



**SAHLGRENSKA AKADEMIN
INSTITUTIONEN FÖR NEUROVETENSKAP OCH FYSIOLOGI
ENHETEN FÖR FYSIOTERAPI**

EXAMENSARBETE

Standing devices, standing posture, pain and range of motion in the lower extremities in children and adolescents with cerebral palsy.

Författare: Jessica Söderborg

Examensarbete:	15hp
Program och kurs:	FYS044 Självständigt arbete för masterexamen i fysioterapi, 15 hp
Nivå:	Avancerad
Termin/år:	HT 2020
Handledare:	Docent, leg sjukgymnast, Elisabet Rodby Bousquet
Examinator:	Docent, leg fysioterapeut Anna Danielsson

Abstrakt

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Nyckelord:	Cerebral pares, CPUP, ståstöd, PPAS, smärta, ROM

Bakgrund:	Cerebral pares är en av de vanligaste orsakerna till motorisk funktionsnedsättning hos barn och ungdomar. Individer med stora funktionsnedsättningar klassificerade enligt Gross Motor Classification System (GMFCS) nivå III-V, har ofta behov av olika former av ståhjälpmedel för att kunna stå. Att kunna stå kan minska sekundära komplikationer som smärta och nedsatt ledrörlighet i nedre extremitet.
Syfte:	Syftet med studien var att analysera användandet av ståhjälpmedel, asymmetrier i stående, smärta och passiv ledrörlighet i nedre extremitet hos barn och ungdomar med cerebral pares i förhållande till GMFCS nivå, ålder och kön.
Metod:	Tvärsnittsstudie baserad på 2019 års registerdata från Cerebral Pares Uppföljningsprogram (CPUP), och nationellt kvalitetsregister. Senaste fysioterapeutiska bedömningen av barn 0-18 år inom GMFCS nivå III-V.
Resultat:	Ståhjälpmedel användes av 918 (70.9%) av de totalt 1308 barnen i GMFCS nivå III-V. 60.2% använde ståskal, 59.3% tippbräda och 8.9% stårullstol. Majoriteten hade en ståposition nära lodlinjen (84.3%) och en abduktionsvinkel på 0-10° i höftleden (71.3%). 74.5% av barnen använde fotortoser och 17.9% använde korsett i ståhjälpmedlet. Den största majoriteten stod 5.7 dagar/ vecka (65.7%) med en ståtid på <1 timme (62.2%). Majoriteten av barnen hade asymmetrier i stående och det var associerat med nedsatt rörlighet.
Konklusion:	Majoriteten av barnen/ungdomarna i denna studie behövde stöd för att uppnå stående och använda ståhjälpmedel, och det mest använda ståhjälpmedlet var ståskal. De stod med en abduktionsvinkel av 0-10 i höftleden samt nära lodlinjen. Ortoser för nedre extremitet användes av majoriteten i stående. De flesta stod 5-7 dagar/vecka med en ståtid upp till 1 timme. Majoriteten hade asymmetrier både i frontal plan och i sagittal plan och det fanns ett samband med posturala asymmetrier och nedsatt rörlighet, men ej med smärta.

Abstract

Master thesis: 15 hec
Program: Master (two year) thesis in Physiotherapy, 15 credits
Level: Second cycle
Term/year: 2020
Supervisor: Associate professor, RPT, Elisabet Rodby Bousquet
Examiner: Associate professor, RPT, Anna Danielsson
Key words: Cerebral palsy, standing aid, posture, pain, range of motion

Background: Cerebral palsy is one of the most common causes of early childhood motor impairments. Even though CP is non-progressive, it is associated with progressive musculoskeletal complications that most commonly affect the spine and lower extremities. Supported standing is generally used to improve activity and body function and prevent secondary complications in non-ambulatory children or children that ambulate less than 2 hours/day.

Aim: The aim of this study was to analyze the use of standing devices, standing posture, pain and range of motion in the lower extremities in children and adolescents with cerebral palsy in the relation to their age, sex and gross motor function

Methods: Cross-sectional study based on registry data from the Swedish cerebral palsy follow-up-program. All children at the age of 0-18 years of age classified level III-V of the Gross motor function classification system, n=1308 were included in the study.

Results: Standing device were used by 918 (70.9%) children/adolescents and several children used more than one type of device. Overall 60.2% used custom molded hip-knee-ankle-foot-orthosis (HKAFO), 59.3% used tilt table/standing frame and 8.9% used standing wheelchair. 84.3%, had a standing position close to vertical (0-10°) and 71.3% had an abduction angle of the hip joints of 0-10°. The vast majority had a standing frequency of 5-7 days/week (65.7%) with a duration of <1 hour (62.2%). The majority had asymmetry in standing and there was an association with limited range of motion.

Conclusion: The vast majority of the children in this study needed support in standing and used some sort of standing device, and the most common used device was HKAFO. They stood with an abduction angle of 0-10° in the hip joint and had a standing position close to vertical. Lower leg orthoses were used by the majority of the participants in their standing device. The standing duration was 5-7 days/week with a standing time of 1 hour/day. The majority of the children had an asymmetry in both frontal and sagittal plane in standing. There was an association between postural asymmetry and range of motion but not for pain.

INTRODUCTION

Cerebral palsy

Cerebral palsy (CP) is one of the most common causes of early childhood motor disabilities with a prevalence of about 2-3/1000 live births (1,2). CP is a neurological disorder with motor impairment and neurological signs such as dyskinesia, ataxia and/or spasticity (3). About 85% have spasticity as primary subtype (2). Rosenbaum et al (1) defined CP as: “Cerebral palsy (CP) describes 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 of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems (1)”. For children with CP movement and posture are key problems (4) and almost one third are non-ambulant (2). Some of the primary manifestations of the brain injury are muscle weakness, abnormal muscle tone, selective motor control, and impaired postural control (1). The degree of neuromuscular deficits and mobility impairments are highly diverse (1). The expanded and revised version of the Gross Motor Function Classification System (GMFCS) is internationally used to classify the severity of the motor impairment. It is a five level classification system (I-V) of gross motor function with six age bands ranging from 0 to 18 years developed for children with CP (5). Level I describing the highest level of function and level V the lowest. The distinctions between the levels represents differences in gross motor function that are meaningful in daily living in individuals with CP including sitting, mobility and transfers, according to the age bands for age-related differences. GMFCS is a good predictor of sitting and standing performance and it is used by both clinicians and researchers (5).

Posture and postural ability

The systems theory developed by Nicolai Bernstein focuses on musculoskeletal and neural aspects and takes environmental factors into account (6). There is no universal definition of posture and postural ability. The definitions of posture and postural ability by Rodby-Bousquet will be used throughout this paper (7). 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”. The term

postural ability is defined as: “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“(7). In other words, posture is the base from which movement occur, so unless we can stabilize the posture we will not be able to move. The postural challenges are typical for children with CP and makes it difficult to maintain a sitting or standing position or move and walk around (8,9). Non-ambulant individuals with CP are particularly vulnerable to early development and rapid deterioration of asymmetrical postural problems (10,11). That could partially be explained by the amount of time spent in the same posture (4,11). The performance of everyday activities is noticeably influenced by postural deficits as it plays a central role in the motor dysfunction of children with CP (12). Reduced postural ability may affect the head control and the ability to eat and swallow, communicate and also vision. It will also affect the trunk stability and reduce arm/hand function (13). A study (4) including young adults with CP showed that postural asymmetries were present at all GMFCS levels and varied in different positions. The postural asymmetries were associated with limitation in hip and knee extension (4).

Secondary complications

Despite the fact that the underlying brain pathology is non-progressive and the musculoskeletal status usually is normal at birth (10), CP is associated with progressive musculoskeletal complications (1). These can affect everyday life more negatively than the primary diagnosis (14). Children with CP often develop muscle contracture, and the underlying mechanisms are not fully understood (15). The lower extremities and the spine are most commonly affected by contractures and joint deformity. These can lead to scoliosis, hip dislocation, windswept hip deformity (WS), hip-, knees- and footdeformities (16). In the whole population of children/adolescents with CP 15-20% have dislocated hips (17) and around 25% develop scoliosis (13). In young adults with CP a study from Rodby-Bousquet et al (4) found that limited range of motion was associated with postural asymmetries and that restricted knee extension in one or both knees was associated with postural asymmetries in standing (4).

Another secondary complication of CP is pain (18-22). A systematic review from 2018 (22) showed that pain prevalence varied widely from 14-76% in children and younger adults with CP. Previous Swedish studies showed a pain prevalence of 32 to 44 % (19-21,23). The prevalence of pain differ among studies (19,21) due to the subjective and changing nature of pain (21) but they all conclude that pain is a significant challenge (18,21). The pain is more frequent in the lower extremities (19,21,22) and hip/thigh pain is associated with most intense pain (21). Furthermore, there is an association between GMFCS level and the pain site (19,21,22) and females rate higher levels of pain (21). Pain prevalence and intensity increase with age (21,22). Non-ambulatory children, GMFCS level IV-V, or children who ambulate less than 2 hours/day often experience painful complications due to extended periods spent in sitting or lying position (24). A recent study from Casey et al (25) showed that there was an association between pain and postural asymmetries in supine and sitting in children with CP.

National health care program

A national health care program for children with CP (CPUP) (26) started in Sweden 1994. CPUP is a multidisciplinary longitudinal follow-up-program that also serves as a national quality registry. It's population-based and more than 95% of the children with CP born 2000 or later are enrolled in CPUP. Inclusion and exclusion criteria for CP in CPUP are in accordance with guidelines of the Surveillance of Cerebral Palsy in Europe (SCPE) (3), and the definition of CP from Rosenbaum et al is used (1). Children with presumed, but not yet confirmed CP are included in CPUP until their diagnosis is confirmed by a neuropaediatrician from the age of 4 years. If they do not full fil the criteria for CP, they are excluded (27). Depending on age and GMFCS level the children are examined every six months, once a year, or every other year (14). Secondary complications to CP such as contractures, hip dislocation and scoliosis can be reduced by early detection and treatment (14). The intervention may target multiple treatment outcomes for different levels of the ICF (International Classification of Functioning, Disability and Health) (28).

Supported standing

Supported standing programs have been used for more than 50 years to optimize activity various aspects of function and to prevent or reduce complications (24). Standing devices are prescribed by pediatric physical therapist for children with CP (24) and are widely used to

improve activity and participation in terms of the different ICF domains head control, maintain standing position and to facilitate weight bearing for children who cannot stand unsupported (28). Supported standing is also used to improve body structure and function such as bone density (29), biomechanical alignment of the body segments and prevent secondary complications (31), such as contracture of soft tissues thereby contributing to improved/maintained passive range of motion in the lower extremities (24,31). Furthermore, it has been associated with prevention of hip dislocation (24,28).

Even though supported standing generally is recommended there is a lack of evidence-based recommendations for effective program dosing (24). A systematic review from Paleg et al showed that supported standing 5 days/week for 45-60 min had a positive effect on ROM in the hip, knee and ankle (24). Furthermore, little is known about the use of standing devices, standing posture, postural ability in standing, pain and range of motion in the lower extremities in children and adolescents with CP.

Aim

The aim of this study was to describe the use of standing devices, standing posture, pain and range of motion in the lower extremities in children and adolescents with cerebral palsy in relation to their age, sex and level of gross motor function.

METHOD

Design

This was a cross-sectional study based on registry data from CPUP.

Participants

In the present study all children and adolescents classified at GMFCS level III-V reported into CPUP between 1 January and 31 December 2019 were included. The last physiotherapy evaluation was used for all participants. There were 1308 children in total (684 males and 624 females), aged 0-18 years (mean age 9.44). The distribution of GMFCS level was: level III 22%, level IV 38% and level V 40% (Table 1).

Study parameters

The assessments are a part of the CPUP assessment and were performed by local physiotherapists throughout Sweden. The full CPUP assessment form and its accompanying manual are available on the CPUP website (<http://cpup.se/in-english/manuals-and-evaluation-forms/>)

Obtained data regarding standing devices include type of device categorized into; standing wheelchair, custom molded hip-knee-ankle-foot-orthosis (HKAFO), or a standing support such as tilt table/standing frame. Time in standing device reported as times/week (7, 5-6, 3-4 or 1-2) and hours/day (>4, 3-4, 1-2 or <1). Any forward or backward tilt from vertical was noted as a tilt angle (0-10° or >10°) and the abduction angle of the hip joints was categorized into three groups (0-10°, 11-20° or 21-30°). The use of additional orthosis (spinal orthosis and/or lower extremity orthoses) in combination with the other standing device was also noted.

Passive range of motion (ROM) was assessed by goniometric measurement in a standardized position according to the CPUP manual (26). Hip abduction, knee extension and dorsiflexion of the foot (with extended knee) was measured in a supine position. Hip extension was measured in either prone or supine position. In this study ROM was categorized into either full ROM or contracture for each joint based on the value of the worst side. Hip abduction, $\geq 30^\circ$ (full ROM) or $< 30^\circ$ (contracture). Hip extension, knee extension and dorsiflexion of the foot, 0° to -5° (full ROM) or $> -5^\circ$ (contracture).

Current pain was either self-reported (by the child) or proxy-reported (families or caregivers) as Yes or No. Pain intensity (from the Short Form Health Survey-36) during the last four weeks was graded into 1=None; 2=Very mild; 3=Mild; 4=Moderate; 5=Severe; 6= Very severe, for the following body locations: hip/thigh, knee, feet/lower leg, or lower extremities unspecified (26). The pain assessment variables in CPUP captures the same patterns of pain prevalence and distribution as other population based studies of children with CP (23). In this study pain in the lower extremities was categorized into Yes or No and grouped any pain reported as very mild to very severe as having pain.

Standing posture and the ability to maintain and change standing position was rated according to the Posture and Postural Ability Scale (PPAS): It has a 7-point ordinal scale for assessment of postural ability in standing (quantity, what the child can do). The score range from level 1 (“unplaceable”) to level 7 (able to move into and out of position). Furthermore, it contains items of quality of posture of the body segments, head, trunk, pelvis, legs, arms, feet and weight bearing, in frontal and sagittal plane. Symmetry and alignment scores 1 point and asymmetry or deviation 0 points for each item, giving a total score between 0-6 points. Frontal and sagittal plane calculated separately. PPAS identifies asymmetries at varying levels of motor function and has an excellent inter-rater reliability for children with CP (Kw= 0.77-0.99) (30). In this study postural ability was categorized into three groups; change position (7p), maintain position (3-6p) and needs support (1-2p). Posture was categorized into four groups; no asymmetry (6p), mild asymmetry (4-5p), moderate asymmetry (2-3p) and severe asymmetry (0-1p) (25).

Ethics

Ethical approval was granted by the Medical Research Ethics Committee in Lund (Dnr 383/2007) and permission to use anonymized data from CPUP was obtained by the Registry. All families to the participants in the CPUP register consent to research based on reported data.

Statistical analysis

To analyze difference in data at different ages the participants were divided into six age groups, 0-3, 4-6, 7-9, 10-12, 13-15, 16-18 years. Characteristics of the participants and study parameters were calculated and described with descriptive statistics. Chi-square was used to evaluate any differences related to gender. For differences related to GMFCS levels and age groups, Chi-square test for trend (Linear by linear association test) was used. To evaluate any linear associations between variables, Spearman’s correlation (ρ) was used. Logistic regressions were reported as odds ratio (OR) and 95% confidence intervals (Cis). Statistical significance at $p < 0.05$ was assumed throughout. All analysis were performed using IBM Statistical Package for Social Services (SPSS version 26.0) computer program.

RESULT

Standing device

Of the 1308 children/adolescents, 918 (70.9%) registered use of some sort of standing device. Overall 553 (60.2%) used HKAFO, 544 (59.3%) used standing frame/tilt table and 82 (8.9%) used standing wheelchair. More than one standing device was used by 28.4%. The use of HKAFO ($p<0.001$) and standing frame/tilt table ($p<0.001$) increased with GMFCS levels. The reverse was seen in standing wheelchairs ($p<0.001$) where the use decreased with increased GMFCS level. Differences in age groups showed that there was an association ($p<0.001$) between increase of age and decreased use of HKAFO ($r_s=0.15$). Standing wheelchairs seemed to be used by a slightly higher proportion, 35.3%, of older children/adolescents (10-18 years) compared to younger children, 17.8% (0-9 years) (Table 2).

A vast majority, 71.3% of the children had a hip abduction angle of 0-10°, while only 3.7% had a hip abduction angle of 21-30° (Table 2). There was association with wider abduction angle and younger age (p -value 0.001). No difference in abduction angle was seen between GMFCS level and gender.

Most children, 84.3% had a standing position close to vertical (0-10°) (Table 2). A tilt angle >10° from vertical was more common in children with higher GMFCS level (p -value 0.001) ranging from 3.5% at GMFCS level III to 27.1% at level V (Table 2).

Of the 918 children using standing devices, 74.5% used them in combination with lower leg orthoses and 17.9% with spinal orthoses in their standing device (table 2). The use of orthosis for the lower leg such as ankle-foot-orthosis (AFO) and spinal orthosis had a significant association (p -value 0.001) with increased GMFCS level.

Most children, 65.7% used their standing devices 5-7days/week and only 9% used it 1-2 days/week. A majority, 62.2% stood <1 hour/day and only 1.9% stood more than 3 hours/day (Table 2). There was a tendency of younger children using their standing device more times/week, but for shorter time periods than older children.

Postural ability and postural asymmetry

A vast majority, 85.7% of the children GMFCS level III-V needed support to maintain a standing position. Only 9.8% of the children and adolescents could change position independently and they were all classified at GMFCS level III or IV (Table 3).

Of 1308 children, 756 had complete data for PPAS (quality of posture) with a total score in frontal and the sagittal plane and of those 88.8% had registered if their standing posture was assessed without support, with support or in standing device (Table 4).

The majority, 34.5%, of the children had a mild asymmetry in the frontal plane and 31.6% of the children a moderate asymmetry in the sagittal plane. Only 13.8% had no asymmetry in the frontal plane and 12.3% in the sagittal plane. Severe asymmetry were found in 22.4% of the children in the frontal plane and 25.7% in the sagittal plane. Of the children being assessed in their standing device only 11.2% had severe asymmetry in the frontal plane and 10.1% in the sagittal plane (Table 4).

Of the children, 37.8% had limited ROM in hip abduction, 16.8% in hip extension, 56.9% in knee extension and 15.5% in dorsiflexion of the foot. There was an association between passive range of motion in the lower extremities and standing posture. In the frontal plane limited, knee extension (OR= 2.2; 95% CI 1.64-2.95) or dorsiflexion of the foot (OR=2.1; 95% CI 1.36-3.34) almost doubled the risk for an asymmetric standing posture. In the sagittal plane limited knee extension (OR=2.8; 95% CI 2.06-3.76) had the highest risk for an asymmetric standing posture (Table 5). There were similar outcomes for children standing in their standing device.

Of the 1308 children 560 (44.9%) reported pain sites and 352 of those reported pain in the lower extremities. There was no association between quality of posture and pain.

DISCUSSION

This study describes the use of standing devices, standing posture, pain and range of motion in the lower extremities in children and adolescents with cerebral palsy in relation to their age, sex and level of gross motor function. A vast majority of children at GMFCS level III-V cannot stand unsupported and most of them (70.9%) use standing device to achieve an upright position. Our result regarding use of standing device in the different GMFCS levels were similar to a study with children/adolescents from 2010 (8) and young adults from 2013 (4). Nearly one third used more than one type of device. Most children stand at least 5 times/week but usually not more than 1 hour/day. According to Goodwin et al (32) environmental and personal factors determined what standing device is the most appropriate to use. In this study, HKAFO was the most common standing device used by 60.2% of the children and more frequent in children at higher GMFCS levels. In Sweden HKAFOs are used as a comprehensive care for children GMFCS level IV-V (28). HKAFO can be used together with another standing device. That probably accounts for some of the children that have more than one type of standing device.

This study showed that the majority (65.7%) of the children/adolescents stood 5-7 days/week which gives the assumption that they also use their standing device at home. The opposite was seen in a study in the United Kingdom (UK) (32) where the majority of the children stood in school or daycare. That could be explained by the fact that there was an issue with space for standing device at home (32). This study showed that nearly one third had more than one device. There is no information where the devices are located, but it is likely that there could be one standing device at home and one at school or daycare. In Sweden the standing devices are prescribed free of charge to the families (8), in the UK however they are not (32). The frequency and duration of 45-60 min supported standing 5 days/week should according to a systematic review from Paley et al (24) have a positive effect on the ROM of the hip, knees and ankle. However, Fehlings et al found no such evidence (33). In the UK the recommendations and prescription of use regarding standing device are not based on national or local guidelines but rather on clinical experience (32). In comparison to other studies (8,32) the use of standing device was more frequent in preschool children and decreased in schoolchildren and adolescents. That could be connected to the findings in Goodwin et al

study (32); physical space in home, older children – larger standing devices, children reporting dislike or experiencing pain while using standing device.

The majority (84.3%) of the children in this study had a standing position close to vertical. Previous studies have shown that inclination has impact on weight bearing, closer to vertical giving more effect on weight bearing (24). More children at lower levels of motor function (GMFCS level V) were tilted more than 10 degrees from vertical. That could be due to the fact that children at more severe GMFCS level have less head control in a vertical position (5). A vast majority (71.3%) had an abduction angle of 0-10 in the hip joint, and there was an association with wider abduction angle and younger age. Earlier studies have suggested that a wider to maximal abduction angle in the hip joint during standing is beneficial for the development of the hips in children two to six years of age (34,35). No differences regarding GMFCS level and abduction was found in this study. Children with more severe motor impairments have a higher risk of developing hip displacement (17), and they might benefit from a wider abduction angle in the hips during standing (34,35). Limited ROM in hip abduction could explain the result due to the fact that restricted ROM is related to lower GMFCS levels and higher age (37). Standing in an abduction angle close to maximum ROM could result in pain (21,38), and the study from Goodwin et al showed that children reported pain and discomfort in their standing device (32).

In management of children with CP orthoses are widely used (37). In the lower limb the ankle-foot orthosis (AFO) is the most frequently used type of orthosis, it is used to improve function or affect body structure. In non-ambulant children they are also used to improve stability in standing (37). In this study lower leg orthosis was used by three of four children in their standing device and had an association with more severe GMFCS level and the use of orthosis. That is consistent with that AFO is used more frequent at lower level of motor function (37). Spinal orthosis were used by 17.9% of the children in their standing device and by a higher proportion of the children at GMFCS level V. In general spinal orthosis can be used both to stabilize and delay progression of scoliosis and to provide functional abilities such as stability and head control (13). A recent study (13) from Pettersson and Rodby-Bousquet showed that 96% of the spinal orthosis are used primarily to improve stability/positioning in children with CP. They also report similar findings with spinal

orthoses used by children at GMFCS level III-V and more frequently by children at higher GMFCS level. In the study by Pettersson and Rodby-Bousquet the use of spinal orthosis increased with age, but in contrast to their findings, the use of lower leg orthoses and spinal orthoses in the standing devices in this study had no association with age or sex.

A vast majority (85.7%) of the children and adolescents in this study needed support to maintain a standing position and only 9.8% could change position independently. Similar results have been shown in other studies (8). There is a difference in standing performance between the different subtypes, where support in standing is used more frequently in children with spastic bilateral or dyskinetic subtypes (8). Our study, however didn't look at the different subtypes. Like previous studies (4,8) the need of support in standing increased with GMFCS level. The study from Rodby-Bousquet and Hägglund (8) showed similar results as ours. In GMFCS level V none of the children could stand without support, and in GMFCS level III <40% of the children could stand unsupported (8). Biomechanical constraints, size of support-base is likely to influence the child's ability to control their posture (9). Because there is a small base of support and a higher center of gravity in standing children with severe disability may need external support to achieve the task (9). The majority of the children in this study had mild (frontal plane) to moderate (sagittal plane) asymmetric standing posture and limited ROM in the knees was seen in 56.9%. Limited range of motion in the knees could be due to inadequate hamstrings length which is essential to an upright standing position (30). Crouched standing posture leads to limited ROM in hip and knee (30). Due to the biomechanical changes in postural alignment healthy children standing in a crouched posture show similar postural responses as children with CP (30).

For individuals with severe physical disabilities there are few assessment tools for posture and postural ability. The Posture and Postural Ability Scale (PPAS) has been evaluated regarding its psychometric properties for adults (10) and children with CP (13). PPAS can identify problems of posture and postural ability at an early stage and gives information on what postural support is appropriate and where it needs to be applied (10,13). Only 27% of the participants were assessed with PPAS in their standing device which could lead to more asymmetry. Rodby-Bousquet et al study (4) of postural asymmetry in young adults with CP showed that the individuals at GMFCS level I-III had more asymmetric posture in standing

than in sitting or supine. That is due to the fact that a standing position requires more postural control. The reverse was seen in GMFCS level V, where there was a higher proportion of asymmetric posture in sitting and lying than in supported standing (4). Postural asymmetries in standing were associated with limited ROM primarily of the knees and ankles. An association between limited ROM and postural asymmetries have previously been described both in standing (4,8), lying (25,39) and sitting (25,40). The studies do however not reveal if limited ROM caused postural asymmetries or if postural asymmetries caused limited ROM. In contrast to recent study showing a clear association between pain and asymmetric posture in sitting and lying (25), we found no association between standing posture and pain. One explanation may be longer time spent in lying and sitting than in standing (25) or the slightly different population including children at all GMFCS levels.

Strengths and limitations

A register study provides the opportunity to include an entire population and conduct a comprehensive survey, and this study had a fairly large study population. Despite this, there were several methodological limitations to the study. Data collected from the national quality register includes a total population of children with CP who are followed in a structured healthcare program and may therefore not be generalized to other populations. The rates of hip dislocations in the Nordic countries is substantially lower than in the rest of the high income countries (28), which makes this study population not homogenous to other children with CP. The data is collected prospectively and in a standardized way but not specific for this study, for example; the question about pain is general and not in combination with the standing activity. There is a restricted number of participants when analyzing the result for each GMFCS level and age group separately. It was a cross-sectional study and do not allow evaluation of casual relationship.

Conclusion

The vast majority of the participants in this study needed support in standing and used some sort of standing device, and the most common used device was HKAFO. They stood with an abduction angle of 0-10 in the hip joint and had a standing position close to vertical. Lower leg orthoses was used by the majority of the participants in their standing device. The standing duration was 5-7 days/week with standing time of 1 hour/day. The majority of the

participants had an asymmetry in both frontal and sagittal plane in standing. There was an association between posture and ROM but not for pain.

Clinical relevance

To prevent postural asymmetry and/or contractures there is a proactive approach in healthcare in Sweden using a 24-hour postural management program (25). Hägglund et al (17) have suggested that continued standing should be part of a comprehensive care strategy to maintain health, activity and participation as well decrease pain. The use of standing devices can be time consuming, take an amount of physical space and some devices refer the children to a specific place during the time of standing. As a physiotherapist it is important to explain and motivate the use of standing device to the children and their families. This study provides some information about the use of standing devices in Sweden. It does not however reveal what the prescriptions of use were regarding frequency/duration or the motivation of choice regarding type of standing device. Further research is relevant to deciding clinical guidelines regarding the use of standing devices. Furthermore, like previous studies (25) it highlights to regularly monitor the children for postural asymmetries for preventing further secondary complications.

Conflict of interest

The authors declare that there is no conflict of interest. The authors alone are responsible for the content and writing of this article. Standing devices in Sweden are free of charge by the Assistive Technology Centre, the result of this study therefore reflects the use of standing device without the regards of the economic situation of the families.

Ethical conflict

The participants in this study could be seen as ethically vulnerably as they are children and adolescents. Since it was a register study, the data had already been collected and didn't require anything extra from the participants or their families. All data was anonymized and presented in larger groups to ensure confidentiality.

Author's contribution

Study design: Jessica Söderborg, Elisabet Rodby-Bousquet.

Analysis: Jessica Söderborg, Kristofer Årestedt (professor and research leader for the iCARE group), Elisabet Rodby-Bousquet.

Manuscript preparation: Jessica Söderborg, Elisabet Rodby-Bousquet

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TABLES

Table 1 Characteristics of the participants the study.

	All participants, n (%)	GMFCS level		
		III, n (%)	IV, n (%)	V, n (%)
GMFCS level*	1308 (100)	288 (22.0)	496 (37.9)	524 (40.1)
Age at assessment (y)				
0-3	161 (12.3)	37 (23.0)	61 (37.9)	63 (39.1)
4-6	237 (18.1)	57 (24.1)	83 (35.0)	97 (40.9)
7-9	261 (20.0)	61 (23.4)	98 (37.6)	102 (39.1)
10-12	243 (18.6)	51 (21.0)	91 (37.5)	101 (41.6)
13-15	256 (19.6)	50 (19.5)	100 (39.1)	106 (41.4)
16-18	150 (11.5)	32 (21.3)	63 (42.0)	55 (36.7)
Sex				
male	684 (52.3)	152 (22.2)	251 (36.7)	281 (41.1)
female	624 (47.7)	136 (21.8)	245 (39.3)	243 (38.9)

*Gross Motor Classification System. Level I-V, where level V is describing the lowest level of functioning

Table 2: Standing device. 918 children/adolescents (70.9% of valid data n=1295, all participants n=1308) have standing device. The children can have more than one type of device.

	Valid data, n (%)	GMFCS level*			Age at assessment (y)						Sex	
		III	IV	V	0-3	4-6	7-9	10-12	13-15	16-18	male	female
Standing device	918 (100)	117 (41.3)	386 (78.5)	415 (79.8)	100 (62.1)	177 (75.6)	197 (76.1)	178 (73.9)	174 (69.1)	92 (62.2)	477 (70.5)	441 (71.4)
HKAFO**	553 (60.2)	57 (48.7)	214 (55.4)	282 (68.0)	73 (73.0)	119 (67.2)	131 (66.5)	103 (57.9)	100 (57.5)	27 (29.4)	282 (59.1)	271 (61.5)
tilt table	544 (59.3)	64 (54.7)	212 (54.9)	268 (64.6)	59 (59.0)	101 (57.1)	118 (59.9)	104 (58.4)	95 (54.6)	67 (72.8)	277 (58.1)	267 (60.5)
standing wheelchair	82 (8.93)	22 (18.8)	49 (12.7)	11 (2.65)	4 (4.0)	10 (5.7)	16 (8.1)	20 (11.2)	21 (12.1)	11 (12.0)	47 (9.9)	35 (7.9)
Abduction angle***	676 (73.6)	85 (72.7)	291 (75.4)	300 (72.3)	80 (80.0)	140 (79.1)	151 (76.7)	130 (73.0)	116 (66.7)	59 (64.1)	351 (73.6)	325 (73.7)
0-10°	482 (71.3)	60 (70.6)	216 (74.2)	206 (68.7)	54 (67.5)	93 (66.4)	95 (62.9)	90 (69.2)	99 (85.3)	51 (86.4)	249 (70.9)	233 (71.7)
11-20°	169 (25.0)	19 (22.4)	68 (23.4)	82 (27.3)	23 (28.8)	39 (27.9)	48 (31.8)	37 (28.5)	15 (12.9)	7 (11.9)	87 (24.8)	85 (26.2)
21-30°	25 (3.7)	6 (7.1)	7 (2.4)	12 (4.0)	3 (3.8)	8 (5.7)	8 (5.3)	3 (2.3)	2 (1.7)	1 (1.7)	15 (4.3)	10 (3.1)
Tilt angle****	682 (74.3)	85 (72.7)	291 (75.4)	306 (73.7)	87 (87.0)	136 (76.8)	155 (78.7)	126 (70.8)	119 (68.4)	59 (64.1)	353 (74.0)	329 (74.6)
0-10°	575 (84.3)	82 (96.5)	270 (92.8)	223 (72.9)	74 (85.1)	119 (87.5)	134 (86.5)	107 (84.9)	94 (79.0)	47 (79.7)	293 (83.0)	282 (85.7)
>10°	107 (15.7)	3 (3.5)	21 (7.2)	83 (27.1)	13 (14.9)	17 (12.5)	21 (13.6)	19 (15.1)	25 (21.0)	12 (20.3)	60 (17.0)	47 (14.3)
Orthoses*****												
lower leg	684 (74.5)	83 (70.9)	282 (73.1)	319 (76.9)	61 (61.0)	119 (67.2)	155 (78.7)	146 (82.0)	134 (77.0)	69 (75.0)	363 (76.1)	321 (72.3)
spinal	165 (18.0)	3 (2.6)	50 (13.0)	112 (27.0)	10 (10.0)	21 (11.9)	49 (24.9)	48 (27.0)	31 (17.8)	6 (6.5)	84 (17.6)	81 (16.1)
Times/week	885 (96.4)	113 (96.6)	372 (96.4)	400 (96.4)	97 (97.0)	172 (97.2)	191 (97.0)	172 (96.6)	165 (94.8)	88 (95.6)	460 (96.4)	425 (96.4)
7	279 (31.5)	23 (20.4)	121 (32.5)	21 (5.3)	43 (44.3)	54 (31.4)	70 (36.7)	55 (32.0)	40 (24.2)	17 (19.3)	148 (32.2)	131 (30.8)
5-6	302 (34.1)	38 (33.6)	117 (31.4)	97 (24.3)	27 (27.8)	75 (43.6)	61 (31.9)	59 (34.3)	50 (30.3)	30 (34.1)	160 (34.8)	142 (33.4)
3-4	224 (25.3)	29 (25.7)	98 (26.3)	147 (36.8)	22 (22.7)	30 (17.4)	48 (25.1)	48 (27.9)	50 (30.3)	26 (29.6)	117 (25.4)	107 (25.2)
1-2	80 (9.0)	23 (20.4)	36 (9.7)	135 (33.8)	5 (5.2)	13 (7.6)	12 (6.3)	10 (5.8)	25 (15.2)	15 (17.1)	35 (7.6)	45 (10.6)
Hours/day	865 (94.2)	112 (95.7)	358 (92.8)	395 (95.2)	95 (95.0)	168 (94.9)	188 (95.4)	167 (93.8)	162 (93.1)	85 (92.4)	450 (94.3)	415 (94.1)
>4	3 (0.4)	1 (0.9)	1 (0.3)	1 (0.3)	0 (0)	2 (1.2)	1 (0.5)	0 (0)	0 (0)	0 (0)	2 (0.4)	1 (0.2)
3-4	13 (1.5)	0 (0)	6 (1.7)	7 (1.7)	4 (4.2)	4 (2.4)	1 (0.5)	1 (0.6)	3 (1.9)	0 (0)	6 (1.3)	7 (1.7)
1-2	311 (40.0)	40 (35.7)	132 (36.9)	139 (35.2)	25 (26.3)	69 (41.1)	79 (42.0)	59 (35.3)	55 (34.0)	24 (28.0)	162 (36.0)	149 (35.9)
<1	538 (62.2)	71 (63.4)	219 (61.2)	248 (62.8)	66 (69.5)	93 (55.4)	107 (56.9)	107 (64.1)	104 (64.2)	61 (70.9)	280 (62.2)	258 (62.2)

*Gross Motor Classification System. Level I-V, where level V is describing the lowest level of functioning.

**HKAFO = Custom molded hip-knee-ankle-foot-orthosis.

Abduction angle in the hip joint. * Tilt angle from vertical. ***** Uses orthoses in their standing device.

Table 3. Posture and postural ability scale (PPAS). Postural ability in standing, 1-7p ordinal scale, change position=7p, maintain position=3-6p and needs support=1-2p. Presented as valid data.

	Valid data, n (%)	PPAS – ability		
		change position	maintain position	needs support
Participants	1149 (87.8)	113 (9.8)	51 (4.4)	985 (85.7)
GMFCS level*				
III	267 (92.7)	106 (39.7)	37 (13.9)	124 (46.4)
IV	436 (87.9)	7 (1.6)	14 (3.2)	415 (95.2)
V	446 (85.1)	0 (0)	0 (0)	446 (100)
Age at assessment (y)				
0-3	152 (94.4)	1 (0.7)	3 (2.0)	148 (97.4)
4-6	207 (87.3)	15 (7.3)	12 (5.8)	180 (87.0)
7-9	234 (89.7)	34 (14.5)	10 (4.3)	190 (81.2)
10-12	216 (88.9)	24 (11.1)	9 (4.2)	183 (84.7)
13-15	209 (81.6)	25 (12.0)	11 (5.3)	173 (82.8)
16-18	131 (87.3)	14 (10.7)	6 (4.6)	111 (84.7)
Sex				
male	601 (87.9)	53 (8.8)	30 (5.0)	518 (86.2)
female	548 (87.8)	60 (10.9)	21 (3.8)	467 (85.2)

*Gross Motor Classification System. Level I-V, where level V is describing the lowest level of functioning.

Table 4a: Posture and postural ability scale (PPAS). Symmetry and alignment scores 1 point and asymmetry or deviation scores 0 points for each item, total score of 0-6 points.

No asymmetry=6p, mild asymmetry=4-5p, moderate asymmetry=2-3p and severe asymmetry= 0-1p.

PPAS – total score	Valid data,	Assessed, n (%)			
	n (%)	standing device	with support	without support	missing data
Frontal plane	756 (57.80)	250 (33.07)	354 (46.83)	67 (8.86)	85 (11.24)
no asymmetry	104 (13.76)	44 (17.60)	38 (10.73)	12 (17.91)	10 (11.76)
mild asymmetry	261 (34.52)	120 (48.00)	96 (27.12)	23 (34.33)	22 (25.88)
moderate asymmetry	222 (29.37)	58 (23.20)	112 (31.64)	24 (35.82)	28 (32.94)
severe asymmetry	169 (22.35)	28 (11.20)	108 (30.51)	8 (11.94)	25 (29.41)
Sagittal plane	756 (57.80)	247 (32.67)	359 (47.49)	66 (8.73)	84 (11.11)
no asymmetry	93 (12.30)	44 (17.81)	31 (8.64)	10 (15.15)	8 (9.52)
mild asymmetry	230 (30.42)	112 (45.34)	82 (22.84)	16 (24.24)	20 (23.81)
moderate asymmetry	239 (31.61)	66 (26.72)	118 (32.87)	32 (48.48)	23 (27.38)
severe asymmetry	194 (25.66)	25 (10.12)	128 (35.65)	8 (12.12)	33 (39.29)

Table 4b: PPAS – total score in standing device.

PPAS – total score	Valid data,		GMFCS level*				Age at assessment (y)				Sex	
	n (%)	III	IV	V	0-3	4-6	7-9	10-12	13-15	16-18	male	female
Frontal plane	250 (27.23)	14 (11.97)	94 (24.34)	142 (34.22)	26 (26.00)	42 (23.73)	56 (28.43)	62 (34.83)	46 (26.44)	18 (19.57)	134 (28.09)	116 (26.30)
no asymmetry	44 (17.60)	7 (50.00)	24 (25.53)	13 (9.15)	5 (19.23)	11 (26.19)	9 (16.07)	11 (17.74)	7 (15.22)	1 (5.56)	19 (14.18)	25 (21.55)
mild asymmetry	120 (48.00)	6 (42.86)	46 (48.94)	68 (47.89)	16 (61.54)	21 (50.00)	30 (53.57)	31 (50.00)	15 (32.61)	7 (38.89)	69 (51.49)	51 (43.97)
moderate asymmetry	58 (23.20)	1 (7.14)	20 (21.28)	37 (26.06)	5 (19.23)	8 (19.05)	12 (21.43)	12 (19.35)	16 (34.78)	5 (27.78)	30 (22.39)	28 (24.14)
severe asymmetry	28 (11.20)	0 (0)	4 (4.26)	24 (16.90)	0 (0)	2 (4.76)	5 (8.93)	8 (12.90)	8 (17.39)	5 (27.78)	16 (11.94)	12 (10.34)
Sagittal plane	247 (26.91)	14 (11.97)	92 (23.83)	141 (33.98)	25 (25.00)	42 (23.73)	56 (28.43)	60 (33.71)	46 (26.44)	18 (19.57)	133 (27.88)	114 (25.85)
no asymmetry	44 (17.81)	8 (57.14)	22 (23.91)	14 (9.93)	10 (40.00)	11 (26.19)	10 (17.86)	9 (15.00)	2 (4.35)	2 (11.11)	26 (19.55)	18 (15.52)
mild asymmetry	112 (45.34)	4 (28.57)	42 (45.65)	66 (46.81)	13 (52.00)	23 (54.76)	27 (48.21)	22 (36.67)	18 (39.13)	9 (50.00)	56 (42.11)	56 (48.28)
moderate asymmetry	66 (26.72)	2 (14.29)	24 (26.09)	40 (28.37)	2 (8.00)	7 (16.67)	14 (25.00)	21 (35.00)	17 (36.96)	5 (27.78)	35 (26.32)	31 (26.72)
severe asymmetry	25 (10.12)	0 (0)	4 (4.35)	21 (14.89)	0 (0)	1 (2.38)	5 (8.93)	8 (13.33)	9 (19.57)	2 (11.11)	16 (12.03)	9 (7.76)

*Gross Motor Classification System. Level I-V, where level V is describing the lowest level of functioning.

Table 5. Risk for asymmetric standing posture presented as Odds Ratios (OR) with 95% Confidence Intervals (CI), estimated for limited range of motion of the lower extremities. Presented as unadjusted and *adjusted ORs for age, sex and GMFCS level**.

	Included in analysis, n (%)	Odds ratio	95% CI	p-value
PPAS***, quality of posture – frontal plane				
Hip abduction	728 (55.7)			
unadjusted		1.67	1.220 - 2.289	0.001
adjusted*		1.39	0.994 - 1.945	0.054
Hip extension	694 (53.1)			
unadjusted		1.83	1.184 - 2.838	0.007
adjusted*		1.60	1.016 - 2.534	0.043
Knee extension	746 (57.03)			
unadjusted		2.20	1.641 - 2.950	0.000
adjusted*		1.85	1.336 - 2.574	0.000
Dorsiflexion of the foot	729 (55.7)			
unadjusted		2.13	1.362 - 3.344	0.001
adjusted*		1.98	1.256 - 3.129	0.003
PPAS***, quality of posture – sagittal plane				
Hip abduction,	728 (55.7)			
unadjusted		1.87	1.351 - 2.586	0.000
adjusted*		1.59	1.123 - 2.246	0.009
Hip extension	694 (53.1)			
unadjusted		2.18	1.136 - 3.493	0.001
adjusted*		1.95	1.197 - 3.190	0.007
Knee extension	746 (57.0)			
unadjusted		2.78	2.056 - 3.758	0.000
adjusted*		2.46	1.755 - 3.447	0.000
Dorsiflexion of the foot	729 (55.7)			
unadjusted		2.15	1.343 - 3.433	0.001
adjusted*		1.92	1.192 - 3.098	0.007

**Gross Motor Classification System. Level I-V, where level V is describing the lowest level of functioning.

***PPAS. Posture and posture ability scale. Symmetry and alignment scores 1 point and asymmetry or deviation scores 0 points for each item, giving a total score of 0-6 points.