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Original Research

Range of Motion Limitations in Middle-aged Adults With Cerebral Palsy

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KEYWORDS
Adult;
Cerebral Palsy;
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Abstract *Objective:* To describe limitations in range of motion (ROM) in middle-aged adults with cerebral palsy (CP), and identify associations with CP subtype, gross motor function, sex and age.
Design: Population-based cohort study.
Setting: Local and regional referral centers.
Participants: Inclusion criteria: diagnosis of CP, born 1959 to 1978 and living in the county of Västra Götaland, Sweden. In the population-based register of CP in Western Sweden, 417 subjects were identified and 139 volunteered to participate. Adults with CP, born elsewhere, who had moved into the area were invited through patient organizations and habilitation units, and eleven chose to participate. In total 150 participants, age 37-58 years (mean 48) 65 women (43%) (N=150). All CP subtypes and Gross Motor Function Classification (GMFCS) levels were represented.
Interventions: Not applicable
Main Outcome Measures: Passive ROM was measured in the upper and lower extremity and was classified into 4 levels (inspired by The Spinal Alignment and Range of Motion Measure and adapted from the values of the American Academy of Orthopedic Surgeons); good=1, vs mild=2, moderate=3 or severe=4 limitation. The results were summarized to obtain a total score of the participants' ROM limitations.
Results: Moderate to severe limitations were present in 98 % of the participants. There was a correlation to GMFCS level in both the upper and lower extremity ($P<.001$), but no correlation with

List of abbreviations: ADL, activity of daily living; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; ROM, range of motion; SRL, Summed ROM limitation.

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age. Upper extremity limitations were most common in dyskinetic CP, lower extremity limitations were most common in dyskinetic CP and bilateral spastic CP. Men had more limitations in the lower extremity (P=.001). The most common limitation in the lower extremity was hamstrings tightness (82%) and hip abduction (80%), and in the upper extremity, limited shoulder abduction (57%).

Conclusions: Limited ROM is common in adults with CP, most pronounced in shoulders, hip joints and hamstrings muscles, with no differences related to age in this age-span.

Cerebral palsy (CP) describes a group of permanent motor impairments due to early brain injury, which cause activity limitations across the lifespan.[1] The severity may vary from mild to severe and multiple disabilities.[2] The Surveillance of Cerebral Palsy in Europe classifies CP in subtypes depending on the dominant neurologic finding; unilateral spastic CP, bilateral spastic CP, dyskinetic CP, and ataxic CP.[3] Gross motor function can be described by the 5 level Gross Motor Function Classification System (GMFCS).[4] CP subtype according to The Surveillance of Cerebral Palsy in Europe and motor function according to GMFCS together add structure and understanding to the diagnosis and provide 1 relevant description of severity.[5]

Despite the fact that CP is a non-progressive brain injury, the consequences of CP change over time.[2] Normal ageing means deterioration of functional skills, but for many people with CP deterioration in physical ability can occur as early as around age 30, which is significantly earlier than in the general population.[6] Changes in function may be due to muscle contractures and decreased range of motion, decreased muscle strength or increased weight,[7,8] leading to pain and fatigue.[6,7] Musculoskeletal problems such as pain and reduced mobility in combination with fatigue are common at all GMFCS levels.[9,10] One longitudinal study showed that at 50 years of age, significantly more people with CP reported problems regarding pain, stiffness and balance compared to what they did 12 years earlier.[11] However, few studies describes functional ability in middle-aged or older adults with CP.

Range of motion (ROM) can be affected by limitations in the joint, increased muscle tone, muscle contractures and pain, features that are common in CP. Studies on children and adolescents with CP has shown decreasing ROM with age,[12] associated with subtype and less functional GMFCS levels.[13] Restrictions in knee joint mobility are common in the ages of 18-23 years.[14,15] One study on adults with CP found an association between GMFCS level and limited ROM in the hip and knee joint.[10] We have found no study describing the presence and severity of limitations in ROM in both upper and lower extremities of middle-aged adults with CP.

Limited ROM in the upper extremity can affect functional abilities such as reaching, maintaining hygiene, eating and fine motor skills.[16-18] Limited ROM in the lower extremity can lead to impaired functional skills such as lying, sitting, standing, and walking,[13] but may also affect activities such as dressing, picking up objects, and bathing.[19]

Many physioterapy interventions are aimed at treating muscle contractures. These interventions are time-consuming for both the patient and the phyiotherapist and can be painful for the patient.[20] There is a lack of knowledge on the amount and distribution of ROM limitations in adults with CP and their effect on daily life, a knowledge needed to be able to prioritize interventions.

In this study, which is part of the population-based study of adults with CP in western Sweden, the aim was to describe limitations in ROM in middle-aged adults with CP. A second aim was to identify associations with age, sex, CP subtype, and gross motor function.

Methods

Participants

Inclusion criteria were people with CP born 1959 to 1978 and living in the county of Västra Götaland, Sweden. Based on the CP register of Western Sweden 417 people were identified and invited to participate in the study of adults with CP, which included interviews and assessments.[21] There was no reply from 184, 86 declined, 5 were deceased, and 3 participants did not want to be measured for ROM at the time of the assessment, leaving 139 individuals. Adults with CP, born elsewhere, who had moved into the area were invited to participate in the study through patient organizations and habilitation units, and eleven chose to participate. GMFCS level was decided based on the medical interview and physical examination at the visit. Subtype was retrieved from the CP register based on medical examination in childhood and confirmed at the examination. Assessments were conducted from 2016 to 2019.

Measurements

Passive ROM was measured bilaterally in supine position with a plastic goniometer for 9 functions in the upper extremity (shoulder: flexion, abduction, external, and internal rotation; elbow: extension, flexion, and supination; wrist: extension with straight fingers and flexion) and for 10 functions in the lower extremities (hip: extension, flexion, abduction, external and internal rotation; knee: hamstrings angle, extension, and flexion; ankle: dorsiflexion with straight knee and dorsiflexion with bent knee). Angle values were recorded to the nearest degree. The measurements were made according to a standardized protocol. When measuring the hamstring angle, hip rotations, and knee flexion, the starting position of the hip was 90 degrees flexion. Results where there was a lack of 15 degrees or more to the

starting position were excluded. The same applied to dorsiflexion of the ankle with a straight knee if the extension defect of the knee was equal to or over 15 degrees. The physical examination was performed by 4 physiotherapists, all with more than 20 years' experience of working with people with CP.

Inspired by The Spinal Alignment and Range of Motion Measure,[22] which was developed to describe joint mobility in the lower extremity of children and adolescents with CP, the degrees of ROM were grouped and classified into 4 levels. The scale was modified by not using the '0' grade (no restriction of ROM and no abnormal posture) and adapted to adults using values of the American Academy of Orthopedic Surgeons.[23] Values were classified in 4 levels, with 1 being good joint mobility and 2, 3, and 4 being mild, moderate, and severe limitation, respectively. The division into levels was based on discussions with colleagues with long clinical experience of the patient group, with a focus on the adult perspective, and on studies of how much ROM is needed for activities of daily living (ADLs).[16,19,24] A mild limitation or less (levels 1 or 2), will still allow the individual to complete most of the tested daily activities in these studies, while more severe limitations (levels 3 or 4) can have a major effect on everyday activities. For exact values for each joint, see supplemental table S1 (available online only at http://www.archives-pmr.org/). To make it possible to compare ROM at a group level, the classifications of the participants' measured ROM on both sides were summarized to create a new variable of ROM limitation for the upper and lower extremity respectively, summed ROM limitation (SRL).

The study was approved by the Regional Ethics Review Board in Gothenburg, Dnr 777-13 2014-01-15 and Dnr T1037-15 2015-12-22. All participants (or their legal guardian) described in this paper have given written consent to inclusion.

Statistical analysis

As data consisted of nominal data and ordinal scales, nonparametric tests were used for statistical analysis. Differences in SRL between subtypes, GMFCS levels, and sex were analyzed with the Kruskal-Wallis test and the paired Mann-Whitney test. Spearman's rank correlation coefficient was used for finding the relationship between SRL, GMFCS levels, and age. Correlations were graded with <0.3 considered negligible, 0.3-0.5 considered low, 0.5-0.7 considered moderate, 0.7-0.9 considered high, and >0.90 considered very high correlation.[25] To investigate differences with respect to sex, age, subtype, and GMFCS level between included participants and non-participants the chi-squared test was used. Level of significance was set at $P<.05$. Statistical analyses were made with SPSS, version 26.[a]

Results

In total, 150 participants were examined, consisting of 85 men (57%) and 65 women (43%); the mean age at the time of the survey was 48 years, (SD 6:6, range 37-58y) (supplemental fig S1, available online only at http://www.archives-pmr.org/). All CP subtypes and GMFCS levels were represented. For characteristics of the participants see supplemental table S2 (available online only at http://www.archives-pmr.org/). Comparison of background variables from the CP register of Western Sweden between the study population (n=150) and nonparticipants (n=278) showed no statistical difference regarding sex and age. There was a difference between the groups regarding subtype, where dyskinetic CP occurred in a higher proportion in the study group and bilateral spastic CP in a lower proportion, and regarding GMFCS level, with fewer participants at GMFCS levels I and II and more at levels IV and V in the study group (supplemental table S2, available online only at http://www.archives-pmr.org/).

Out of all 150 participants, only 3 (2%) did not have any moderate or severe limitations (level 3 or 4) and 97 (65%) had at least 5 measured limitations at these levels. How the level of limitation for each measured ROM was distributed is presented in table 1 and figure 1. Limited ROM was more common and more severe in the lower extremity than in the upper extremity. Regarding the upper extremity, more than 80% had good joint mobility in elbow flexion and wrist flexion. Limitations were most frequent in shoulder abduction (57%) and internal rotation (54%). Limitations were also more severe in shoulder abduction, classified as moderate to severe in 19%. Regarding the lower extremity, knee flexion was least affected, with more than 70% of the participants graded as having good joint mobility. Most limitations were found in the hamstrings angle, where 82% showed some limitation, 52% graded as moderate to severe. For hip abduction, 80% had some form of limitation and for internal rotation 74%, with more than 40% moderate to severe. In hip flexion, knee extension, and dorsiflexion of the ankle, both with a straight and a bent knee, more than 20% had moderate to severe limitations. It was not possible to measure hip extension and ankle dorsiflexion with a straight knee in many participants because of difficulties in assuming the correct starting position, leading to missing data in 20% for these movements.

Results from calculation of summed ROM limitation (SRL) are presented in table 2 and the distribution of levels are presented in figure 2. In the calculation of SRL, hip extension and ankle dorsiflexion with a straight knee were excluded because of the amount of missing data (see table 1). As a result, the total number of measurements included in the SRL was 18 for the upper extremity, with a maximum sum of 72 (indicating severe limitation in all ROM functions) and 16 for the lower extremity, with a maximum sum of 64. Participants with less than 18 measured functions for the upper and 16 for the lower extremity have been excluded from the statistical analysis, leaving 133 participants for the upper and 127 for the lower extremity to be included. Excluded participants were mainly at GMFCS level V, 6/17 for the upper extremity and 13/23 for the lower; the majority of excluded participants were of dyskinetic CP subtype. The median value for the upper extremity in total was 24 and was 29 for the lower extremity.

There was a visible trend toward more limitations in individuals at a more severe GMFCS level, with a low correlation for the upper extremity (rho=0.460, $P<.001$) and moderate for the lower extremity (rho=0.563, $P<.001$). Comparison between the different subtypes showed that limitations in the upper extremity were most common in participants with

Table 1 ROM in the upper and lower extremity, classified into four levels based on severity of limitation.

Shoulder	Level 1 Good mobility n (%)	Level 2 Mild limitation n (%)	Level 3 Moderate limitation n (%)	Level 4 Severe limitation n (%)	Missing data n %
Flexion	159 (53)	112 (37)	16 (5)	11 (4)	2 (1)
Abduction	126 (42)	113 (38)	42 (14)	16 (5)	3 (1)
External rotation	208 (69)	59 (20)	22 (7)	5 (2)	6 (2)
Internal rotation	128 (43)	130 (43)	31 (10)	3 (1)	8 (3)
Elbow					
Extension	211 (70)	54 (18)	24 (8)	9 (3)	2 (1)
Flexion	252 (84)	41 (14)	2 (1)	1 (0)	4 (1)
Wrist					
Extension	229 (76)	39 (13)	14 (5)	8 (3)	10 (3)
Flexion	246 (82)	35 (12)	8 (3)	1 (0)	10 (3)
Supination	206 (69)	49 (16)	26 (9)	6 (2)	13 (4)
Hip					
Extension	47 (16)	138 (46)	49 (16)	5 (2)	61 (20)
Flexion	123 (41)	93 (31)	57 (19)	26 (9)	1 (0)
Abduction	56 (19)	119 (40)	104 (35)	15 (5)	7 (2)
External rotation	137 (46)	95 (32)	34 (11)	8 (3)	26 (9)
Internal rotation	52 (17)	89 (30)	90 (30)	42 (14)	27 (9)
Knee					
Hamstrings	33 (11)	91 (30)	106 (35)	51 (17)	19 (6)
Extension	152 (51)	84 (28)	42 (14)	20 (7)	2 (1)
Flexion	221 (74)	47 (16)	19 (6)	6 (2)	7 (2)
Ankle					
Dorsiflexion with straight knee	42 (14)	113 (38)	76 (25)	7 (2)	62 (21)
Dorsiflexion with bent knee	130 (43)	90 (30)	60 (20)	13 (4)	8 (3)

NOTE: All participants are measured on both the right and left side, total number of measurements n=300. Data are reported as number (%). For exact values for each function, see supplemental table S1 (available online only at http://www.archives-pmr.org/).

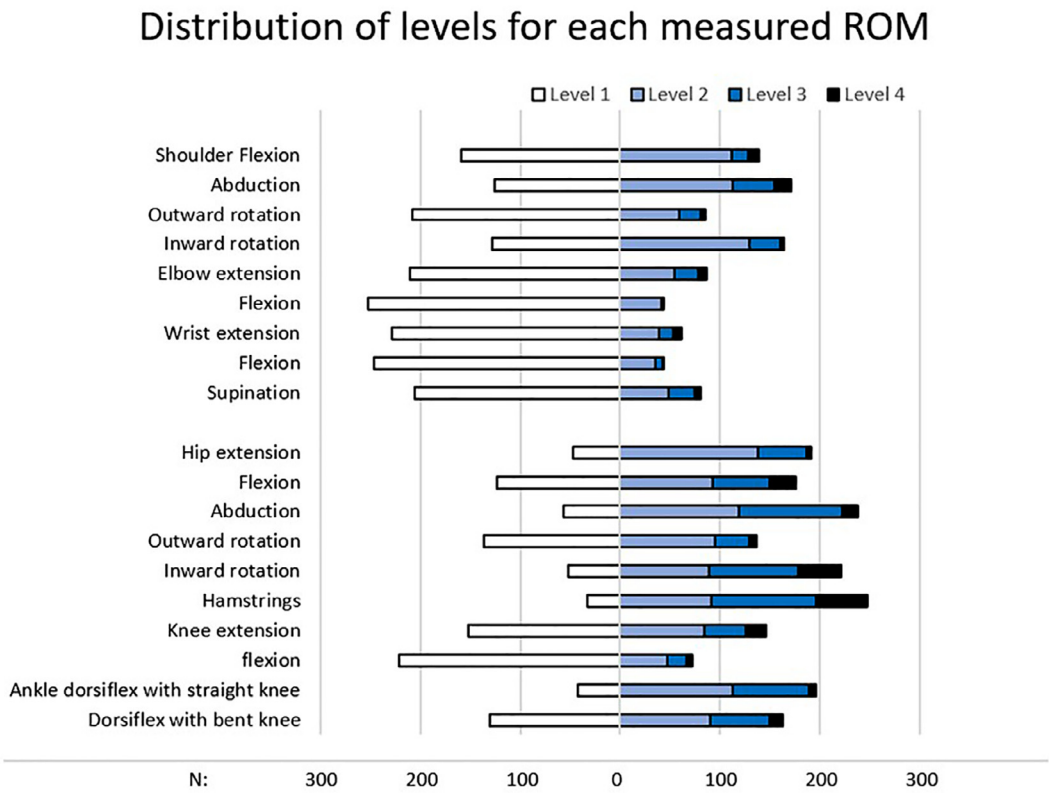

Fig 1 ROM in the upper and lower extremity, classified into four levels based on severity of limitation: 1=good ROM, 2=mild limitation, 3=moderate limitation, and 4=severe limitation. Level 1=good ROM is displayed to the left and the limitation levels 2-4 to the right. All 150 participants are measured on both the right and left side, for a total of 300 measurements.

Table 2 SRL for the upper and lower extremity, reported as median and IQR in relation to CP subtype and GMFCS level.

		SRL					
	Study population n=150 (%)	Upper extremity			Lower extremity		
Subtype		n	median	IQR	n	median	IQR
USCP	62 (41)	58	23	6	60	26	7
BSCP	53 (35)	50	23.5	8	44	34	12
DCP	29 (19)	22	28	12	17	31	12
ACP	6 (4)	3	20	.	6	28	13
GMFCS							
I	60 (40)	59	22	5	58	26	6
II	28 (19)	26	23	6	28	31	9
III	20 (13)	16	25.5	7	17	30	15
IV	25 (17)	21	29	12	20	38	9
V	17 (11)	11	33	12	4	34	16

NOTE: For the upper extremity 17 participants were excluded and for the lower extremity 23 participants.
Abbreviations: ACP, ataxic cerebral palsy; BSCP, bilateral spastic cerebral palsy; DCP, dyskinetic cerebral palsy; IQR, interquartile range; USCP, unilateral spastic cerebral palsy

dyskinetic CP and in the lower extremity limitations were most common in bilateral spastic CP and dyskinetic CP. (table 2, fig 2).

There was a sex difference for the lower extremity regarding SRL, where the median value for men (31) was higher than for women (27) (*P*=.001). The difference for the upper extremity was not significant (*P*=.349). There was negligible correlation between SRL and age in the age span of the group (upper extremity rho=0.025, *P*=.778; lower extremity rho=0.043, *P*=.635).

Discussion

This descriptive study showed that limited ROM was common in middle-aged adults with CP, more common with increasing

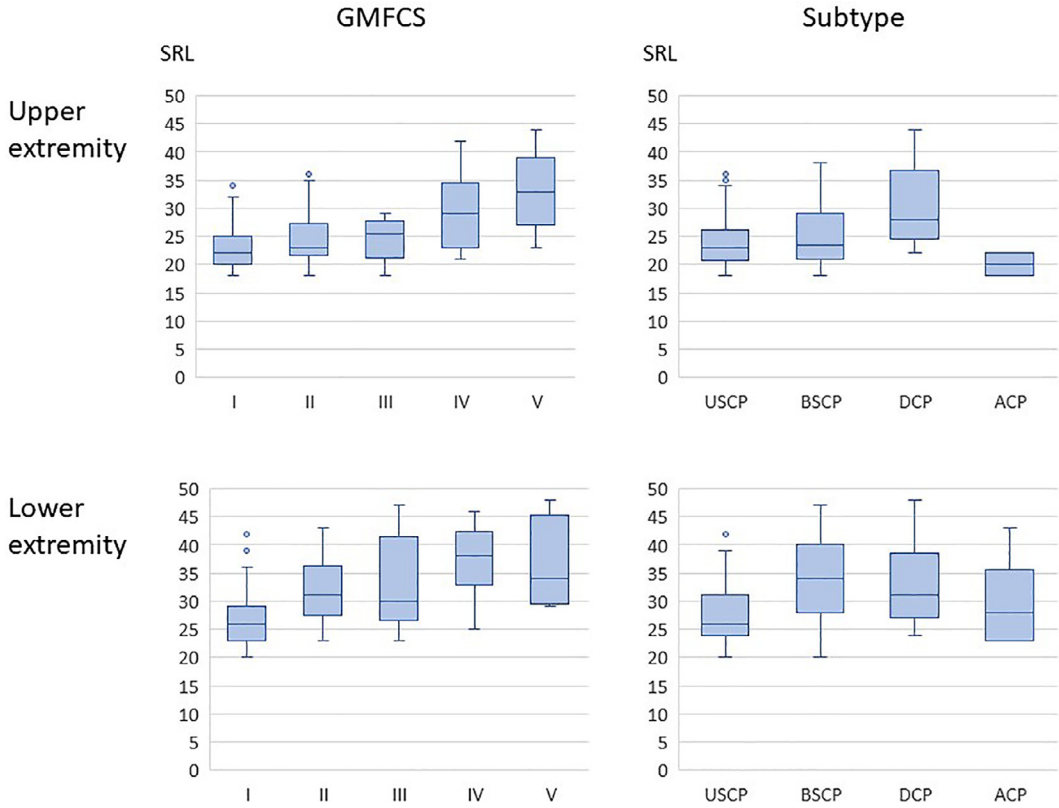

Fig 2 Box and whisker plots showing median and percentiles of summed ROM limitation (SRL) in the upper and the lower extremity for GMFCS levels I-V and for subtypes: USCP (unilateral spastic cerebral palsy), BSCP (bilateral spastic cerebral palsy), DCP (dyskinetic cerebral palsy), ACP (ataxic cerebral palsy).

motor severity. There were differences between subtypes with dyskinetic CP having more limitations in the upper extremity, and, in the lower extremity, bilateral spastic CP and dyskinetic CP had more limitations. Men tended to have more limitations than women in the lower extremity.

The limitations did not increase with age in this group of persons between 37 and 58 years of age, contrary to previous longitudinal studies of children and adolescents, all reporting that limitations increase with age,[12,13,26] suggesting that most limitations arise at younger ages. This is important knowledge pointing to the importance of early intervention to prevent contractures.

The classification of ROM aimed to describe limitation based on its possible effect on everyday life, with levels 3 and 4 potentially affecting motor function. Kinematic studies have presented minimum ROM ranges to be able to complete selected ADL in healthy adults such as eating, toileting, and reaching. However, they differ in exact degrees and in their definition of movements.[16-18] In the upper extremity it is particularly difficult to describe the amount of ROM needed for daily activities because of the complexity of movement patterns. In the lower extremity, while it is known how much ROM is needed for walking,[24] few studies describe the ROM needed for activities such as dressing, putting on shoes, toileting, taking a bath, or picking up objects from the floor.[19] A hip extension deficit can also lead to an asymmetrical position in lying and the so-called windswept position.[14] In our study, the 3 most common limitations in the upper extremity were in the shoulder (abduction, internal rotation, and flexion), limitations that can lead to reduced independence in activities such as going to the toilet and maintaining hygiene.[17] Limitations in the lower extremity were most pronounced for the hamstrings and hip abduction, which may have a major effect on the sitting position, and activities such as dressing and hygiene. Especially for individuals at GMFCS level IV and V, stable sitting is vital for many everyday activities, and a prerequisite for these activities is to be able to use hands and eyes in a purposeful manner. Comparing our classification to values on how much is needed for ADL[16,19,24] confirmed that level 1-2, a mild limitation or less, is required to complete most of the tested daily activities in these studies. However, for adults with CP who already have small margins, even mild limitations in combination with reduced muscle strength, fatigue, pain, and impaired balance can affect independence in everyday activities.[6,7] To what extent the ROM limitations had an effect on the participants' daily activities was not part of this study but would be interesting to explore in future studies.

Reporting the summarized score, SRL, for the upper and lower extremities respectively, was a way of achieving a more overall picture of the participants' difficulties and make it easier to compare on a group level. There was a moderate correlation between GMFCS level and limitations of ROM in in the lower extremity. Not surprisingly, the correlation between GMFCS level and SRL in the upper extremity was low, as arm function is less vital for gross motor function. The correlation between GMFCS level and limited ROM is similar to previous studies.[10,26]

Comparison between subtypes showed that people with dyskinetic CP had more limitations in the upper extremity, similar to findings from Hedberg-Graff.[12] There was a significant difference between dyskinetic CP and the spastic subtypes, and a little unexpected that dyskinetic CP, with tone change and constant movements having more limitations than bilateral spastic CP. The presence in dyskinetic CP of primitive reflexes, such as the asymmetrical and symmetrical tonic neck reflex, may lead to muscle contractures. Moreover, co-occurring spasticity, which may lead to contractures, was found in 70% of children with dyskinetic CP in a population-based study.[27] Furthermore, there were more participants with dyskinetic CP being excluded because of pain and difficulties to assume the correct starting position, which may lead to an underestimation of the problem. Participants with ataxic CP were very few, making it difficult to draw conclusions about this group.

In the present study, men had significantly more limitations than women in the lower extremity. Sex differences have also been noted in studies of adults with no motor problems,[28,29] where women had better mobility in plantar flexion and hip flexion, while men had better internal and external rotations in the hip,[28] and mobility was almost equal between men and women for the upper extremity, which is similar to the findings in our study.[29]

Study limitations

This is a cross-sectional study and did not assess changes in the ROM of individual subjects as they age, which limits the generalizability.

All subtypes were represented in the study. However, there was a difference between participants and non-participants regarding subtype. In the study group, there was an over-representation of participants with dyskinetic CP. All participants were measured bilaterally, which meant that the group with unilateral spastic CP could not be distinguished in the study.

When analyzing the SRL, hip extension and ankle dorsiflexion with a straight knee were excluded because of the amount of missing data. Causes of exclusion were pain and contractures in adjacent joints that prevented the correct position for the measurement, mostly because of more than 15 degrees limitation in knee extension. Participants where 1 or more joints could not be measured were also excluded. These factors may lead to an underestimation of the number of limitations, as a large majority of the participants that were excluded were classified at GMFCS level V, which also affected the results when comparing GMFCS levels.

Conclusions

The study provides an overview of ROM in middle-aged adults with CP, where limited ROM is common, most pronounced in shoulder and hip joints, including hamstrings muscles. The finding that there were no significant differences related to age in this group differs from studies in children and young adults where deterioration increases with age. The study provides valuable knowledge both to the individual and to health professionals on what to focus on in in earlier ages to prevent problems later in life. For most of the participants in our study, specialized follow-up was discontinued when they turned 18. As adults, many have not

had any contact with health professionals specialized in CP. In the future, these results may serve as comparison in the evaluation of if more recent follow-up programs, such as the Swedish surveillance program for people with CP,[30] can affect the development of joint mobility and its effect on everyday life.

Suppliers

a. SPSS version 26; IBM

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