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Severe hip displacement reduces health-related quality of life in children with cerebral palsy

A population-based study of 67 children

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Background and purpose — Hip displacement is common in children with severe cerebral palsy (CP) and can cause problems such as pain, contractures, and nursing difficulties. Caregiver priorities and child health index of life with disabilities (CPCHILD) is a recently developed measure of health-related quality of life (HRQL) in children with severe CP. The associations between CPCHILD scores and hip displacement have not been investigated. We explored the effect of hip displacement on HRQL.

Patients and methods — 67 children were recruited from the population-based Norwegian CP register. Mean age was 9 (7–12) years. There were 40 boys. Gross motor function classification system (GMFCS) distribution was 12 level III, 17 level IV, and 38 level V. Hip displacement was assessed by radiographic migration percentage (MP). The criterion for hip displacement was MP of the worst hip of ≥ 40%. Primary caregivers responded to 5 of the 6 domains of the CPCHILD questionnaire.

Results — Hip displacement was found in 18 children and it was significantly associated with lower scores on the CPCHILD domains 3 (Comfort and Emotions) and 5 (Health), but not with domains 1 (Activities of Daily Living/Personal Care), 2 (Positioning, Transfer, and Mobility), and 6 (Overall Quality of Life). GMFCS level V was a significant predictor of low scores in all the domains.

Interpretation — For the assessment of HRQL in children with severe CP and hip problems, we propose a modified and simplified version of the CPCHILD consisting of 14 of 37 questions. This would reduce the responders' burden and probably increase the response rate in clinical studies without losing important information.

Hip displacement is one of the major health issues in non-ambulatory children with cerebral palsy (CP). The incidence increases with decreasing gross motor function (Hägglund et al. 2007, Terjesen 2012) and is approximately 70% in children at Gross Motor Function Classification System (GMFCS) level V (Palisano et al. 1997). Untreated hip dislocation is associated with serious problems such as hip pain, adduction contractures, impaired sitting balance, difficult perineal nursing care, pelvic obliquity, scoliosis, and decubitus ulceration (Samilson et al. 1972, Knapp and Cortes 2002). Hip surveillance programs recommend consultation with an orthopedic surgeon when hip displacement (migration percentage (MP)) exceeds 33% (Mugglestone et al. 2012), and surgery aimed at improving hip containment is recommended when hip displacement reaches 40% (Dobson et al. 2002, Hägglund et al. 2005, Terjesen 2012).

As there is a significant association between severe hip displacement and hip pain (Ramstad and Terjesen 2016), changes in hip pain could be used as an outcome measure after surgery or other forms of treatment intended to reduce hip displacement. Another outcome measure would be the child's health-related quality of life (HRQL), since this would probably reflect a broader and more comprehensive evaluation of the patient's health status and functional and emotional problems. To evaluate HRQL in children with CP, the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) was developed and validated for severely impaired children (Narayanan et al. 2006, Jung et al. 2014). A systematic review of quality of life (QOL) outcome measures for children with CP identified the CPCHILD as 1 of 2 outcome measures with the strongest psychometric properties and clinical utility (Carlon et al. 2010).

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Table 1. Children with cerebral palsy (GMFCS III–V, age 7–12 years): participants in the study compared to non-responders

	Participants, n	Non-responders, n	p-value
Sex			0. 9
Boys	40	42	
Girls	27	27	
Age in years (mean, SD)	9.1 (1.4)	9.4 (1.6)	0.4
CP type			0.1
Spastic diplegia	18	21	
Spastic quadriplegia	36	26	
Bilateral dyskinetic	13	19	
Ataxic	0	3	
Ambulation			0.3
GMFCS III	12	20	
GMFCS IV	17	17	
GMFCS V	38	32	

GMFCS: gross motor function classification system.

The CPCHILD is a comprehensive questionnaire with 37 items distributed over 6 domains. This might contribute both to reduced responsiveness to change and reduced feasibility compared to a more targeted questionnaire. In the present study, we reduced the CPCHILD somewhat and used it in children with severe CP. We hypothesized that positioning of the hip is an important factor for scores on certain domains, but not for all.

The aim of the study was to explore the effect of hip displacement on HRQL, using selected domains of the CPCHILD questionnaire.

Patients and methods

This was a population-based cohort study of HRQL in children with CP. Potential participants were children enrolled in the Norwegian CP follow-up program (CPOP) (Terjesen 2012), born 2002–2006, with bilateral CP, gross motor function GMFCS III–V, and living in 1 of the 10 south-eastern counties of Norway. Invitations were sent to caregivers of the 139 children identified, in September 2013. 3 children had been operated with femoral head resection and were not included. Of the remaining 136 children, 67 (49%) participated in the study. There were 27 girls and 40 boys, and their mean age was 9 (7–12) years.

Data on diagnosis and classification of CP according to international consensus (Rosenbaum et al. 2007) and the International Classification of Diseases (ICD-10) (World Health Organisation 2010) and GMFCS level (Palisano et al. 1997) were retrieved from the CPOP register for all invited children. A comparison between participants and non-responders showed no statistically significant differences (Table 1). For participants, data on hip surgery were retrieved from the medical records. 38 children had undergone surgery to correct hip displacement.

The CPCHILD questionnaire (Narayanan et al. 2006) consists of 37 items distributed over 6 domains: (1) Activities of Daily Living/Personal Care (9 items); (2) Positioning, Transfer, and Mobility (8 items); (3) Comfort and Emotions (9 items); (4) Communication and Social Interaction (7 items); (5) Health (3 items); and (6) Overall Quality of Life (1 item). Scores for each domain are standardized and range from 0 (worst) to 100 (best). In the present study, domain 4 was omitted because it consists of items (difficulties in understanding, playing, attending school, and attending recreational activities) which we thought would be less relevant to hip displacement.

In domains 1 and 2, lists of activities (items) are given. Caregivers were asked to rate how difficult each activity was to perform during the previous 2 weeks on a 7-point scale, from impossible (0) to very easy (6), and to choose the level of assistance that was required to help the child perform the activity on a 4-point scale from totally dependent (0) to independent (3). Domain 1 items are feeding, maintaining oral hygiene, bathing and washing, toilet activities, changing diapers and underwear, putting on and taking off upper body and lower body clothing, putting on and wearing footwear, and hair care. Domain 2 items are getting in and out of bed, transferring in and out of a wheelchair or chair, standing for exercise and transfers, moving about in the home, moving about out of doors, getting in and out of a motor vehicle, and visiting public places. In domain 3, the items are: "How often did your child experience discomfort or pain during eating, toileting, clothing, transfers, sitting, lying, and sleeping?", followed by 2 questions on the child being agitated or sad. Both the frequency and the intensity of the discomfort or emotional or behavioral problem is rated. The items in domain 5 are: "How many times has your child had to visit the doctor or the hospital in the past 2 weeks? How would you rate your child's overall health?" (0–5 scale) and "List the medications your child has been taking in the past 2 weeks." The only item of domain 6 is "How would you rate your child's quality of life?" (0–5 scale). The CPCHILD was translated into Norwegian in 2011, including back translation, consensus, and piloting (Åslund et al. 2011). Test-retest reliability showed satisfactory results, with high reliability for both total scores and domain scores (Bjerke 2014).

An anteroposterior radiograph of the pelvis and hip joints with the child in supine position was obtained. Care was taken to position the child correctly with the legs parallel, and to avoid rotation of the pelvis and legs. The radiographs were sent to and stored in our Picture Archiving and Communication System (PACS; Sectra, Linköping, Sweden) and measured by one of the authors (TT), who has many years of experience in measuring radiographs of children's hips. The radiographs were enlarged 2-fold to obtain better visualization of the landmarks, and measurements were performed digitally with the standard equipment in PACS. For the present study, we used the radiograph taken nearest to the time the questionnaire was

answered. The mean length of time between radiograph and questionnaire was 5.4 (0–25) months, and no surgery was performed during this interval.

MP was measured in both hips according to Reimers (1980). MP is the percentage of the femoral head lateral to the acetabulum (lateral to Perkins' line), measured parallel to Hilgenreiner's line. For the present study, we used the worst hip (with highest MP) in each child. Depending on their MP, the hips were classified as normal (no or slight displacement) when MP was < 40% and as displaced when MP was ≥ 40%.

Statistics

Participants in the study and non-responders were compared with Pearson chi-square tests (for categorical outcome variables) and the independent-samples t-test (for continuous outcome variables). Distribution of CPCHILD domain and item scores was analyzed using independent-samples t-tests (Tables 2 and 3), 1-way ANOVA with Scheffe's post hoc tests, and using multivariable linear regression (Table 4). Correlations were assessed with Pearson's correlation coefficient (r). All tests were 2-sided. A significance level of 0.05 was chosen. SPSS software, version 21, was used for the statistical analysis.

Ethics

The study protocol was approved by the Regional Committee for Research Ethics (ref. 2012/2258 REK). The caregivers gave written informed consent before participation in the study.

Table 2. CPCHILD domain scores: associations with GMFCS level and hip displacement (MP)

Domain	mean	Score mean diff., 95% CI	p-value
Activities of Daily Living/Personal Care (1)			
GMFCS III	51	10 (–4 to 24)	0.2 (III vs. IV)
GMFCS IV	41	4 (–6 to 15)	0.7 (IV vs. V)
GMFCS V	37	14 (2 to 26)	0.2 (III vs. V)
MP < 40	42	7 (–1 to 15)	0.1
MP ≥ 40	35		
Positioning, Transfer and Mobility (2)			
GMFCS III	63	23 (10 to 36)	< 0.001 (III vs. IV)
GMFCS IV	40	8 (–2 to 18)	0.1 (IV vs. V)
GMFCS V	32	31 (20 to 43)	< 0.001 (III vs. V)
MP < 40	42	9 (–1 to 18)	0.1
MP ≥ 40	33		
Comfort and Emotions (3)			
GMFCS III	87	11 (–4 to 27)	0.2 (III vs. IV)
GMFCS IV	75	8 (–4 to 20)	0.3 (IV vs. V)
GMFCS V	67	19 (5 to 33)	0.004 (III vs. V)
MP < 40	78	18 (9 to 27)	< 0.001
MP ≥ 40	60		
Health (5)			
GMFCS III	95	14 (–3 to 32)	0.1 (III vs. IV)
GMFCS IV	81	23 (10 to 37)	< 0.001 (IV vs. V)
GMFCS V	57	38 (23 to 53)	< 0.001 (III vs. V)
MP < 40	75	18 (6 to 30)	0.004
MP ≥ 40	57		
Overall Quality of Life (6)			
GMFCS III	80	6 (–16 to 28)	0.8 (III vs. IV)
GMFCS IV	74	15 (–2 to 32)	0.09 (IV vs. V)
GMFCS V	59	22 (2 to 41)	0.03 (III vs. V)
MP < 40	69	9 (–5 to 23)	0.2
MP ≥ 40	60		

GMFCS: gross motor function classification system.
MP: hip displacement expressed as migration percentage.

Results

The hip with the highest MP was normal in 49 children and displaced in 18 children. The numbers of children with displaced hips were 0 of 12 at GMFCS level III, 4 of 17 at GMFCS level IV, and 14 of 38 at GMFCS level V. MP of the hip with the highest MP in operated and unoperated children was similar (p = 1.0). Hip displacement was statistically significantly associated with lower score on domain 3 (Comfort and Emotions) and 5 (Health) (p < 0.001 and p = 0.004, respectively) (Table 2). Participants with hip displacement had lower scores on all other domains as well, but the differences did not reach statistical significance (with p-values of 0.1–0.2). Participants at GMFCS level V had lower scores in all domains compared with participants at level III (Table 2), whereas the differences between level IV and V were statistically significant only in domain 5. Sex, age, and previous hip surgery were not statistically significantly associated with any of the domain scores.

Within domain 3, hip displacement was statistically significantly associated with lower scores on the Toileting, Clothing, Transfers, Sitting, Lying, and Sleeping items, but not regarding the items Eating, Agitated, and Unhappy (Table 3). Participants at GMFCS level V had lower scores than those at level III in all items except Agitated and Unhappy. Sex, age, and previous hip surgery had no statistically significant associations with any of the domain 3 items.

In order to eliminate the effect of confounding factors when analyzing risk factors for low scores on the CPCHILD domains, multivariable regression analysis was used (Table 4). GMFCS level V was a statistically significant independent risk factor for low scores in all 5 domains. Hip displacement was a statistically significantly independent risk factor in domain 3 only.

The mean total score of the 5 domains examined was 58. The total scores for GMFCS III, IV, and V were 75, 62, and 50, respectively. Mean scores on each CPCHILD domain were: Personal Care: 40 (SD 16); Positioning, Transferring, and Mobility: 39 (SD 18); Comfort and Emotions: 73 (SD 18); Health: 70 (SD 24); and Overall Quality of Life: 66 (SD 24). There were statistically significant correlations between all 5 domains (r = 0.73–0.29; p < 0.001 to 0.02). Mean domain scores for participants at GMFCS V were compared with those given for children at GMFCS V in the CPCHILD manual (Narayanan et al. 2007) (Table 5). The difference was

Table 3. Associations of CPCHILD Comfort and Emotion item scores with GMFCS level and hip displacement (MP)

Item	mean	Score mean diff., 95% CI	p-value
Eating			
GMFCS III	96	8 (–13 to 29)	0.6 (III vs. IV)
GMFCS IV	88	11 (–5 to 28)	0.2 (IV vs. V)
GMFCS V	77	19 (1 to 38)	0.04 (III vs. V)
MP < 40	86	10 (–3 to 22)	0.1
MP ≥ 40	76		
Toileting			
GMFCS III	96	18 (–3 to 40)	0.1 (III vs. IV)
GMFCS IV	78	8 (–9 to 24)	0.5 (IV vs. V)
GMFCS V	71	26 (7 to 45)	0.01 (III vs. V)
MP < 40	84	25 (14 to 38)	< 0.001
MP ≥ 40	59		
Clothing			
GMFCS III	98	14 (–8 to 35)	0.3 (III vs. IV)
GMFCS IV	84	13 (–4 to 30)	0.2 (IV vs. V)
GMFCS V	71	27 (8 to 45)	0.003 (III vs. V)
MP < 40	86	27 (15 to 39)	< 0.001
MP ≥ 40	60		
Transfers			
GMFCS III	88	8 (–12 to 29)	0.6 (III vs. IV)
GMFCS IV	80	13 (–2 to 30)	0.1 (IV vs. V)
GMFCS V	67	22 (4 to 40)	0.01 (III vs. V)
MP < 40	80	22 (10 to 33)	< 0.001
MP ≥ 40	58		
Sitting			
GMFCS III	100	20 (–2 to 43)	0.09 (III vs. IV)
GMFCS IV	80	10 (–7 to 28)	0.3 (IV vs. V)
GMFCS V	70	31 (11 to 50)	0.001 (III vs. V)
MP < 40	82	17 (3 to 31)	0.02
MP ≥ 40	65		
Lying			
GMFCS III	75	18 (–5 to 41)	0.2 (III vs. IV)
GMFCS IV	57	3 (–14 to 21)	0.9 (IV vs. V)
GMFCS V	53	21 (1 to 41)	0.04 (III vs. V)
MP < 40	64	21 (8 to 34)	0.002
MP ≥ 40	43		
Sleeping			
GMFCS III	95	19 (–9 to 47)	0.3 (III vs. IV)
GMFCS IV	77	15 (–7 to 36)	0.2 (IV vs. V)
GMFCS V	62	34 (9 to 58)	0.004 (III vs. V)
MP < 40	79	28 (12 to 44)	0.001
MP ≥ 40	51		
Agitated			
GMFCS III	60	4 (–21 to 28)	0.9 (III vs. IV)
GMFCS IV	61	–4 (–23 to 15)	0.9 (IV vs. V)
GMFCS V	65	–1 (–22 to 20)	1.0 (III vs. V)
MP < 40	65	5 (–10 to 19)	0.5
MP ≥ 40	60		
Unhappy			
GMFCS III	66	–7 (–31 to 18)	0.8 (III vs. IV)
GMFCS IV	72	2 (–17 to 22)	1.0 (IV vs. V)
GMFCS V	70	–4 (–26 to 17)	0.9 (III vs. V)
MP < 40	71	5 (–9 to 20)	0.5
MP ≥ 40	66		

GMFCS: gross motor function classification system.
MP: hip displacement expressed as migration percentage.

less than 4 in domains 2, 3, 5, and 6. In domain 1, the mean score of the study participants was 5.8 points higher than that of the reference population.

Table 4. Associations between hip displacement and GMFCS levels and scores on the 5 CPCHILD domains, assessed by multivariable linear regression

CPCHILD domain	Beta (95% CI)	p-value
If MP ≥ 40%		
Activities of Daily Living/ Personal Care	–3.7 (–12.0 to 4.7)	0.4
Positioning, Transfer and Mobility	–1.0 (–9.1 to 7.0)	0.8
Comfort and Emotions	–14.1 (–23.1 to –5.1)	0.003
Health	–8.4 (–18.7 to 1.9)	0.1
Overall Quality of Life	–3.3 (–16.8 to 10.3)	0.6
Increasing GMFCS level		
Activities of Daily Living/ Personal Care	–6.0 (–10.8 to –1.2)	0.02
Positioning, Transfer and Mobility	–14.2 (–18.8 to –9.6)	< 0.001
Comfort and Emotions	–6.9 (–12.0 to –1.7)	0.01
Health	–18.2 (–24.1 to –12.2)	< 0.001
Overall Quality of Life	–10.7 (–18.5 to –2.9)	0.008

GMFCS: gross motor function classification system;
MP: migration percentage

Table 5. CPCHILD domain scores for children at GMFCS V and corresponding scores given in the CPCHILD manual (Narayanan et al. 2007). Values are mean (SD)

CPCHILD domain	Study sample (n = 38)	CPCHILD manual sample (n = 35)
Activities of Daily Living/Personal Care	37 (14)	31 (15)
Positioning, Transfer and Mobility	32 (14)	28 (14)
Comfort and Emotions	67 (20)	68 (23)
Communication and Social Interaction	Not examined	43 (24)
Health	57(22)	57 (17)
Overall Quality of Life	59 (27)	55 (25)

Discussion

When planning this study, we searched for a HRQL measure that included items of special clinical relevance to hip displacement and assumed that the CPCHILD would be promising for that purpose. We realized that the CPCHILD domains 1–3 and 5–6 reflect positioning of the hips and/or pain or discomfort, and included them in the study. This assumption was probably correct regarding domains 3 and 5, since hip displacement in terms of MP ≥ 40% predicted lower scores in these domains. We omitted domain 4 (Communication and Social Interaction). The items of this domain are about difficulties in understanding, playing, attending school, and attending recreational activities, which we thought would be less relevant to hip displacement. This assumption may have been wrong, as after we had decided our study design Jung et al. (2014) reported that scores on domain 4 were significantly associated with hip displacement.

The 5 CPCHILD domain scores used in our study were all influenced by GMFCS levels, with level V being a risk factor for poor HRQL. This is in accordance with the CPCHILD total score in the initial validation of the questionnaire (Narayanan et al. 2006). For participants at GMFCS level V, the domain scores were comparable to those given in the CPCHILD manual and interpretation guide (Narayanan et al. 2007), with the exception of the Activities of Daily Living/Personal Care domain, where we had a somewhat higher score. A recent Dutch study of 66 non-walking children with CP also found that GMFCS V predicted low CPCHILD total score and low score on domain 1 (Elema et al. 2016). In that study, socioeconomic factors were included in addition to child characteristics. 28 participants had MP ≥ 30%, but the influence of MP on CPCHILD scores was not analyzed.

We found a statistically significant association between hip displacement and domain 3 (Comfort and Emotions) score, as opposed to previous reports. An Australian study of 26 children with CP at GMFCS levels IV–V (Zarrinkalam et al. 2011) and a German study of 34 children with CP at GMFCS levels III–V (Jung et al. 2014) found no such association. Since these studies did not report the separate CPCHILD domain scores, direct comparisons could not be made. The different results could be due both to differences in hip displacement and to type-II error because of small study samples (few patients with MP > 40%). CPCHILD scores in patients with MP > 40% were similar to scores in participants at GMFCS level V in all domains except domain 3. This could indicate that GMFCS level V was a confounding factor, tending to both increase MP and decrease CPCHILD scores. However, most participants at GMFCS level V did not have displaced hips, and the possible confounding effect of GMFCS levels was eliminated in the multivariable regression analysis (Table 4). This supports the assumption that hip displacement had an independent effect on certain CPCHILD scores.

The present study had several limitations. Firstly, the response rate was 49%, which may have reduced the reliability of the results. However, there were no significant differences in demographic and clinical data between participants and non-participants. The number of participants in our study was greater than in previous studies that have used CPCHILD to examine the effects of hip displacement on HRQL in children with CP (Zarrinkalam et al. 2011, Jung et al. 2014). Still, further studies with a larger number of participants are needed to explore associations between hip displacement and CPCHILD scores. Secondly, self-reporting was not obtained, even though we cannot exclude the possibility that some of the children would have been able to self-report. Still, assessment of HRQL in severely disabled children often has to rely on observation of behavior, because the child is not able to communicate verbally. Thirdly, our results do not represent the natural history of hip migration since more than half of the children had undergone surgical treatment to avoid deterioration of their hips. Finally, a CPCHILD total score could not be given because domain 4 was omitted. However, for the other domains, there was a good accordance between scores in our study sample and those in previous studies. The main strength of the study was that participants were recruited from a population-based CP register. To our knowledge, this is the first population-based study on the association between hip displacement and CPCHILD scores.

In targeting patient-reported outcome measures in patients with hip problems, we consider that classifications with the ability to detect significant differences in HRQL when using MP > 40% as a cutoff value for hip displacement is preferable, since this limit is in accordance with recommendations for hip surgery (Dobson et al. 2002, Hägglund et al. 2005, Terjesen 2012). Our ambitions in using a reduced version of the CPCHILD were to include only domains of importance for children with hip displacement, and to reduce the the workload of the responders when answering the questions. During development of the CPCHILD (Narayanan et al. 2006), caregivers rated the importance of each item's contribution to their child's QOL. Items relating to domains 3 and 4 were considered to be more important than items relating to domains 1 and 2. Since the latter 2 domains were not significantly associated with hip displacement, either in the present study or 2 previous studies (Zarrinkalam et al. 2011, Jung et al. 2014), they could be omitted. Domain 3, which relates to pain and discomfort, was significantly related to hip problems in our study and should therefore be part of a simplified questionnaire. However, 2 of the items (Agitated and Unhappy) had no associations with MP and could be omitted. Domain 4 could be included in a simplified questionnaire, since it was found to correlate with hip migration by Jung et al. (2014), although 3 of the items (difficulties in understanding and being understood) seem less relevant to hip problems. Domain 5 was of importance in both our study and that of Jung et al. (2014), and should therefore be included, whereas domain 6 could be omitted since it was of no significant relevance (Jung et al. 2014, Zarrinkalam et al. 2011). An additional argument for reducing the number of domains is that there were significant correlations between all 5 domains in our study, and between the Comfort and Emotions domain and Health domain and the other domains in a previous report (Zarrinkalam et al. 2011). Thus, a simplified version of the CPCHILD questionnaire, targeted to children with hip problems, could include 7 of the 9 items of domain 3 (Pain and Discomfort), 4 of the 7 items of domain 4 (Communication and Social Interaction), and the 3 items of domain 5 (Health), thus reducing the total number of items from 37 to 14. This modified and simplified version would reduce the responders' burden substantially and probably increase the response rate in clinical studies without losing important information. On the other hand, if one prefers a more comprehensive assessment of the child's HRQL, the full CPCHILD questionnaire should be used.

KR initiated and planned the study, performed the clinical part of the study, analyzed the data, and wrote the manuscript. RBJ contributed to planning of the study and revision of the manuscript. TT initiated and planned the study, performed the radiographic measurements, analyzed the data, and revised the manuscript.

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