.se).

Sitting and standing

Physical therapy interventions include provision of postural support such as adaptive seating and standing support to compensate for postural deficits and increase function. Almost one third of children with CP are non-ambulant and spend most of their lives in a sitting or lying position. The postural deficits seriously affect the performance of daily activities in those with severe impairments. Difficulties in controlling voluntary movement and functional performance can be traced to deficient postural ability. Adaptive seating reduces the need for assistance from a caregiver and may facilitate daily activities and functions such as playing, eating, breathing and arm and hand function. A standing position requires more postural ability to keep the centre of gravity within the base of support, while a sitting position provides a larger base of support and less joints to stabilise. A crouched standing posture leads to a reduced hip and knee extension that worsens over time, due to gravity and the altered position of the body segments in relation to each other. Even healthy children standing in a crouched posture show similar postural responses as children with CP due to biomechanical changes in postural alignment.
Mobility

Mobility in terms of transferring from one place to another, is important for the cognitive and psychosocial development of children. Children with CP usually start to walk later than nondisabled children, and they walk with a slower speed and higher energy cost. Normal walking is extremely efficient and advances the body safely from place to place with a minimum of energy. In children with CP there is a strong correlation between the energy cost of walking and the degree of motor impairment. The energy consumption is increased when walking with assistive devices. Many children with CP walk in a crouched posture. The crouched gait often worsens over time as a result of increasing muscle contractures, increasing body weight, and decreasing muscle strength compounded by gravity. Thus, the achieved walking ability is not always maintained through adolescence and adulthood.

Independent mobility is important for activity, participation, and self-sufficiency, reducing the dependence on caregivers and the environment. Environmental and personal factors influence a particular child’s performance in an everyday life situation. Safety and efficiency are important aspects when choosing mobility methods in different environments. Assistive devices for mobility such as wheelchairs and walking aids can provide independent mobility to children with disabilities, allowing them to explore their environment, improving activity, participation, satisfaction and quality of life. Powered wheelchairs facilitate independent mobility while manual wheelchairs mainly ease the care load. The single most important factor for the experience of participation in adolescents with disabilities is the possibility to be ‘where it happens’, which is closely related to independent mobility.

Systems theory and motor control

Two motor control theories have been used to describe development of posture and movement in children with cerebral palsy. The reflex-hierarchical theory from the early 1900s, where the nervous system was considered to be organized in a top down vertical hierarchical structure where higher centres control lower centres. Motor development was seen as a maturation of the central nervous system with increasing corticalization, resulting in emergence of higher levels of control over the lower levels of reflexes. Any damage to the higher levels of the brain would result in persistent primitive lower reflexes. The treatment would focus on techniques to facilitate normal motor patterns and inhibit reflexes and abnormal motor patterns.
The systems theory which takes musculoskeletal and environmental factors into account, was first described by Nicolai Bernstein (1967). He viewed the body as a mechanical system consisting of several joints and muscles with multiple degrees of freedom. To perform coordinated movements some body segments need to be stabilized in order to allow mobility in other segments. The specific segments to be stabilized will vary with the task. The external forces applied to the body are gravity and reaction forces from the supporting surface. Internal muscular forces counteract the external forces, providing the stability necessary to accomplish a task. This control of posture includes controlling the body’s position in space with respect to both stability and orientation ensuring that the line of gravity falls within the base of support and each body segment is balanced relative to the segments below.

According to the systems theory, movement emerges from interaction between the individual, the task and the environment, through coordination of many brain structures and processes. This requires motor programmes, perception and cognition. Postural control may also be affected by the attention required when performing dual tasks. The assessment and training of motor function according to the systems theory focuses on both musculoskeletal and neural aspects. The therapist should try to identify constraints within the person, the task or environment that prevent the person from succeeding in functional tasks.

Posture and postural ability

There is no universal definition of posture. In this thesis, the term ‘Posture’, relates to the shape of the body i.e. the anatomical alignment of the body segments in relation to each other and the supporting surface and also to the relationship between the body and the environment. ‘Postural ability’ refers to the ability to stabilize the body segments relative to each other and to the supporting surface; to get into the most appropriate body configuration for the performance of the particular task and environment. This means control of the centre of gravity relative to the base of support during both static and dynamic conditions.

CP is characterized by disorders of posture and movement. Posture is the base from which movement occur so the ability to control posture is an important prerequisite for all voluntary movements. This requires muscle tone predominantly in trunk, neck and antigravity muscles of the legs to produce joint stiffness, in order to counteract the forces imposed by gravity and the ground reaction forces. The antigravity function (stability) provides the mechanical support necessary for performing movements. Even a simple task such as
raising the arm requires complex control over numerous joints and muscles both to stabilize posture and to perform the movement. Normally postural responses such as righting, equilibrium and balance reactions are controlled unconsciously by the brain stem, spinal cord and basal ganglia. Damage in these areas may cause deficits of postural ability varying from being unable to move within or change position to having limited ability necessitating compensatory strategies that lead to asymmetry. Children with CP have difficulties in fine-tuning postural adjustments. Typical characteristics are top-down recruitment of postural muscles, antagonist co-activation and incomplete modulation of muscular response. These neuromuscular response patterns are due to both neurological deficits and to biomechanical changes in their postural alignment. Asymmetric postures have long been known to cause progressive deformities in immobile people with CP due to the effect of gravity. Whenever the body deviates from midline, a gravitational moment is produced which compounds the deviation.

Assessment tools for posture

There are few tools for assessment of posture and postural ability in lying, sitting and standing position which have been evaluated for people with severe physical disabilities, and none of them has been evaluated for adults with CP.

For any measurement tool to be scientifically and clinically useful, it must meet basic psychometric criteria regarding reliability and validity. For use in a clinical setting the instrument should be relatively short and simple to complete and not require expensive equipment. The Physical Ability Scale for assessment of postural ability in children with severe disabilities was developed by Noreen Hare during the 1970’s and 80’s. This inspired Pountney and co-workers to develop the Chailey Levels of Ability to describe stages of motor development in typically developing infants and children with motor impairments. Its’ validity has been evaluated for children and youth with CP. These instruments form the basis of the Postural Ability Scale (PAS) developed by Pauline Pope in the early 1990’s to assess both posture and postural ability in people with severe physical disabilities regardless of age and diagnosis. This assessment tool allows postural ability and posture to be assessed separately. It is in clinical use for trained professionals but has not been evaluated for its psychometric properties. During the years of 2009-2011, the PAS was developed further by Pope and co-workers. The levels of ability were slightly modified and items added to the quality of posture to allow assessment of posture from a sagittal as well as a frontal view. This modified and expanded version of the PAS called
the Posture and Postural Ability Scale (PPAS) has not previously been tested for reliability or validity.

The Posture and Postural Ability Scale

The Posture and Postural Ability Scale (Table 2) contains a 7-point ordinal scale for the assessment of postural ability in standing, sitting, supine and prone and six items for assessment of quality of posture in the frontal plane and another six items in the sagittal plane. Postural symmetry and alignment gives 1 point for each item while asymmetry or deviation from midline gives 0 points. The total score of 0-6 points is calculated separately for each position in the frontal and sagittal plane.

Figure 3 Example of a supine and a standing posture when the person is unable to maintain an aligned position independently.

The two lower levels of postural ability are in fact a rating of no ability, that is, they are unable to maintain or change position by themselves (Figure 3). The difference between those two levels is whether the person can (level 2) or cannot (level 1) conform to the position when placed by another person, i.e. in anatomical alignment when supported. When a person cannot be placed in prone and standing due to hip dislocation or severe contractures, especially of the hip flexors, postural ability is scored as level 1= unplaceable and posture is scored 0.
Table 2 The Posture and postural ability scale (PPAS) with the 7-point ordinal scale for assessment of postural ability in standing, sitting, supine and prone position; followed by assessment of quality of posture. There are six items for assessment of posture in the frontal plane and another six items in the sagittal plane.

<table>
<thead>
<tr>
<th>PPAS Levels of postural ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
</tr>
<tr>
<td>Level 2</td>
</tr>
<tr>
<td>Level 3</td>
</tr>
<tr>
<td>Level 4</td>
</tr>
<tr>
<td>Level 5</td>
</tr>
<tr>
<td>Level 6</td>
</tr>
<tr>
<td>Level 7</td>
</tr>
</tbody>
</table>

Quality of posture, frontal view, (Yes = 1 point, No = 0 points)

<table>
<thead>
<tr>
<th>Standing</th>
<th>Sitting</th>
<th>Supine</th>
<th>Prone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head midline</td>
<td>Head midline</td>
<td>Head midline</td>
<td>Head to one side</td>
</tr>
<tr>
<td>Trunk symmetrical</td>
<td>Trunk symmetrical</td>
<td>Trunk symmetrical</td>
<td>Trunk symmetrical</td>
</tr>
<tr>
<td>Pelvis neutral</td>
<td>Pelvis neutral</td>
<td>Pelvis neutral</td>
<td>Pelvis neutral</td>
</tr>
<tr>
<td>Legs separated and straight relative to pelvis</td>
<td>Legs separated and straight relative to pelvis</td>
<td>Legs separated and straight relative to pelvis</td>
<td>Legs separated and straight relative to pelvis</td>
</tr>
<tr>
<td>Arms resting by side</td>
<td>Arms resting by side</td>
<td>Arms resting by side</td>
<td>Arms resting by side (elevated, mid-position)</td>
</tr>
<tr>
<td>Weight evenly distributed</td>
<td>Weight evenly distributed</td>
<td>Weight evenly distributed</td>
<td>Weight evenly distributed</td>
</tr>
</tbody>
</table>

Quality of posture, sagittal view, (Yes = 1 point, No = 0 points)

<table>
<thead>
<tr>
<th>Standing</th>
<th>Sitting</th>
<th>Supine</th>
<th>Prone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head midline</td>
<td>Head midline</td>
<td>Head midline</td>
<td>Trunk in neutral position</td>
</tr>
<tr>
<td>Trunk in neutral position</td>
<td>Trunk in neutral position</td>
<td>Trunk in neutral position</td>
<td>Pelvis neutral</td>
</tr>
<tr>
<td>Pelvis neutral</td>
<td>Pelvis neutral</td>
<td>Pelvis neutral</td>
<td>Hips extended</td>
</tr>
<tr>
<td>Legs straight, hips/knees extended</td>
<td>Hips mid-position (90°)</td>
<td>Legs straight, hips/knees extended</td>
<td>Knees extended</td>
</tr>
<tr>
<td>Feet mid-position/flat on floor</td>
<td>Knees mid-position (90°)</td>
<td>Feet resting in normal position</td>
<td>Arms resting (elevated, mid-position)</td>
</tr>
<tr>
<td>Weight evenly distributed</td>
<td>Feet mid-position/flat on floor</td>
<td>Weight evenly distributed</td>
<td>Weight evenly distributed</td>
</tr>
</tbody>
</table>
The Functional Mobility Scale

The Functional Mobility Scale (FMS)\textsuperscript{125} version 2 can be used for assessment of the child’s walking performance at three different distances and environments: 5, 50 and 500 m representing the child’s mobility at home, at school, and in the community, respectively (Table 3). The mobility is rated according to the need of assistive devices and is assessed by questions put to the child or parent and not by direct observation. The FMS has been evaluated for reliability, validity, and sensitivity\textsuperscript{125} and shows substantial agreement between direct observation and parental report\textsuperscript{126}.

Table 3 The Functional Mobility Scale (FMS) Version 2.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does your child move around for short distances in the house? (5 m)</td>
<td>6. Independent on all surfaces</td>
</tr>
<tr>
<td>How does your child move in and between classes at school? (50 m)</td>
<td>5. Independent on level surfaces</td>
</tr>
<tr>
<td>How does your child move around for long distances such as at the shopping center? (500 m)</td>
<td>4. Uses sticks (one or two)</td>
</tr>
<tr>
<td></td>
<td>3. Uses crutches</td>
</tr>
<tr>
<td></td>
<td>2. Uses a walker or frame</td>
</tr>
<tr>
<td></td>
<td>1. Uses wheelchair</td>
</tr>
<tr>
<td></td>
<td>C. Crawling</td>
</tr>
<tr>
<td></td>
<td>N. Does not apply, eg, child does not complete the distance</td>
</tr>
</tbody>
</table>
Aims

The overall ambition of this thesis was to enhance knowledge of posture, postural ability and mobility in individuals with CP, the use of assistive devices and also to evaluate a clinical tool for assessment of posture and postural ability.

Study I: To describe how children with CP usually sit, stand, move between sitting and standing position, and their use of support/assistive devices, related to age, CP subtype and level of gross motor function.

Study II: To analyse the use of manual and powered wheelchair indoors and outdoors, and the degree of independent wheeled mobility, in children with CP.

Study III: To describe walking performance and mobility in children with CP, and to examine the association between walking performance and level of gross motor function, CP subtype and age.

Study IV: To describe posture in supine, sitting and standing position, the ability to change position, and also to analyse the association between posture and pain, joint range of motion, hip dislocation, scoliosis and ability to change position in young adults with CP.

Study V: To evaluate reliability, internal consistency and validity of the Posture and Postural Ability Scale in adults with CP, in supine, prone, sitting and standing position.
Methods

Design

Study I-III were cross-sectional studies of a total population of children with CP describing their sitting and standing performance and the use of assistive devices (study I), wheeled mobility (study II), and walking performance according to the Functional Mobility Scale (study III). Study IV was a cross-sectional study describing postural asymmetries and ability to change position in adults with CP, and the relation of posture to pain, joint range of motion, hip dislocation, scoliosis and ability to change position. Study V evaluated the psychometric properties of the Posture and Postural Ability Scale for adults with CP from photos and videos of adults at GMFCS level I-V.

Participants

Study I-III included all children with CP followed by the CPUP and living in southern Sweden during 2008. There was a total of 562 children (326 boys, 236 girls) aged 3 to 18 years (mean age 10.9 years) born 1990-2005 (Table 4).

Study IV included all 102 adults with CP born 1988-1991 (63 males, 39 females) examined within the CPUP program for adults in southern Sweden, from the start in October 2009 until the end of 2011. The participants were 19-23 years at examination (mean age 20.5 years) (Table 4). A total of 172 adults with CP were identified through medical records. Ten were previously not informed about the CP diagnosis and were excluded. Invitations to participate in the CPUP health care programme for adults were sent to 162 persons, of which 26 declined, 20 did not answer, and 116 accepted. Four of them were recently assessed in the child rehabilitation services according to their CPUP program, and ten failed to appear. In total 102 adults were examined before the end of 2011. There were no statistically significant differences found between the characteristics of participants and non-participants, except the proportion of unknown GMFCS levels.
Study V included 30 adults with CP (15 males, 15 females) born 1988-1991 (age range 19-22) (Table 4). The participants were recruited in October 2009-October 2010, during the project in the south of Sweden to expand CPUP and include adults in the follow up program. The subjects who agreed to join the CPUP for adults were invited to participate in this study until six persons at each GMFCS level had accepted. One additional client with CP at GMFCS V was recruited from the Rehabilitation Centre of Excellence in Kópavogur, Iceland. Written consent was collected from all participants or by proxy where the participant was unable to give such consent.

Table 4 Participants of study I-V

<table>
<thead>
<tr>
<th>Participants</th>
<th>Study I-III</th>
<th>Study IV</th>
<th>Study V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>3-18</td>
<td>19-23</td>
<td>19-22</td>
</tr>
<tr>
<td>Number</td>
<td>562</td>
<td>102</td>
<td>30</td>
</tr>
<tr>
<td>Female /Male</td>
<td>236/326</td>
<td>39/63</td>
<td>15/15</td>
</tr>
<tr>
<td>GMFCS I</td>
<td>264</td>
<td>38</td>
<td>6</td>
</tr>
<tr>
<td>GMFCS II</td>
<td>76</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>GMFCS III</td>
<td>64</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>GMFCS IV</td>
<td>84</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>GMFCS V</td>
<td>74</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>Unilateral spastic CP</td>
<td>163</td>
<td>26</td>
<td>-</td>
</tr>
<tr>
<td>Bilateral spastic CP</td>
<td>209</td>
<td>45</td>
<td>-</td>
</tr>
<tr>
<td>Dyskinetic CP</td>
<td>83</td>
<td>19</td>
<td>-</td>
</tr>
<tr>
<td>Ataxic CP</td>
<td>48</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>Unclassified/mixed CP</td>
<td>59</td>
<td>0</td>
<td>-</td>
</tr>
</tbody>
</table>

In all studies (I-V), cerebral palsy was defined according to Rosenbaum et al\textsuperscript{17}. The CP diagnosis was confirmed and the neurological subtypes were classified by a neuropaediatrician according to the Surveillance of Cerebral Palsy in Europe network (SCPE)\textsuperscript{20}. Exclusion and inclusion criteria were in accordance with the SCPE\textsuperscript{20} including motor impairment and specific neurological signs caused by non-progressive brain dysfunction arising before the age of two. Gross motor function was determined by the local physiotherapists according to the expanded and revised version of the GMFCS\textsuperscript{23}.
Data collection

For study I-III data was extracted from the CPUP register, based on the latest physiotherapy report for all children with CP born 1990-2005 in the south of Sweden during 2008. Sitting, standing, wheeled mobility, walking performance according to the Functional Mobility Scale, the degree of independence and use of assistive devices were reported by client or by proxy. Data was analyzed in relation to GMFCS level, CP subtype and age. To analyze data the children were divided into different age groups according to the Swedish school system: 3 to 6, 7 to 9, 10 to 12, 13 to 15, and 16 to 18 years.

In study I the questions were: A. What kind of chair does the child usually sit in? The options were: The child uses (1) a standard chair, (2) adaptive seating or (3) does not sit. Adaptive seating was defined as any special seating, high chair or seating system provided as an assistive device to those who cannot sit in a standard chair due to postural deficit or physical disability.

B. How does the child usually maintain a standing position; get into a standing position from sitting on a chair; sit down on a chair from a standing position? The options were: The child (1) does it independently without external support; (2) does it with external support or (3) cannot. External support denotes support from the environment (wall, furniture, assistive devices) or from another person.

To obtain information on the child’s wheelchair performance (study II), the children and their caregivers answered the following questions: Does the child usually use a: (A) Manual wheelchair for mobility indoors? (B) Powered wheelchair for mobility indoors? (C) Manual wheelchair for mobility outdoors? (D) Powered wheelchair for mobility outdoors? The options were: (1) No, the child does not use a wheelchair; (2) Yes, the child self-propels/operates independently; (3) Yes, the child is pushed by an adult.

The Functional Mobility Scale (FMS)\(^{125}\) was used for assessment of walking performance, mobility (study III), and need for assistive devices at home (5 m), at school (50 m), and in the community (500 m) (Table 3).

In study IV data was extracted from the most recent assessment in the CPUP register for adults born 1988-1991 in the south of Sweden. Posture was assessed by a physiotherapist using items from the Postural Ability Scale (PAS)\(^{116}\). Any deviations from midline in head, trunk, leg, foot position or asymmetries in arm position or weight bearing gives 0 point each and symmetric, neutral position gives 1 point each with a total score of 0-6 points where a maximum score of 6 points indicates no postural asymmetry. Passive joint range of motion (ROM) was assessed by goniometric measurement and classified as limited if extension of hips, knees or elbows were less than 0 degrees on one or both sides, or inability to
reach 0 degrees of dorsiflexion of the feet. Scoliosis was defined as either having a spinal curve at clinical examination by a physiotherapist or had a spinal fusion. Hip dislocation was determined by an orthopaedic surgeon from radiographs and defined as Reimers’s migration percentage of 100% in at least one hip. Presence of pain, use of assistive devices, ability to maintain and change position and sleeping positions were reported by client or by proxy.

The psychometric evaluation of the Posture and Postural Ability Scale (study V) was based on ratings from photos and videos of 30 adults with CP at GMFCS level I-V. Photos of habitual posture of each individual were taken from a frontal and sagittal view of the whole body in supine, prone, sitting and standing position. Habitual refers to the posture customarily adopted by the individual when instructed to sit, stand or lay down in prone or supine as straight as possible or, the posture the body assumes when placed as straight as possible in any of these positions and allowed to settle. The positions were supine lying on a plinth with arms resting by side; prone lying on a plinth with the head to one side and arms resting in an elevated position (flexion in elbows and abduction, external rotation of shoulders); sitting on a plinth with feet on the floor; standing on the floor. Those who were unable to maintain position independently were provided the manual support needed to stay in position. Those who required total body support in standing such as in GMFCS level V, were assessed in a standing brace or on a tilt table. Videos recorded the participants’ postural ability while instructed to assume and get out of the four positions. If unable to do this they were placed in each position. Assessment of ability was then carried out sequentially corresponding to the points on the Posture and Postural Ability Scale (Table 2) by three experienced physiotherapists independently.

Statistical analysis

For all statistical analyses P-values less than 0.05 were considered significant. The statistical analyses were performed using SPSS version 17.0 (study I-III), SPSS version 20.0 and Stata (study IV), and the R software environment (study V).

The chi-squared test for trend (the linear-by-linear association test) was used for analyzing increasing or decreasing trends in ordinal data such as sitting, standing, wheeled mobility and walking performance related to GMFCS level and age (study I-III).

The Kruskal-Wallis test was used to analyze differences between nominal groups such as CP subtypes (study I-III). Post hoc analyses were performed using the Mann-Whitney U-test (study I-III). Z-test comparison of proportions with Bonferroni adjusted p-values was used to analyze differences between participants.
and non-participants (study IV). Pearson’s Chi square and Fishers exact test were used to analyze differences in ordinal and categorical data.

Spearman’s rank correlation coefficient was used to estimate correlation coefficients among ordinal variables (study I-IV), and to analyze relationship between asymmetric postures and categorical variables such as pain, joint range of motion, hip dislocation and scoliosis (study IV).

Binary logistic regression analysis with adjustment for CP subtype was used to estimate the relationship between independent walking and age (study III). Ordinal logistic regression was used to estimate the relationship between asymmetric posture and joint range of motion, hip dislocation, scoliosis and pain (study IV).

Interrater reliability (study V) was calculated using weighted kappa scores which takes the degree of disagreement into account. The magnitude of weighted kappa indicates the agreement beyond chance and was interpreted according to Fleiss 1981, where ≤ 0.40 signifies poor agreement, 0.40-0.75 fair to good agreement and ≥ 0.75 signifies excellent agreement.

Internal consistency (study V) was evaluated using Cronbach’s alpha if item is deleted and Corrected Item-total correlation based on averaged values for three raters. Cronbach’s alpha if item is deleted corresponds to the value achieved if a specific item is removed. The Corrected Item-total correlation shows the correlation between each item and the total score of the measurement and any item with a value <0.2 should be discarded.

For analysis of reliability and consistency all GMFCS levels were combined and 95% nonparametric bootstrap confidence intervals were generated based on a 1000 re samples.

Construct validity (study V) was evaluated for known-groups based on GMFCS I-V with median/range. The Jonckheere-Terpstra test was used when analyzing arithmetic average values given by the raters.

**Ethical considerations**

Ethical approval was obtained from the Medical Research Ethics Committee at Lund University for study I-IV (LU-443-99) and V (2009/361).
Results

Sitting and standing (study I)

The use of assistive devices and support to sit, stand and move between those positions correlated to the GMFCS (Table 5), varied between the subtypes (p<0.001), and was more frequent in pre-school children compared to school- children (p<0.05).

Table 5 Correlations (p<0.001) between GMFCS levels and independence/use of support to sit, stand, stand up (move from sit-to-stand) and sit down (move from stand-to-sit).

<table>
<thead>
<tr>
<th></th>
<th>GMFCS</th>
<th>Sit</th>
<th>Stand</th>
<th>Stand up</th>
<th>Sit down</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS</td>
<td>1.00</td>
<td>0.73</td>
<td>0.85</td>
<td>0.88</td>
<td>0.88</td>
</tr>
<tr>
<td>Sit</td>
<td>0.73</td>
<td>1.00</td>
<td>0.70</td>
<td>0.72</td>
<td>0.72</td>
</tr>
<tr>
<td>Stand</td>
<td>0.85</td>
<td>0.70</td>
<td>1.00</td>
<td>0.91</td>
<td>0.91</td>
</tr>
<tr>
<td>Stand up</td>
<td>0.88</td>
<td>0.72</td>
<td>0.91</td>
<td>1.00</td>
<td>0.99</td>
</tr>
<tr>
<td>Sit down</td>
<td>0.88</td>
<td>0.72</td>
<td>0.91</td>
<td>0.99</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Of the 562 children 57% used standard chairs, 65% stood independently and 62% moved between sitting and standing position without support. Adaptive seating was used by 42%, 31% used support to stand and 18-19% to move between sitting and standing position. Two children could not sit, 4% (21 children) could not stand and 18% (102 children) could not move from sit-to-stand.

Adaptive seating was most frequent within the dyskinetic subtype and used by 89%. It was also used by 46% of those with bilateral spastic CP and by 40% of those with ataxic CP. All children at GMFCS level V used adaptive seating, so did 95% at level IV, 54% at level III and 33% at level II.

Supported standing was used by 48% of the children with spastic bilateral or dyskinetic CP. At GMFCS IV-V, 84% stood with support. The most frequent standing device was a standing brace used by 130 children (3 of 4), in some cases...
in combination with a standing frame or a tilt table. Standing frames or tilt tables were used by 57 children, and standing wheelchairs by 23 children.

Most children who stood independently, also moved into a standing position without support (Table 5). Of the 172 children who stood with support, half required support to move from sit-to-stand, and the other half could not move from sit-to-stand even with support. At GMFCS levels III and IV almost two thirds (64%) required support to move from sit-to-stand. All children with unilateral spastic CP could get from sit-to-stand and only 4% required support. Of the children with ataxic CP 19% used support, as did 29% of those with bilateral spastic CP while 16% could not move from sit-to-stand. In the dyskinetic subtype only 17% moved from sit-to-stand independently while 55% could not move from sit-to-stand even with support.

Wheeled mobility (study II)

Wheelchairs for mobility were used by 165 of the 562 children (29%) indoors, and by 228 children (41%) outdoors. The use of wheelchairs varied between the subtypes, and increased with age and GMFCS level. Wheelchairs were most frequent in children with dyskinetic CP where 69% were pushed in manual wheelchairs outdoors and 13% operated powered wheelchairs.

Manual wheelchairs were used by 163 children indoors (30% self-propelled and 70% were pushed), and by 219 children outdoors (14% self-propelled and 86% were pushed). Powered wheelchairs were used by 35 children indoors and by 56 children outdoors. Of those using powered wheelchairs 83% operated independently indoors and 86% outdoors while the remaining 14-17% required assistance.

Indoors, wheelchairs were used by 4% at GMFCS level II, 48% at level III and 84% at levels IV-V. Outdoors, 39% at GMFCS level II used a wheelchair, so did 85-90% at levels III-V. Most powered wheelchairs were operated by children at GMFCS level IV and only one child at level V operated a powered wheelchair outdoors. All the 25 children at levels III-V who did not use a wheelchair for outdoor mobility were aged 3-6 years. No child under the age of 4 had independent wheeled mobility outdoors. In total 5 children under the age of 7 years used powered wheelchairs.
Walking performance (study III)

Walking performance was reported according to the Functional Mobility Scale (FMS). Of the 562 children, 63% walked without aids at home, 60% at school, and 57% in the community setting. Walking aids were used by 4-8% in different environments. There was a high correlation ($r^2 = -0.91$) between the FMS and the GMFCS at all distances. Most children at GMFCS levels I-II walked all distances independently but with more difficulties on uneven surfaces and in longer distances for those at GMFCS II. Walking aids were most frequently used by children at level III, 33% at home and 52% at school. At GMFCS level IV 10-11% used walking aids for shorter distances.

Almost all children with spastic unilateral CP walked all three distances without aids. Walking aids were mostly used by children with ataxic or spastic bilateral CP in the school environment. In children with ataxic CP 65-81% walked with or without walking aids in different environments, the corresponding number was 52-64% for children with bilateral spastic CP, and 16-24% of those with dyskinetic CP.

The walking performance without aids (FMS 5 and 6) increased from preschool children up to 7 years and then remained at that level. However, an increased proportion walked on uneven surfaces (e.g. stairs, curbs) (FMS 6) in each successive age group up to 18 years. Compared to preschool children the odds ratio was 4.92 for 16-18 year-olds to walk on all surfaces at 500 m (Table 6). This implies that an 18 year-old has a larger chance than a 7 year-old of walking independently on all surfaces in the community.

Table 6 Binary logistic regression of independent walking in relation to age adjusted for cerebral palsy subtypes. Odds ratios (OR) with 95% confidence interval (CI) and p values for independent walking on all surfaces (FMS 6) and independent walking on level surfaces (FMS 5) compared to all other categories; age was used as a categorical variable with 3-6 years as reference category.

<table>
<thead>
<tr>
<th>Category</th>
<th>Age</th>
<th>OR 5m (CI 95%)</th>
<th>P-value</th>
<th>OR 50 m (CI 95%)</th>
<th>P-value</th>
<th>OR 500 m (CI 95%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FMS 6</td>
<td>3–6</td>
<td>ref</td>
<td>1.84 (0.94 3.57)</td>
<td>=0.073</td>
<td>2.19 (1.12 4.29)</td>
<td>=0.023</td>
<td>2.08 (1.05 4.10)</td>
</tr>
<tr>
<td></td>
<td>7–9</td>
<td>1.84 (0.94 3.57)</td>
<td>2.19 (1.12 4.29)</td>
<td>=0.023</td>
<td>2.08 (1.05 4.10)</td>
<td>=0.036</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10–12</td>
<td>2.56 (1.34 4.89)</td>
<td>2.90 (1.51 5.59)</td>
<td>=0.001</td>
<td>3.18 (1.64 6.17)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13–15</td>
<td>3.00 (1.54 5.85)</td>
<td>3.42 (1.74 6.74)</td>
<td>&lt;0.001</td>
<td>3.80 (1.91 7.53)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16–18</td>
<td>3.84 (1.94 7.60)</td>
<td>4.17 (2.08 8.33)</td>
<td>&lt;0.001</td>
<td>4.92 (2.45 9.88)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>FMS 5–6</td>
<td>3–6</td>
<td>ref</td>
<td>1.53 (0.77 3.03)</td>
<td>=0.227</td>
<td>2.01 (1.01 3.99)</td>
<td>=0.047</td>
<td>2.17 (1.09 4.33)</td>
</tr>
<tr>
<td></td>
<td>7–9</td>
<td>1.53 (0.77 3.03)</td>
<td>2.01 (1.01 3.99)</td>
<td>=0.047</td>
<td>2.17 (1.09 4.33)</td>
<td>=0.028</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10–12</td>
<td>1.82 (0.94 3.55)</td>
<td>1.81 (0.93 3.51)</td>
<td>=0.081</td>
<td>2.05 (1.04 4.01)</td>
<td>=0.038</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13–15</td>
<td>1.53 (0.77 3.04)</td>
<td>1.86 (0.94 3.68)</td>
<td>=0.077</td>
<td>2.34 (1.17 4.69)</td>
<td>=0.016</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16–18</td>
<td>1.83 (0.91 3.68)</td>
<td>1.87 (0.94 3.74)</td>
<td>=0.076</td>
<td>2.55 (1.27 5.13)</td>
<td>=0.009</td>
<td></td>
</tr>
</tbody>
</table>
Postural asymmetries (study IV)

Asymmetric posture, in terms of a low total score on the Postural Ability Scale (PAS), was present at all GMFCS levels but more frequently at lower levels of gross motor function. GMFCS correlated significantly ($p<0.001$) to PAS total score for posture in supine ($r^2 = -0.78$), sitting ($r^2 = -0.72$) and standing ($r^2 = -0.51$).

At GMFCS level I-II head and trunk asymmetries were more common while asymmetries varied more due to position at level III-V (Table 7). Postural asymmetries were more frequent in standing compared to supine lying and sitting for individuals at level I-III. The reverse was seen at GMFCS V with less asymmetry in standing with support compared to supine lying and sitting.

Table 7 Distribution of postural asymmetries according to PAS in supine, sitting and standing for each GMFCS level I-V. Results presented as number of people and fractions (f) who scored 0 = No, at each item. Fisher’s exact test showed significant differences ($p<0.01$) between GMFCS levels for all items marked *, ($p>0.05$) for remaining items.

<table>
<thead>
<tr>
<th>Position</th>
<th>PAS items</th>
<th>I N=38</th>
<th>II N=21</th>
<th>III N=13</th>
<th>IV N=10</th>
<th>V N=20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (f)</td>
<td>n (f)</td>
<td>n (f)</td>
<td>n (f)</td>
<td>n (f)</td>
<td>n (f)</td>
</tr>
<tr>
<td>Supine</td>
<td>Head midline*</td>
<td>3 (0.1)</td>
<td>7 (0.4)</td>
<td>1 (0.1)</td>
<td>2 (0.2)</td>
<td>11 (0.6)</td>
</tr>
<tr>
<td></td>
<td>Trunk symmetrical *</td>
<td>3 (0.1)</td>
<td>7 (0.4)</td>
<td>3 (0.3)</td>
<td>2 (0.2)</td>
<td>15 (0.8)</td>
</tr>
<tr>
<td></td>
<td>Legs straight relative to pelvis*</td>
<td>2 (0.1)</td>
<td>6 (0.3)</td>
<td>7 (0.6)</td>
<td>7 (0.7)</td>
<td>19 (1.0)</td>
</tr>
<tr>
<td></td>
<td>Legs separated*</td>
<td>0 (0)</td>
<td>2 (0.1)</td>
<td>4 (0.3)</td>
<td>6 (0.7)</td>
<td>12 (0.6)</td>
</tr>
<tr>
<td></td>
<td>Arms resting by side*</td>
<td>3 (0.1)</td>
<td>3 (0.2)</td>
<td>1 (0.1)</td>
<td>7 (0.7)</td>
<td>18 (1.0)</td>
</tr>
<tr>
<td></td>
<td>Weight evenly distributed*</td>
<td>0 (0)</td>
<td>4 (0.2)</td>
<td>5 (0.4)</td>
<td>7 (0.7)</td>
<td>17 (0.9)</td>
</tr>
<tr>
<td>Sitting</td>
<td>Head midline*</td>
<td>1 (0)</td>
<td>5 (0.3)</td>
<td>2 (0.2)</td>
<td>3 (0.3)</td>
<td>11 (0.7)</td>
</tr>
<tr>
<td></td>
<td>Trunk symmetrical *</td>
<td>4 (0.1)</td>
<td>8 (0.4)</td>
<td>5 (0.4)</td>
<td>6 (0.6)</td>
<td>12 (0.7)</td>
</tr>
<tr>
<td></td>
<td>Legs separated and in neutral position*</td>
<td>1 (0)</td>
<td>2 (0.1)</td>
<td>2 (0.1)</td>
<td>5 (0.5)</td>
<td>12 (0.7)</td>
</tr>
<tr>
<td></td>
<td>Arms resting by side*</td>
<td>2 (0.1)</td>
<td>1 (0.1)</td>
<td>2 (0.2)</td>
<td>6 (0.6)</td>
<td>16 (0.9)</td>
</tr>
<tr>
<td></td>
<td>Both feet flat on floor*</td>
<td>0 (0)</td>
<td>1 (0.1)</td>
<td>1 (0.2)</td>
<td>5 (0.5)</td>
<td>12 (0.7)</td>
</tr>
<tr>
<td></td>
<td>Weight evenly distributed*</td>
<td>2 (0.1)</td>
<td>3 (0.2)</td>
<td>3 (0.2)</td>
<td>6 (0.7)</td>
<td>14 (0.8)</td>
</tr>
<tr>
<td>Standing</td>
<td>Head midline</td>
<td>7 (0.2)</td>
<td>7 (0.4)</td>
<td>3 (0.3)</td>
<td>2 (0.3)</td>
<td>3 (0.4)</td>
</tr>
<tr>
<td></td>
<td>Trunk symmetrical *</td>
<td>9 (0.3)</td>
<td>14 (0.8)</td>
<td>5 (0.5)</td>
<td>3 (0.6)</td>
<td>4 (0.6)</td>
</tr>
<tr>
<td></td>
<td>Legs straight hips and knees extended*</td>
<td>4 (0.1)</td>
<td>7 (0.4)</td>
<td>8 (0.7)</td>
<td>5 (0.8)</td>
<td>5 (0.7)</td>
</tr>
<tr>
<td></td>
<td>Legs separated*</td>
<td>0 (0)</td>
<td>2 (0.1)</td>
<td>5 (0.5)</td>
<td>4 (0.7)</td>
<td>2 (0.3)</td>
</tr>
<tr>
<td></td>
<td>Both feet flat on floor*</td>
<td>2 (0.1)</td>
<td>1 (0.1)</td>
<td>4 (0.4)</td>
<td>3 (0.5)</td>
<td>4 (0.5)</td>
</tr>
<tr>
<td></td>
<td>Weight evenly distributed</td>
<td>9 (0.3)</td>
<td>11 (0.6)</td>
<td>5 (0.5)</td>
<td>4 (0.7)</td>
<td>4 (0.6)</td>
</tr>
</tbody>
</table>
Some limitations of knee, foot and elbow extension were present at all GMFCS levels while limited hip extension was found at GMFCS level II-V and dislocated hips at GMFCS III-V (Table 8). Pain was reported by 63 of 102 individuals.

Table 8 Number of people and fractions (f) with hip dislocation, scoliosis, limited ROM, and pain in relation to GMFCS level.

<table>
<thead>
<tr>
<th></th>
<th>I (N=38)</th>
<th>II (N=21)</th>
<th>III (N=13)</th>
<th>IV (N=10)</th>
<th>V (N=20)</th>
<th>Total (N=102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (f)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hip dislocation</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (0.1)</td>
<td>1 (0.1)</td>
<td>8 (0.4)</td>
<td>10 (0.1)</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>12 (0.4)</td>
<td>7 (0.3)</td>
<td>6 (0.5)</td>
<td>6 (0.6)</td>
<td>17 (0.9)</td>
<td>48 (0.5)</td>
</tr>
<tr>
<td>Limited elbow extension</td>
<td>11 (0.3)</td>
<td>6 (0.3)</td>
<td>5 (0.4)</td>
<td>6 (0.6)</td>
<td>10 (0.6)</td>
<td>38 (0.4)</td>
</tr>
<tr>
<td>Limited hip extension</td>
<td>0 (0)</td>
<td>3 (0.2)</td>
<td>4 (0.3)</td>
<td>3 (0.3)</td>
<td>11 (0.6)</td>
<td>21 (0.2)</td>
</tr>
<tr>
<td>Limited knee extension</td>
<td>18 (0.5)</td>
<td>6 (0.3)</td>
<td>10 (0.8)</td>
<td>8 (0.8)</td>
<td>18 (0.9)</td>
<td>60 (0.6)</td>
</tr>
<tr>
<td>Limited foot dorsiflexion</td>
<td>7 (0.2)</td>
<td>8 (0.4)</td>
<td>3 (0.2)</td>
<td>3 (0.3)</td>
<td>4 (0.2)</td>
<td>25 (0.3)</td>
</tr>
<tr>
<td>Pain</td>
<td>23 (0.6)</td>
<td>13 (0.6)</td>
<td>7 (0.5)</td>
<td>8 (0.8)</td>
<td>12 (0.6)</td>
<td>63 (0.6)</td>
</tr>
</tbody>
</table>

Asymmetric supine posture correlated (p<0.001) to limited knee extension (r^2=0.42), hip extension (r^2=0.52), hip dislocation (r^2=0.54), and scoliosis (r^2=0.45). Asymmetric sitting posture correlated to hip dislocation and scoliosis (r^2=0.46). Asymmetric standing posture correlated to limited knee extension (r^2=0.52). Inability to put feet flat on floor in standing had a significant correlation to limited knee extension (r^2=0.40) but not to limited dorsiflexion of the feet. No correlation was found between posture and pain.

The odds ratio for an asymmetric posture was 8 times higher in supine for those with limited hip extension and 3 times higher for those with limited knee extension. The odds ratio for an asymmetric posture was 2.5 times higher in standing and 4 times higher in supine and sitting for those with scoliosis. It was 7 times higher in sitting and 19 times higher in supine for those with hip dislocation.

All adults at GMFCS levels I-III maintained lying position independently, while 10% of those at GMFCS IV and 60% at GMFCS V needed support to maintain position. The correlation between GMFCS and ability to change position in lying was r^2=0.67 (p<0.001). Fifty percent of those at GMFCS level IV and V had only one lying position, the other half used two or three positions. Only eight people, all at GMFCS I-III, used all four positions; prone, supine, side lying left and right. The ability to change position correlated to quality of posture in supine (r^2 = -0.60, p<0.001). Seven out of nine adults with an asymmetric posture (0 points) could
not change position and required total assistance; six of them had only one sleeping position.

All individuals at GMFCS IV and V used postural support to maintain sitting. The ability to change position from sit-to-stand and stand-to-sit showed a high correlation to GMFCS levels ($r^2= 0.88$, $p<0.001$). The ability to move from sit to stand also correlated with sitting posture ($r^2= -0.71$, $p<0.001$).

All adults at GMFCS level I-II and 38% at level III stood unsupported, while supported standing was used by 46% at level III, 90 % at level IV and 74 % at level V. The remaining 26% at GMFCS V did not stand at all. The correlation of standing ability to GMFCS was ($r^2= -0.60$, $p<0.001$). Of the 26 adults using standing support; seven stood 1-2 hours/day and the remaining 19 stood less than 1 hour/day.

Evaluation of the Posture and Postural Ability Scale (study V)

The Posture and Postural Ability Scale (PPAS) showed excellent interrater reliability for three independent raters with weighted Kappa values of 0.85-0.99. There was a high internal consistency for all items. Cronbach’s alpha if item deleted was 0.96-0.97 with a 95% confidence interval of 0.93-0.98 for all items. Corrected item-total correlation varied between 0.60-0.91 with the lowest correlation for sitting posture in the sagittal view.

Table 9 Construct validity of the PPAS. Median values and range for GMFCS I-V and p-values of averaged values for the three raters.

<table>
<thead>
<tr>
<th>GMFCS</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
<th>V</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postural ability</td>
<td>7 (7-7)</td>
<td>7 (7-7)</td>
<td>7 (6-7)</td>
<td>4 (3-7)</td>
<td>1.5 (1-4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture frontal</td>
<td>6 (2-6)</td>
<td>4 (2-5)</td>
<td>1 (0-6)</td>
<td>0 (0-1)</td>
<td>0 (0-1)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture sagittal</td>
<td>6 (4-6)</td>
<td>4 (1-6)</td>
<td>2.5 (0-6)</td>
<td>0.5 (0-3)</td>
<td>1 (0-3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Prone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postural ability</td>
<td>7 (7-7)</td>
<td>7 (7-7)</td>
<td>6 (5-7)</td>
<td>4 (1-6)</td>
<td>1 (1-3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture frontal</td>
<td>5 (2-6)</td>
<td>4 (2-5)</td>
<td>2 (0-5)</td>
<td>1 (0-3)</td>
<td>0 (0-3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture sagittal</td>
<td>6 (2-6)</td>
<td>5 (2-6)</td>
<td>3 (0-6)</td>
<td>1 (0-4)</td>
<td>0 (0-4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Sitting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postural ability</td>
<td>7 (7-7)</td>
<td>7 (7-7)</td>
<td>7 (2-7)</td>
<td>2 (2-6)</td>
<td>2 (1-2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture frontal</td>
<td>6 (4-6)</td>
<td>4 (1-6)</td>
<td>3 (0-6)</td>
<td>0 (0-2)</td>
<td>0 (0-4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture sagittal</td>
<td>3.5 (2-6)</td>
<td>2 (0-5)</td>
<td>3.5 (0-6)</td>
<td>0 (0-4)</td>
<td>1 (0-5)</td>
<td>0.019</td>
</tr>
<tr>
<td>Standing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postural ability</td>
<td>7 (7-7)</td>
<td>7 (7-7)</td>
<td>4 (1-7)</td>
<td>1.5 (1-2)</td>
<td>1 (1-2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture frontal</td>
<td>6 (3-6)</td>
<td>3 (0-5)</td>
<td>0 (0-3)</td>
<td>0 (0-2)</td>
<td>0 (0-2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Posture sagittal</td>
<td>5 (4-6)</td>
<td>2 (0-6)</td>
<td>1 (0-4)</td>
<td>0 (0-3)</td>
<td>0 (0-3)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
The PPAS showed construct validity based on the ability of the assessment tool to differ between known groups represented by the GMFCS levels I-V. Median values and range in terms of min and max values are presented together with p-values (p<0.02) calculated with Jonckheere-Terpstra for averaged values (Table 9). Distribution of scores at each level of gross motor function in all four positions is provided for all three raters (Figure 4). The PPAS could not identify differences in postural ability between individuals at levels I-II but was able to detect postural asymmetries at all GMFCS levels.

**Figure 4** Distribution of PPAS scores at GMFCS I-V in all four positions. All observations are marked with different colours for each rater; red= rater A, blue= rater B, green=rater C. The squared points connected with a line are means of each gross motor function level.
Discussion

The overall ambition of this thesis was to enhance knowledge of posture, postural ability and mobility in people with CP; their use of assistive devices and also to evaluate a clinical tool for assessment of posture and postural ability.

The samples of study I-IV represent a total population of children or young adults with CP in the south of Sweden. Therefore the results are likely to give a true picture of the performance in children and adults of all CP subtypes and all GMFCS levels. However all participants of study I-III were included in the CPUP health care programme which may have reduced the number of children who were unable to sit, stand, walk or move and may also have affected their use of assistive devices compared to children in areas without prevention programme. The results show what the children usually do, i.e. their performance, not what they can do, i.e. their ability. In children with disabilities, ability usually exceeds performance\(^\text{102}\). The discrepancy between ability and performance may relate to differences in environmental factors\(^\text{102}\). The cross-sectional design of study I-IV can describe differences between groups at a specific moment, not changes over time.

Sitting and standing

The number of children with CP using adaptive seating decreased with age, increased with GMFCS levels and was most frequent in dyskinetic CP. Unilateral spastic CP and ataxic CP were associated with a better sitting and standing performance than bilateral spastic CP or dyskinetic CP. There was a high correlation for all outcome measures related to the expanded and revised version of the GMFCS. The GMFCS is age-related and as most children remain at the same GMFCS level this classification system seems useful for prediction of the individual child’s future sitting and standing performance.

Several studies show a significant improvement of sitting posture and postural control in children with CP using adaptive seating such as seat inserts, external supports and modular seating systems\(^{65; 68; 74; 131}\). Adaptive seating also allows parents to sit facing their child instead of holding them from behind, and this
facilitates feeding at mealtimes, play, communication and social interaction\textsuperscript{77}. Pope et al.\textsuperscript{63} found improvements in both posture and mobility with the use of adaptive seating over a three year period in children with CP aged 2.5-9 years who were unable to sit independently. There is contradictory evidence regarding the best position for sitting and the optimum inclination of seat surface\textsuperscript{132; 133}. Due to the variability in people with CP, the particular task and environment, individual assessment is required to provide appropriate support. Improvements in sitting ability can also be achieved through training\textsuperscript{134; 135}. However it is vital to have attainable, realistic goals depending on GMFCS level, bearing in mind that postural ability and attention may be affected when performing dual tasks\textsuperscript{113; 114}.

The use of support to stand, and to move between sitting and standing position was more frequent in preschool children than in schoolchildren and adolescents. However it was not clarified whether this was due to natural development or to environmental factors. Standing support such as tilt tables, standing frames and standing braces can provide postural support to maintain upright position. According to Pin et al.\textsuperscript{136} static weight bearing has been shown to increase bone density in children with CP. A study by Kecskemethy et al.\textsuperscript{137} showed a wide range of weight bearing loads in people with CP aged 6-21 years, with differences of up to 29\% of body weight between different standers. Gibson et al.\textsuperscript{138} showed a significant lengthening of hamstrings in children with CP aged 6-9 years when using a standing frame for 1 hour/day, 5 days per week.

In this study three of five children moved between sitting and standing position independently, one of five used external support and one of five could not. Moving between sitting and standing position requires more postural ability than maintaining a static position, since the centre of gravity can move out of the base of support while changing position\textsuperscript{120; 139}. People with CP have more difficulties in recovering stability when exposed to balance threats\textsuperscript{117}. Musculoskeletal constraints contribute to atypical postural patterns in standing such as a high degree of antagonist co-activation\textsuperscript{83}. According to a review by dos Santos et al.\textsuperscript{140} there are several studies describing sit-to-stand movement in smaller samples of children with spastic diplegic CP or hemiplegic CP, but our study is the first study of a total population of children with CP including all subtypes and GMFCS levels.

In Sweden, assistive devices such as adaptive seating, standing support, wheelchairs and walking aids are provided free of charge by the Assistive Technology Centres. This means that the results of these studies reflect the use of assistive devices without regard to the economic situation of the families. The opinions of the child and family, the rehabilitation team and the physical surroundings influence the need for, or use of, assistive devices. Strategies to alter the environment such as providing assistive devices in order to compensate for functional impairments and enhance activity and participation have become more
accepted in paediatric rehabilitation. Assistive devices enhance function in children with CP and reduce the demand on caregivers. It is therefore important that different types of assistive device are carefully considered for children with CP.

Wheeled mobility

The use of manual wheelchairs increased with GMFCS level, but the use of manual wheelchairs for self-mobility was more frequent in children at GMFCS III. The 25 children at GMFCS levels III–V who did not use a wheelchair for outdoor mobility were all aged 3–6 years and were probably seated in a buggy outdoors. Powered wheelchairs were most frequent in children at GMFCS IV. Children at GMFCS levels III–IV achieved a higher degree of independent mobility using manual and powered wheelchairs. Only one child at GMFCS level V had independent wheelchair mobility outdoors using a powered wheelchair. This corresponds to the results seen in the study by Östensjö et al., where the largest increase in wheeled mobility was seen at GMFCS level IV. Palisano et al. analysed the mobility methods in Ontario, Canada. In 360 children at GMFCS level III–V aged 4–12 years, 67% were pushed in manual wheelchairs outdoors, 7% self-propelled a manual wheelchair and 12% operated a powered wheelchair. The corresponding numbers for the same age group in the present study were almost equal: 62% were pushed, 6% self-propelled in manual wheelchairs and 15% operated powered wheelchairs.

Postural instability restricts functional performance and upper extremity function in children with CP. Lacoste et al. found that in children with CP who self-propelled their wheelchairs, 41% had difficulties in driving due to postural instability. Of children using manual wheelchairs, 89% became unstable when propelling, as did 61% when operating their powered wheelchairs. Providing a stable sitting posture is an important prerequisite for improvement in function and wheeled mobility.

The use of wheelchairs was most frequent in children with dyskinetic CP. Arner et al. also reported difficulties with manual activities in 80% of children with dyskinetic CP, in 41% of those with ataxic CP and in 39% of those with bilateral spastic CP. The reduced hand function in combination with postural instability may contribute to the fact that no child with dyskinetic CP self-propelled a manual wheelchair outdoors, while 77% of those having a powered wheelchair operated independently. The results indicate that children with dyskinetic CP need a powered wheelchair to achieve independent wheeled mobility. However, powered
wheelchairs require more training and are not as easily transported in cars so environmental factors must be considered.

Powered wheelchairs were only used by five children (4%) before the age of seven, even though early self-produced mobility is crucial for the child’s cognitive and psychosocial development. Wheelchairs are often used to symbolize handicap or disability, so the stereotype of disability is easily reflected by them. This may explain why some parents prefer buggies to wheelchairs hoping to avoid drawing attention to the disability. However, children with motor impairments may be at risk of developing learned helplessness if their development of independence is not supported. Experience of self-produced mobility in healthy infants as young as 8-9 months improves postural compensation to optic flow, whether it is achieved through walkers, creeping or powered mobility. Powered mobility at an early age is not only a question of learning to drive but rather a question of driving to learn.

Self-produced mobility can be obtained by powered wheelchairs at an early age, but powered mobility still appears to be viewed as the last option for older children when all other forms of mobility have failed. This may be explained by the traditional view of motor development as hierarchical where children were expected to walk as much as possible to attain independent walking although it may not have been the primary or goal of the child or the most functional method for all environments. Fortunately this approach to modify the child rather than the external factors has changed over the last decades. More attention is now paid to alter the environment in order to facilitate efficient mobility and increase participation in age-appropriate activities.

Bottos et al. showed that 21 of 27 children with severe motor disability aged 3–8 years were able to operate a powered wheelchair with no or minimal adult assistance. A majority of the parents were opposed to the idea of a power wheelchair initially, but after provision almost all were positive. The driving skill was related to the time spent in the powered wheelchair and not to IQ or motor impairment. Butler reported improved self-initiated behaviours such as interaction with objects, communication and changes in location in children aged 2-3 years provided with powered mobility. A randomized controlled study by Jones et al. of 28 children with motor impairments aged 14-30 months, showed significant improvements in functional mobility and receptive communication in the children using powered wheelchairs compared to a control group. There was also a reduction of caregiver assistance with mobility and self-care. In a study by Tefft, parents reported lower levels of stress, and increased satisfaction with their child’s ability to move around and to interact, socialize and play with the family when provided with a powered wheelchair. They also experienced a greater acceptance by the general public to powered mobility for their children. Powered mobility may also increase alertness and improve sleep/wake pattern.
Participation and social interaction opportunities in the school environment improved with the use of assistive devices in children with CP\textsuperscript{145}.

Östensjö et al\textsuperscript{76} reported improvements in independent mobility in children with the use of powered mobility, while manual wheelchairs mainly eased the care load for parents. Our study supports these results since a majority of children using powered wheelchairs operated independently while only one child out of seven attained independent wheeled mobility in a manual wheelchair.

**Walking performance**

Walking performance in children with CP varies due to personal and environmental factors. This study shows the most frequent mobility method at different distances and environments in an unselected total population of children with CP, 3-18 years. The Functional Mobility Scale (FMS) was used to describe walking performance at home (5 m), at school (50 m), in the community (500 m), and its relation to GMFCS level, CP subtype and age.

A limitation to this study is that the ratings of the FMS only provide the child’s most frequent mobility method. Some children may use several methods such as both walking with devices and using a wheelchair.

In an analysis from the SCPE database comprising 10,042 children with CP in Europe, Beckung et al\textsuperscript{154} reported that in 5-year-old children, 54% had unaided walking and 16% walked with aids. Rumeau-Rouquette et al\textsuperscript{155}, in a French study reported that in children aged 8-14 years, 38-44% had unaided walking and 13-28% walked with aids. The number of children with unaided walking in the present study is similar to Beckung et al. but higher than Rumeau-Rouquette et al. In the previous studies it is not clear at what distance or in which environment the walking ability was recorded. The proportion of children using walking aids was smaller in our study. The use of walking aids was most common in children at GMFCS level III and in children with ataxic or spastic bilateral CP in the school environment.

The walking performance increased with GMFCS level. A relationship between the FMS and the GMFCS would be expected but has, to our knowledge, not previously been examined. We found a high correlation between the two classifications, indicating that GMFCS is a good predictor of walking performance. FMS is developed to measure functional mobility in children corresponding to GMFCS levels I to IV but does not discriminate between assisted and independent wheelchair mobility. To overcome this problem a further level, between FMS 1 and N, could be considered.
The number of children who walked without aids increased up to 7 years of age. This is in agreement with the study by Bleck\textsuperscript{156}, who observed that walking ability reached a plateau by the age of 7. It is also in agreement with longitudinal analysis of motor growth curves showing peak motor performance at 6 to 7 years of age\textsuperscript{157-159}. The present study found, however, that the proportion of children walking independently on uneven surfaces (FMS 6) was incrementally higher in each age group up to 18 years. Hanna et al\textsuperscript{158} reported increased gross motor function (ie capability) in adolescents at GMFCS I-II. Palisano et al.\textsuperscript{160} described improved walking performance outdoors in adolescents at GMFCS II. Ability to walk on uneven surfaces is important to achieve independent mobility and improve accessibility in the community, where different surfaces, inclines, curbs, and stairs are more common\textsuperscript{100}. This has clinical relevance because older children and adolescents do more activities outside the home with friends than younger children\textsuperscript{99}. Those at GMFCS I do more activities outside than those at levels II-III\textsuperscript{99}. This result reflects their unrestricted walking performance.

Hanna et al\textsuperscript{158} showed a decline in gross motor function in children at GMFCS III-V from 8 years of age. Strauss et al.\textsuperscript{35} showed a decline in walking ability from 20 years and Jahnsen et al.\textsuperscript{24} reported a reduction in gross motor function in adults at GMFCS II-III, mostly due to lack of balance, fear of falling, pain and exhaustion. Several studies have shown increased energy consumption when walking with assistive devices\textsuperscript{89-92}. Gibson et al.\textsuperscript{103} found that children with CP at GMFCS III-IV consider walking as exercise rather than a functional ability, and walking interventions were often associated with pain and fear.\textsuperscript{103} The children were affected by normative ideas about walking as a moral good that must be pursued frequently, contributing to negative self-identities in the children and leading to angst and doubt in parents who feel they didn’t do enough if they let their children use a wheelchair.\textsuperscript{103}

Raja et al.\textsuperscript{88} showed an increasing energy cost with each level of decreasing FMS score when walking as well as a doubling in energy cost when walking outdoors on uneven surfaces compared with even surfaces indoors\textsuperscript{88}. This may explain why 59% of the children at GMFCS level III walked 5 m at home, whereas only 16% walked 500 m in the community. Franks et al.\textsuperscript{89} reported that mobility methods affect school performance; the use of a wheelchair had a less negative impact on visuomotor accuracy because the children were less tired than when walking with assistive devices. Jahnsen et al.\textsuperscript{24} reported an increased experience of freedom, speed of locomotion, and reduced energy cost in adults with CP at GMFCS III when starting to use a wheelchair for mobility.

In the present study there was no decline in walking performance in adolescents. As a result of the CPUP programme, the number of children who develop severe contractures has been reduced\textsuperscript{55}. This improvement could result in a diminished or delayed decrease in walking performance. In general, younger children with CP
get a more intense treatment and follow up by their physiotherapists than adolescents and adults. A continuous treatment and training programme in order to increase oxygen uptake, improve balance and strength, maintain joint range of motion and reduce pain throughout adolescence may improve walking performance or prevent a reduction in walking ability in those with a higher level of gross motor function. The CPUP health care programme continues to monitor the adolescents with CP as they grow into adults.

Postural asymmetries

Although the brain lesion in CP is non-progressive, many secondarily acquired clinical problems are progressive, and musculoskeletal abnormalities may develop continuously during the lifespan. Asymmetric postures increase the risk of tissue adaptation leading to contractures and progressive deformities which most commonly affect the spine and the lower extremities. Study IV is, to our knowledge, the first study of postural asymmetries in a total population of adults with CP.

A limitation of this study is the restricted number of participants when analyzing the results for each GMFCS level separately. Although the proportion of participants may seem low, it is compensated by the total population approach; non-participants were known and compared to participants, which is a strength of the study. The study group is a representative part of the total population in this part of Sweden, with the CP prevalence 2.3/1000 at 17-20 years of age. The distribution of subtypes in the present study almost equals that of the previous studies. According to the prevalence and distribution of gender, subtypes and GMFCS levels, the study population is probably representative for other areas and countries with similar development.

Postural asymmetries were present at all GMFCS levels, but more frequently at lower levels of gross motor function and varied in different positions. Normally a standing position require more postural ability, and those at GMFCS levels I-III demonstrated more asymmetries in standing compared to sitting and supine lying. However the reverse was seen at GMFCS level V with a higher proportion of postural asymmetries in supine and sitting compared to supported standing. This indicates a lack of postural support in lying and sitting, while supported standing corrects at least some of the asymmetry. Postural asymmetries can lead to asymmetric weight bearing which affects the base of support within the center of gravity can move. A crouched posture reduce the ability to recover balance.

The time spent in different positions has a great impact on the development of contractures and deformities. In this study no one who used standing support stood
more than 1-2 hours/day. This implies that 22-24 out of the 24 hours/day were spent in a more asymmetric position in sitting or lying for those at GMFCS level V. In addition they are unable to change their position while lying or sitting. Of those who were unable to change position in lying half had only one lying position, indicating that they were not assisted in changing position. Porter 42; 52 showed that preferred lying posture influence the direction of deformity with windsweeping, hip dislocation and spinal curve in children with CP unable to move out of their preferred posture. A study by Pountney 56 on posture management to prevent hip dislocation supports the importance of maintaining symmetry without compromising function for those unable to change position. This highlights the need for a proper assessment of posture, and provision of postural support when needed, to prevent a sustained asymmetric posture.

Pain was reported by 63 of the 102 participants but no association between posture and pain was found in this study. There was less reported pain compared to previous studies by Jahnsen et al. 31 (79%) and Andersson & Mattsson 34 (82%). It may be due to the older age of participants in their studies (mean age 34, 36 years respectively). Limited range of motion was associated with postural asymmetries. Andersson 34 reported contractures in 80% of 221 adults with CP, where knee contractures were most frequent. This corresponds to our findings where 60% of all adults with CP had restricted passive knee extension in one or both knees. This limitation was associated with postural asymmetries in both supine and standing which requires extended legs. Supine posture was also affected by limited hip extension, which was present in 22%. Previous studies 39-42 indicate that a sustained asymmetric posture predisposes to progressive deformities in people with CP. This study has shown an association between posture and limited range of motion but did not reveal if the contractures were caused by asymmetric posture or if the limited range of motion caused the postural asymmetries. This illustrates the importance of continuous monitoring of range of motion and posture in people with CP.

Hip dislocations and scoliosis were associated with postural asymmetries in all positions. The prevalence of hip dislocation (10 of 102) in this sample, not included in the hip prevention programme, corresponds to reports from other areas 46; 162. Hip dislocation, windswept-deformity and scoliosis are interrelated 50 and can be reduced with a hip surveillance programme. Progression of scoliosis increases with age even after skeletal maturity 37-49. Risk factors for progression are early onset, large curve magnitude, thoracolumbar curve, total body involvement and being confined to bed 48; 49. Since 1995 all children in the study area born in 1992 and later are included in a hip surveillance programme, which has reduced the proportions of hip dislocations, windswept deformities and scoliosis 45; 46; 50; 51; 55. The association between these deformities and postural asymmetries shows the value of hip surveillance programmes. This study illustrates the importance of
monitoring range of motion and posture not only from an early age in children, but also ongoing in adults with CP, to allow early identification and preventive treatment of contractures and postural asymmetries.

Evaluation of the Posture and Postural Ability Scale

The Posture and Postural Ability Scale (PPAS) showed an excellent interrater reliability, a high internal consistency and construct validity in a standing, sitting, prone and supine position for adults with CP. Even though an asymmetric posture is known to cause progressive deformities in people with CP there has been a lack of clinical assessment tools for posture and postural ability evaluated for adults with CP. This is, to our knowledge, the first study evaluating an assessment tool for posture and postural ability in a lying, sitting and standing position for adults.

A limitation of the study is that all three raters participated in the development of the PPAS; they have long clinical experience and are specialized in posture management. Further research is needed to examine interrater reliability for trained practitioners not involved in the modification of the assessment tool. A further limitation is that the ratings were based on photos and videos. This removes some variability that arises in clinical practise. Photos provide only a one point in time reflection of the posture. However, the condition of people with severe disabilities may alter during the day due to fatigue, pain etc. It may also change over time making a measurement on different occasions such as test-retest and intrarater reliability more difficult to interpret. Therefore we chose to evaluate agreement between different raters and used photos and videos to standardize the occasion and minimize disagreement due to different performances and circumstances.

Internal consistency represents the average of the correlations among all items. The scale demonstrated a high internal consistency for all items where Cronbach’s alpha if item deleted was 0.96-0.97, which exceeds the 0.8 recommended by Streiner Norman. Corrected Item-total correlation showed a slightly lower value for sitting posture in the sagittal view compared to the other items. This is probably explained by the fact that the height of the plinth was not optimal in some photos which affected the ratings of hips and knees mid-position. An adjustable plinth is not always available in clinical practice. If the plinth is not adjustable or if using a chair it would be desirable to provide additional support for the feet when needed.

Construct validity was evaluated through the PPAS’s ability to differ between known groups in terms of the GMFCS levels in CP. According to this classification, individuals at level I and II can walk and stand unsupported. The
highest level of the PPAS is to move into and out of position and therefore the assessment tool was not expected to differ between GMFCS levels I and II in postural ability. The basic level of postural ability is intact at GMFCS I-III, with difficulties in fine-tuning muscle contractions to specific tasks and conditions. The distribution of individuals at maximum and minimum score showed an anticipated ceiling effect for postural ability in all four positions for adults at level I-II, while the floor effect was higher for posture indicating a better quantity in terms of ability than quality of posture. This indicates a need for assessing posture and postural ability separately and as distinct from gross motor function, in order to detect postural asymmetries and identify need for postural support. A strength of the PPAS is that it identified postural asymmetries and deviations at all levels of gross motor function in this study of adults with CP.

The PPAS was sufficiently sensitive to detect small postural asymmetries and deviations even at GMFCS I and is likely to detect postural asymmetries at an early stage. The assessment tool has no grading and cannot differ between a mild, moderate or severe deviation. The rationale is that any deviation will increase by forces imposed by gravity so it is clinically relevant to detect asymmetric posture early in order to identify and apply the appropriate intervention to minimize progressive deformities and contractures.

The PPAS does not require any special equipment and is easy to use in a clinical setting. It provides important information of the need for postural support and where it needs to be applied. Although the instrument has been used in clinical practice for different client groups further research to evaluate its psychometric properties for people with other diagnoses than cerebral palsy is desirable. All assessment tools for posture and postural ability currently used in clinical practice require additional training of the professionals intending to use them.
Conclusions

About 60% of children with CP, aged 3–18, used standard chairs, stood and moved between sitting and standing position without external support. Adding those using adaptive seating and external support, 99% of the children could sit, 96% could stand and 81% could move between sitting and standing position. Unilateral spastic CP and ataxic CP were associated with a better sitting and standing performance than the other subtypes. Sitting and standing performance and the ability to move between these positions were highly correlated to the expanded and revised version of the GMFCS. The GMFCS is age-related and as most children remain at the same GMFCS level this classification system seems useful for prediction of the individual child’s future sitting and standing performance.

A majority of the children using manual wheelchairs were pushed while powered wheelchairs provided independent mobility in most cases. Most children with dyskinetic CP needed a powered wheelchair to achieve independent wheeled mobility. To achieve as high a level of independent mobility as possible, powered wheelchairs should be considered at an early age for all children with impaired walking ability.

We found a variation in walking performance related to CP subtype and a high correlation between the FMS and the GMFCS. The walking performance without aids increased from preschool children up to 7 years and then remained at that level, but the proportion of children walking independently on uneven surfaces was incrementally higher in each age group up to 18 years. The improved performance on uneven surfaces is important for achieving independent walking and improves accessibility in the community. Continuous follow up and treatment to improve and maintain walking performance is important both in children and adolescents at higher levels of gross motor function.

Postural asymmetries were found at all GMFCS levels in young adults with CP, but more frequently at lower levels of gross motor function. Postural asymmetries were associated with scoliosis, hip dislocation, hip and knee contractures, and inability to change position. It is important to monitor range of motion, hips, spine and posture from an early age, but also continuously in adults with CP, to allow early identification and preventive treatment of contractures and postural asymmetries.
The Posture and Postural Ability Scale showed excellent interrater reliability for experienced raters, high internal consistency and good construct validity. It showed an anticipated ceiling effect for postural ability at GMFCS I-II while it identified postural asymmetries at all GMFCS levels indicating a better quantity in terms of ability than quality of posture in adults with CP. This indicates a need for assessing posture and postural ability separately and as distinct from gross motor function in order to detect postural asymmetries and identify need for postural support. The PPAS was sensitive to detect postural asymmetries and deviations even at GMFCS I and is likely to detect postural asymmetries at an early stage.

Further research

It is desirable to perform additional studies with longitudinal data based on the CPUP quality register to enhance further knowledge of functional performance and posture in a total population of children and adults with CP.

Further studies of postural stability in wheelchair seating are needed to evaluate, its impact on wheeled mobility and postural asymmetries in people with CP.

Further research is planned to describe how long adults with CP remain in different positions, their ability to maintain and change position and their use of assistive devices.

Further research is needed to examine interrater reliability for trained professionals not involved with the development of the Posture and Postural Ability Scale and its application to other client groups. An evaluation of its responsiveness is also desirable.

Det övergripande syftet med denna avhandling var att öka kunskaperna kring position, postural förmåga, förflyttning och hjälpmedelsanvändning hos personer med CP och att utvärdera ett kliniskt instrument för bedömning av position och postural förmåga.

av validitet och reliabilitet för bedömningsinstrumentet Posture and Postural Ability Scale för vuxna med CP.

Omfaring 60% av barnen med CP satt och stod utan stöd. Om man lägger till de som använder hjälpmedel och externt stöd så klarade 99% att sitta, 96% att stå och 81% att resa sig och sätta sig. Det var högst andel barn med unilateral spastisk CP och ataktisk CP som satt och stod utan stöd. Sitt och ståförmågan var starkt korrelerad till GMFCS nivå. GMFCS är åldersrelaterad och eftersom de flesta barn behåller sin GMFCS nivå förefaller denna klassificering användbar för att prediktera sitt och ståförmåga hos barn med CP (studie I).

Rullstolar användes av 29% inomhus och 41% utomhus. Elrullstol möjliggjorde självständig förflyttning i de flesta fall medan endast ett av sju barn körde sin manuella rullstol själv. De flesta barn med dyskinetisk CP behövde elrullstol för att kunna köra rullstolen själv. För att öka andelen barn med självständig förflyttning bör elrullstol övervägas redan vid låg ålder för de barn som har nedsatt gångförmåga (studie II).


Posturala asymmetrier förekom vid alla GMFCS nivåer men var vanligare vid lägre funktionsnivå. Asymmetrierna har ett samband med skolios, höftluxation, höft- och knäkontrakturer samt oförmåga att ändra position. Det är viktigt att kontinuerligt följa ledörlighet, höfter, rygg och position från låg ålder men även upp i vuxen ålder vid CP för att möjliggöra tidig upptäckt och preventiv behandling av kontrakturer och posturala asymmetrier (studie IV).

Det kliniska bedömningsinstrumentet Posture and Postural Ability Scale visade mycket hög interbedömarreliabilitet, goda interna mätegenskaper och begreppsvalliditet. Det identifierade asymmetrier i liggande, sittande och stående vid samtliga funktionsnivåer hos vuxna med CP och borde därför kunna möjliggöra tidig upptäckt av posturala asymmetrier (studie V).
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