

# Cerebral palsy research news

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**Professor Nadia Badawi AM** CP Alliance Chair of Cerebral Palsy Research

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# **Interventions and Management**

### 1. Novel evaluation of upper-limb motor performance after stroke based on normal reaching movement model

James Hyungsup Moon, Jongbum Kim, Yeji Hwang, Sungho Jang, Jonghyun Kim

J Neuroeng Rehabil. 2023 May 25;20(1):66. doi: 10.1186/s12984-023-01189-6.

Background: Upper-limb rehabilitation robots provide repetitive reaching movement training to post-stroke patients. Beyond a pre-determined set of movements, a robot-aided training protocol requires optimization to account for the individuals' unique motor characteristics. Therefore, an objective evaluation method should consider the pre-stroke motor performance of the affected arm to compare one's performance relative to normalcy. However, no study has attempted to evaluate performance based on an individual's normal performance. Herein, we present a novel method for evaluating upper limb motor performance after a stroke based on a normal reaching movement model. Methods: To represent the normal reaching performance of individuals, we opted for three candidate models: (1) Fitts' law for the speed-accuracy relationship, (2) the Almanji model for the mouse-pointing task of cerebral palsy, and (3) our proposed model. We first obtained the kinematic data of healthy (n = 12) and post-stroke (n = 7) subjects with a robot to validate the model and evaluation method and conducted a pilot study with a group of post-stroke patients (n = 12) in a clinical setting. Using the models obtained from the reaching performance of the less-affected arm, we predicted the patients' normal reaching performance to set the standard for evaluating the affected arm. Results: We verified that the proposed normal reaching model identifies the reaching of all healthy (n = 12) and less-affected arm (n = 19; 16 of them showed an R2 > 0.7) but did not identify erroneous reaching of the affected arm. Furthermore, our evaluation method intuitively and visually demonstrated the unique motor characteristics of the affected arms. Conclusions: The proposed method can be used to evaluate an individual's reaching characteristics based on an individuals normal reaching model. It has the potential to provide individualized training by prioritizing a set of reaching movements.

# PMID: <u>37226265</u>

### 2. System identification: a feasible, reliable and valid way to quantify upper limb motor impairments

Mark van de Ruit, Levinia L van der Velden, Bram Onneweer, Joyce L Benner, Claudia J W Haarman, Gerard M Ribbers, Ruud W Selles

J Neuroeng Rehabil. 2023 May 25;20(1):67. doi: 10.1186/s12984-023-01192-x.

Background: Upper limb impairments in a hemiparetic arm are clinically quantified by well-established clinical scales, known to suffer poor validity, reliability, and sensitivity. Alternatively, robotics can assess motor impairments by characterizing joint dynamics through system identification. In this study, we establish the merits of quantifying abnormal synergy, spasticity, and changes in joint viscoelasticity using system identification, evaluating (1) feasibility and quality of parametric estimates, (2) test-retest reliability, (3) differences between healthy controls and patients with upper limb impairments, and (4) construct validity. Methods: Forty-five healthy controls, twenty-nine stroke patients, and twenty cerebral palsy patients participated. Participants were seated with the affected arm immobilized in the Shoulder-Elbow-Perturbator (SEP). The SEP is a one-degree-of-freedom perturbator that enables applying torque perturbations to the elbow while providing varying amounts of

weight support to the human arm. Participants performed either a 'do not intervene' or a resist task. Elbow joint admittance was quantified and used to extract elbow viscosity and stiffness. Fifty-four of the participants performed two sessions to establish the test-retest reliability of the parameters. Construct validity was assessed by correlating system identification parameters to parameters extracted using a SEP protocol that objectifies current clinical scales (Re-Arm protocol). Results: Feasibility was confirmed by all participants successfully completing the study protocol within ~ 25 min without reporting pain or burden. The parametric estimates were good with a variance-accounted-for of ~ 80%. A fair to excellent test-retest reliability was found ([Formula: see text]) for patients, except for elbow stiffness during the 'do not intervene' task and lower viscosity and stiffness during the resist task. Construct validity was confirmed by a significant (all [Formula: see text]) but weak to moderate ([Formula: see text]) correlation with parameters from the Re-Arm protocol. Conclusions: This work demonstrates that system identification is feasible and reliable for quantifying upper limb motor impairments. Validity was confirmed by differences between patients and controls and correlations with other measurements, but further work is required to optimize the experimental protocol and establish clinical value.

# PMID: 37231496

# 3. Outcomes Associated with a Single Joystick-Operated Ride-on-Toy Navigation Training Incorporated into a Constraint-Induced Movement Therapy Program: A Pilot Feasibility Study

Sudha Srinivasan, Nidhi Amonkar, Patrick Kumavor, Kristin Morgan, Deborah Bubela

Behav Sci (Basel). 2023 May 15;13(5):413. doi: 10.3390/bs13050413.

Our research aims to evaluate the utility of joystick-operated ride-on-toys (ROTs) as therapeutic adjuncts to improve upper extremity (UE) function in children with hemiplegic cerebral palsy (HCP). This study assessed changes in affected UE use and function following a three-week ROT navigation training incorporated into an existing constraint-induced movement therapy (CIMT) camp in 11 children (3-14 years old) with HCP. We report changes in scores on the standardized Shriners Hospital Upper Extremity Evaluation (SHUEE) from pretest-to-posttest and changes from early-to-late sessions in percent time spent by the affected arm in: (a) "moderate-to-vigorous activity", "light activity" and "no activity" bouts based on accelerometer data and (b) "independent", "assisted", and "no activity" bouts based on video data. We also explored relationships between standardized measures and training-specific measures of affected UE activity. We found small-to-medium improvements in the SHUEE scores. Between 90 and 100% of children also showed medium-to-large improvements in affected UE activity from early-to-late sessions using accelerometers and small improvements via video-based assessments. Exploratory analyses suggested trends for relationships between pretest-posttest and training-specific objective and subjective measures of arm use and function. Our pilot data suggest that single joystick-operated ROTs may serve as motivating, child-friendly tools that can augment conventional therapies such as CIMT to boost treatment dosing, promote affected UE movement practice during real-world navigation tasks, and ultimately improve functional outcomes in children with HCP.

# PMID: 37232651

# 4. Utilization of shear wave elastography to quantify and predict response to upper extremity botulinum toxin injections in patients with cerebral palsy: A pilot study

Meghan Jardon, Joseph Nguyen, Emily Casaletto, Lydia Ko, Aviva Wolff, Aaron Daluiski, O Kenechi Nwawka

Clin Neurol Neurosurg. 2023 May 22;230:107798. doi: 10.1016/j.clineuro.2023.107798. Online ahead of print.

Objective: Shear wave elastography (SWE) was used to quantify change in upper extremity muscle stiffness in patients with unilateral spastic cerebral palsy (USCP) following botulinum toxin A (BTX-A) therapy. We hypothesized that SWE measures would decrease following ultrasound-guided BTX-A injection, and correlate with functional improvement. Methods: SWE measures of BTX-A treated muscles were recorded immediately pre-injection, and at 1-, 3- and 6-months post-injection. At the same timepoints, functional assessment was performed using the Modified Ashworth Scale (MAS), and passive and active range of motion (PROM and AROM) measures. Correlation of SWE with MAS, PROM and AROM, as well as the relationship between change in SWE and change in MAS, PROM and AROM was determined using Spearman's rank correlation coefficient and generalized estimating equation modeling. Results: 16 muscles were injected and longitudinally assessed. SWE and MAS scores decreased following BTX-A injection (p = 0.030 and 0.004, respectively), reflecting decreased quantitative and qualitative muscle stiffness. Decreased SWE reached statistical significance at 1- and 3-months, and 1-, 3- and 6-months for MAS. When comparing relative change in SWE to relative change in AROM, larger change in SWE strongly correlated with positive change in AROM (p-value range:<0.001-0.057). BTX-A responders also demonstrated lower baseline SWE (1.4 m/s) vs. non-responders (1.9 m/s), p = 0.035. Conclusion: Ultrasound-guided BTX-A injections in patients with USCP resulted in decreased quantitative and qualitative muscle stiffness. Strong correlation between change in SWE and AROM, as well as the significant difference in baseline SWE for BTX-A responders and non-responders, suggests SWE may provide a useful tool to predict and monitor BTX-A response.

#### PMID: 37236005

### 5. A digital bridge between brain and spinal cord restores walking after paralysis

No authors listed.

Nature. 2023 May 24. doi: 10.1038/d41586-023-01345-x. Online ahead of print.

No abstract available

PMID: <u>37225795</u>

# 6. Measuring hip migration percentage in cerebral palsy using the HipScreen app

John Amen, Oliver Perkins, Jill Cadwgan, Stephen J Cooke, Konstantinos Kafchitsas, Michail Kokkinakis

Bone Jt Open. 2023 May 22;4(5):363-369. doi: 10.1302/2633-1462.45.BJO-2023-0031.R1.

Aims: Reimers migration percentage (MP) is a key measure to inform decision-making around the management of hip displacement in cerebral palsy (CP). The aim of this study is to assess validity and inter- and intra-rater reliability of a novel method of measuring MP using a smart phone app (HipScreen (HS) app). Methods: A total of 20 pelvis radiographs (40 hips) were used to measure MP by using the HS app. Measurements were performed by five different members of the multidisciplinary team, with varying levels of expertise in MP measurement. The same measurements were repeated two weeks later. A senior orthopaedic surgeon measured the MP on picture archiving and communication system (PACS) as the gold standard and repeated the measurements using HS app. Pearson's correlation coefficient (r) was used to compare PACS measurements and all HS app measurements and assess validity. Intraclass correlation coefficient (ICC) was used to assess intra- and inter-rater reliability. Results: All HS app measurements (from 5 raters at week 0 and week 2 and PACS rater) showed highly significant correlation with the PACS measurements (p < 0.001). Pearson's correlation coefficient (r) was constantly over 0.9, suggesting high validity. Correlation of all HS app measures from different raters to each other was significant with r > 0.874 and p < 0.001, which also confirms high validity. Both inter- and intra-rater reliability were excellent with ICC > 0.9. In a 95% confidence interval for repeated measurements, the deviation of each specific measurement was less than 4% MP for single measurer and 5% for different measurers. Conclusion: The HS app provides a valid method to measure hip MP in CP, with excellent inter- and intra-rater reliability across different medical and allied health specialties. This can be used in hip surveillance programmes by interdisciplinary measurers.

# PMID: <u>37212198</u>

# 7. Effect of hip CPM on gross motor function and development of the hip joint: a single-center randomized controlled study on spastic cerebral palsy children with hip dysplasia

Lulu Wang, Nuochen Zhang, Liwei Fang, Zhenzhen Cui, Huihui Niu, Fuli Lv, Dayong Hu, De Wu

Front Pediatr. 2023 May 9;11:1090919. doi: 10.3389/fped.2023.1090919. eCollection 2023.

Objective: To investigate the effectiveness of hip continuous passive motion (hCPM) on hip development at skeletal maturity and gross motor function for spastic cerebral palsy children with hip dysplasia. Methods: Prospective case-control research of hCPM with goal-directed training versus merely goal-directed training. On the basis of goal-directed training, the hCPM group used the hip joint CPM instrument (the external fixator was connected to the power device to make the hip joint carry out continuous passive movement) for 40-60 min, twice a day, and five times a week, and received continuous training for 8 weeks simultaneously. The control group received only goal-directed training for 8 weeks. Functional outcomes pertaining to the affected hip joints were assessed via gross motor function measure (GMFM), migration percentage (MP), acetabular index (AI), and Harris hip functional score (HHS) at the time of enrollment and the end of the intervention. Results: The case-control research included 65 participants (mean age = 46.20 months, SD = 17.09 months; Gross Motor Function Grading System level: III = 41, IV = 24) who were randomly selected to either the hCPM (n = 45) or the control group (n = 20). No differences were found in baseline (acquisition phase) GMFM, MP, AI, or HHS (t = -1.720, P = 0.090; t\* = 1.836, P\* = 0.071; t# = -1.517, P# = 0.139; t\* = -1.310, P\* = 0.195; t# = -1.084, P# = 0.097; t = -1.041, P = 0.301). At the 8-week follow-up, GMFM, MP, AI, and HHS significantly improved over baseline in the hCPM group (hCPM group:  $t = 18.59, 20.172^*, 40.291^{\#}, 16.820^*, 32.900^{\#}, 16.820^*, 10.900^{\#}, 10.820^{\#},$ 28.081; P < 0.001). Between-group differences at 8-week follow-up times points favored the hCPM group for GMFM (t = -2.637, P = 0.011), MP (t\* = 2.615, P\* = 0.014; t# = 3.000, P# = 0.006), AI (t\* = 2.055, P\* = 0.044; t# = 2.223, P# = 0.030), HHS (t = -4.685, P < 0.001) (\*: left side; #: right side). Conclusion: Spastic cerebral palsy children with hip dysplasia achieved meaningful functional improvement after 8 weeks of goal-directed training with hCPM therapy.

PMID: 37228431

# 8. Powered Mobility Device Use and Developmental Change of Young Children with Cerebral Palsy

Samuel W Logan, Bethany M Sloane, Lisa K Kenyon, Heather A Feldner

Behav Sci (Basel). 2023 May 10;13(5):399. doi: 10.3390/bs13050399.

Mobility is a fundamental human right and is supported by the United Nations and the ON Time Mobility framework. The purpose of this study was to understand the effect of a powered mobility intervention on developmental changes of children with cerebral palsy (CP). This study was a randomized, crossover clinical trial involving 24 children (12-36 months) diagnosed with CP or with high probability of future CP diagnosis based on birth history and current developmental status. Children received the Explorer Mini and a modified ride-on car in randomized order, each for 8 weeks. The Bayley Scales of Infant and Toddler Development-4th Edition was administered at baseline, mid-study, and end-of-study. Raw change scores were used for analysis. Total minutes of use per device was categorized as low or high use for analysis based on caregiver-reported driving diaries. Explorer Mini: The high use group exhibited significantly greater positive change scores compared to the low use group on receptive communication, expressive communication, and gross motor subscales (p < 0.05). Modified ride-on car: No significant differences between low and high use groups. Regardless of device, low use was associated with no significant developmental change and high use was associated with positive developmental changes. Mobility access is critical to maximize the development of children with CP and may be augmented by using powered mobility devices. Results may have implications for the development of evidence-based guidelines on dosage for powered mobility use.

### PMID: 37232636

# 9. Differences between Novice and Expert Raters Assessing Trunk Control Using the Trunk Control Measurement Scale Spanish Version (TCMS-S) in Children with Cerebral Palsy

Javier López-Ruiz, Cecilia Estrada-Barranco, Maria José Giménez-Mestre ,Isabel Villarroya-Mateos, Patricia Martín-Casas, and Ibai López-de-Uralde-Villanueva

J Clin Med. 2023 May 19;12(10):3568. doi: 10.3390/jcm12103568.

The Trunk Control Measurement Scale (TCMS) is a valid and reliable tool to assess static and dynamic trunk control in cerebral palsy. However, there is no evidence informing about differences between novice and expert raters. A cross-sectional study was conducted with participants between the ages of 6 and 18 years with a CP diagnosis. The TCMS Spanish version (TCMS-S) was administered in-person by an expert rater, and video recordings were taken for later scoring by the expert and three other raters with varying levels of clinical experience. The intraclass correlation coefficient (ICC) was used to evaluate reliability between raters for the total and subscales of the TCMS-S scores. Standard Error of Measurement (SEM) and Minimal Detectable Change (MDC) were also calculated. There was a high level of agreement between expert raters (ICC  $\geq$  0.93), while novice raters demonstrated good agreement (ICC > 0.72). Additionally, it was observed that novice raters had a slightly higher SEM and MDC than expert raters. The Selective Movement Control subscale exhibited slightly higher SEM and MDC values compared to the TCMS-S total and other subscales, irrespective of the rater's level of expertise. Overall, the study showed that the TCMS-S is a reliable tool for evaluating trunk control in the Spanish pediatric population with cerebral palsy, regardless of the rater's experience level.

### PMID: 37240674

### 10. Persistent increase in anterior pelvic tilt after hamstring lengthening in children with cerebral palsy

Alison M Hanson, Tishya A L Wren, Susan A Rethlefsen, Eva Ciccodicola, Boris Rubel, Robert M Kay

Gait Posture. 2023 May 19;103:184-189. doi: 10.1016/j.gaitpost.2023.05.016. Online ahead of print.

Background: Hamstring lengthening has traditionally been the surgical treatment of choice to correct flexed knee gait in children with cerebral palsy (CP). Improved passive knee extension and knee extension during gait are reported post hamstring lengthening, but concurrent increased anterior pelvic tilt also occurs. Research question: Does anterior pelvic tilt increase after hamstring lengthening in children with CP both in the short-term and mid-term, and what predicts increased post-operative anterior pelvic tilt? Methods: 44 participants were included (age 7.2, SD 2.0 years; 5 GMFCS I, 17 GMFCS II, 21 GMFCS III, 1 GMFCS IV). Mean pelvic tilt was compared between visits, and the effect of potential predictors of change in pelvic tilt was examined using linear mixed models. The relationship of change in pelvic tilt to change in other variables was examined using Pearson correlation. Results: Anterior pelvic tilt increased significantly post-operatively by  $4.8^{\circ}$  (p < 0.001). It remained significantly higher by  $3.8^{\circ}$  at 2-15 years follow-up (p < 0.001). Change in pelvic tilt was not affected by sex, age at surgery, GMFCS level, assistance during walking, time since surgery, or baseline values of hip extensor strength, knee extensor strength, popliteal angle, hip flexion contracture, step length, walking speed, maximum hip power in stance, or minimum knee flexion in stance. Pre-operative dynamic hamstring length was associated with greater anterior pelvic

tilt at all visits but did not affect amount of change in pelvic tilt. Patients in GMFCS I-II showed a similar pattern of change in pelvic tilt to GMFCS III-IV. Significance: When considering hamstring lengthening for ambulatory children with CP, surgeons should weigh increased mid-term anterior pelvic tilt post-operatively with the desired outcome of improved knee extension in stance. Patients with neutral or posterior pelvic tilt and short dynamic hamstring lengths pre-operatively have lowest risk of excessive post-operative anterior pelvic tilt.

### PMID: 37236054

# 11. Zoledronate increases bone mineral density in non-ambulant children with cerebral palsy: A randomized, controlled trial

Jakob Bie Granild-Jensen, Bjarne Møller-Madsen, Gija Rackauskaite, Stense Farholt, Charlotte Søndergaard, Tine Høg Sørensen, Esben Thyssen Vestergaard, Bente Lomholt Langdahl

J Clin Endocrinol Metab. 2023 May 26;dgad299. doi: 10.1210/clinem/dgad299. Online ahead of print.

Aim: To investigate the effect of zoledronate on bone mineral density (BMD) Z-scores in children with non-ambulant cerebral palsy in a randomized, controlled, double-blind trial. Method: Five- to sixteen-year-old, non-ambulant children with cerebral palsy were randomized 1:1 to receive two doses of zoledronate or placebo at a 6-month interval. BMD Z-score changes at the lumbar spine and the lateral distal femur (LDF) were calculated from DXA scans. Monitoring included weight, bone age, pubertal staging, knee-heel length, adverse events, biochemical markers, and questionnaires. Results: Twenty-four participants were randomized and all completed the study. Fourteen were assigned to zoledronate. The mean lumbar spine BMD Z-score increased (95% CIs) 0.8 SD (0.4; 1.2) in the zoledronate group, which was significant when compared to 0.0 SD (-0.3; 0.3) in the placebo group. Similarly, the LDF BMD Z-scores increased more in the zoledronate group. Severe acute phase symptoms affected 50% of the patients in the zoledronate group, but were reported exclusively after the first dose. Growth parameters were similar in both groups. Interpretation: Zoledronate for twelve months increased BMD Z-scores significantly without affecting growth, but first-dose side-effects were common and considerable. Studies into lower first doses and long-term outcomes are needed.

# PMID: 37235798

# 12. Causal modelling demonstrates metabolic power is largely affected by gait kinematics and motor control in children with cerebral palsy

Pavreet K Gill, Katherine M Steele, J Maxwell Donelan, Michael H Schwartz

PLoS One. 2023 May 24;18(5):e0285667. doi: 10.1371/journal.pone.0285667. eCollection 2023.

Metabolic power (net energy consumed while walking per unit time) is, on average, two-to-three times greater in children with cerebral palsy (CP) than their typically developing peers, contributing to greater physical fatigue, lower levels of physical activity and greater risk of cardiovascular disease. The goal of this study was to identify the causal effects of clinical factors that may contribute to high metabolic power demand in children with CP. We included children who 1) visited Gillette Children's Specialty Healthcare for a quantitative gait assessment after the year 2000, 2) were formally diagnosed with CP, 3) were classified as level I-III under the Gross Motor Function Classification System and 4) were 18 years old or younger. We created a structural causal model that specified the assumed relationships of a child's gait pattern (i.e., gait deviation index, GDI) and common impairments (i.e., dynamic and selective motor control, strength, and spasticity) with metabolic power. We estimated causal effects using Bayesian additive regression trees, adjusting for factors identified by the causal model. There were 2157 children who met our criteria. We found that a child's gait pattern, as summarized by the GDI, affected metabolic power approximately twice as much as the next largest contributor. Selective motor control, dynamic motor control, and spasticity had the next largest effects. Among the factors we considered, strength had the smallest effect on metabolic power. Our results suggest that children with CP may benefit more from treatments that improve their gait pattern and motor control than treatments that improve spasticity or strength.

# PMID: <u>37224117</u>

# 13. Fatigue-related gait adaptations in children with cerebral palsy

Laura M Oudenhoven, Marjolein M Van Der Krogt, Sanne Ettema, Karin Roeleveld, Merel A Brehm, Annemieke I Buizer

Dev Med Child Neurol. 2023 May 27. doi: 10.1111/dmcn.15660. Online ahead of print.

Aim: To obtain insights into the effects of fatigue on the kinematics, kinetics, and energy cost of walking (ECoW) in children with cerebral palsy (CP). Method: In this prospective observational study, 12 children with CP (mean age 12 years 9 months, SD 2 years 7 months; four females, eight males) and 15 typically developing children (mean age 10 years 8 months, SD 2 years

4 months; seven females, eight males) followed a prolonged intensity-based walking protocol on an instrumented treadmill, combined with gas analysis measurements. The protocol consisted of consecutive stages, including a 6-minute walking exercise (6MW) at comfortable speed, 2 minutes of moderate-intensity walking (MIW) (with a heart rate > 70% of its predicted maximal), and 4 minutes walking after MIW. If necessary, the speed and slope were incremented to reach MIW. Outcomes were evaluated at the beginning and end of the 6MW and after MIW. Results: With prolonged walking, Gait Profile Scores deteriorated slightly for both groups (p < 0.01). Knee flexion increased during early stance (p = 0.004) and ankle dorsiflexion increased during late stance (p = 0.034) in children with CP only. Negligible effects were found for kinetics. No demonstrable change in ECoW was found in either group (p = 0.195). Interpretation: Kinematic deviations in children with CP are progressive with prolonged walking. The large variation in adaptations indicates that an individual approach is recommended to investigate the effects of physical fatigue on gait in clinical practice.

# PMID: 37243486

# 14. Enhancing Post-Operative Recovery in Spastic Diplegia through Physical Therapy Rehabilitation following Selective Dorsal Rhizotomy: A Case Report and Thorough Literature Analysis

Jawaria Shahid, Ayesha Kashif, Muhammad Kashif Shahid

Case Reports Children (Basel). 2023 May 6;10(5):842. doi: 10.3390/children10050842.

Spasticity is a common issue among children, especially those with bilateral spastic cerebral palsy (CP). Selective dorsal rhizotomy (SDR) is a surgical procedure that is often used to decrease lower limb rigidity, alongside other treatment options such as intrathecal medication, peripheral nerve surgery, and deep brain stimulation (DBS). The objective of these therapies is to improve the standard of living for young individuals. This article intends to explain the motor deficits observed in spastic diplegia and a rehabilitation program using physical therapy after SDR. The information can help with counseling parents about the prognosis and developing a clinical treatment plan. The article presents a case study of a 12-year-old girl who recently underwent L3, L4, and L5 nerve root rhizotomy in the physical therapy department. It highlights the importance of long-term physical therapy follow-up and orthotic usage in the management of spastic diplegia.

### PMID: 37238390

#### 15. Gut dysmotility in children with neurological impairment: the nutritional management

Antonio Corsello, Lorenzo Scatigno, Annalisa Govoni, Gianvincenzo Zuccotti, Frédéric Gottrand, Claudio Romano, Elvira Verduci

Review Front Neurol. 2023 May 5;14:1200101. doi: 10.3389/fneur.2023.1200101. eCollection 2023.

Intestinal motility disorders represent a frequent problem in children with neurological impairment. These conditions are characterized by abnormal movements of the gut, which can result in symptoms such as constipation, diarrhea, reflux, and vomiting. The underlying mechanisms leading to dysmotility are various, and the clinical manifestations are often nonspecific. Nutritional management is an important aspect of care for children with gut dysmotility, as it can help to improve their quality of life. Oral feeding, when safe and in the absence of risk of ingestion or severe dysphagia, should always be encouraged. When oral nutrition is insufficient or potentially harmful, it is necessary to switch to an enteral by tube or parenteral nutrition before the onset of malnutrition. In most cases, children with severe gut dysmotility may require feeding via a permanent gastrostomy tube to ensure adequate nutrition and hydration. Drugs may be necessary to help manage gut dysmotility, such as laxatives, anticholinergics and prokinetic agents. Nutritional management of patients with neurological impairment often requires an individualized care plan to optimize growth and nutrition and to improve overall health outcomes. This review tries to sum up most significant neurogenetic and neurometabolic disorders associated with gut dysmotility that may require a specific multidisciplinary care, identifying a proposal of nutritional and medical management.

### PMID: 37213895

# 16. Translation and psychometric properties of the Persian version of the Feeding/Swallowing Impact Survey in Iranian mothers

Maryam Mokhlesin, Abbas Ebadi, Fariba Yadegari, Zahra Sadat Ghoreishi

Folia Phoniatr Logop. 2023 May 15;1. doi: 10.1159/000531023. Online ahead of print.

Introduction: Feeding is an interactive process between a child and a parent and its early and chronic problems can affect the stress and quality of life of caregivers. Since the health and support of caregivers can affect the child's disability and performance, it is important to consider the impact of pediatric feeding and swallowing disorders on caregivers. For this purpose, the present study translated and investigated the validity and reliability of the Feeding/swallowing Impact survey (FS-

IS) in Persian. Methods: This methodological study consisted of two phases: translating the test to Persian (P-FS-IS) and evaluating psychometric properties including face and content validity (through experts' opinion and cognitive interviews), construct validity (by known-group validity and exploratory factor analysis), and reliability of the instrument (by internal consistency and test-retest reliability). The present study was performed on 97 Iranian mothers of children with cerebral palsy aged 2-18 years with swallowing impairments. Results: Exploratory factor analysis using the maximum likelihood method rendered two factors with a cumulative variance of 59.71%. When evaluating known-group validity, the questionnaire scores were significantly different across the groups with different severity of the disorder [F(2, 94)=57.1, p $\leq$ 0.001]. P-FS-IS had a high internal consistency with Cronbach's alpha of 0.95, and there was an appropriate intra-class correlation coefficient of 0.97 for the total questionnaire. Conclusion: P-FS-IS has good validity and reliability and is a suitable instrument for assessing the impact of pediatric feeding and swallowing disorders on Persian language caregivers. This questionnaire can be used in research and clinical settings to evaluate and determine therapeutic goals.

# PMID: 37231856

#### 17. Disability and caregiver burden: Unique challenges in a developing country

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J Pediatr Rehabil Med. 2023 May 19. doi: 10.3233/PRM-220070. Online ahead of print.

Purpose: This study aimed to identify factors, including degree of disability, that contribute to the caregiver burden of raising children with cerebral palsy in Sri Lanka. Methods: Participants were caregivers of children with cerebral palsy attending the pediatric neurology clinic of the only tertiary care center in southern Sri Lanka. The locally validated Caregiver Difficulties Scale (CDS) was administered, and demographic information was obtained in a structured interview. Disability data was accessed through the medical record. Results: Of 163 caregivers who participated in this study, 133 (81.2%) demonstrated a moderate to high level of burden, and 91 (55.8%) were at high risk for psychological burden. In the bivariate analysis, caregiver burden significantly correlated with degree of physical disability based on the Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System (MACS), the presence of medical co-morbidities, and having two or more children. However, only the GMFCS level and number of children remained significant predictors of caregiver burden after controlling for confounding effects. Conclusion: Raising a child with cerebral palsy in Sri Lanka is likely to cause caregiver burden, particularly if they have a high level of disability or one or more siblings. Monitoring caregiver burden as part of routine cerebral palsy management is important, which allows targeting psychosocial support to families most in need.

# PMID: <u>37212077</u>

# 18. Provision of augmentative and alternative communication interventions to Norwegian preschool children with cerebral palsy: are the right children receiving interventions?

Hilde Aven Lillehaug, Gunvor Lilleholt Klevberg, Kristine Stadskleiv

Augment Altern Commun. 2023 May 22;1-11. doi: 10.1080/07434618.2023.2212068. Online ahead of print.

Preschool children with cerebral palsy (CP) with no or unintelligible speech need augmentative and alternative communication (AAC), but not all children needing AAC have access to it. This study describes the use and perceived benefit of AAC and explores factors associated with receiving AAC interventions. Using a cross-sectional design, we combined parent-reported data with data from the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP). Communication, speech and hand function was classified according to the Communication Function Classification System (CFCS), Viking Speech Scale (VSS), and Manual Ability Classification System (MACS), accordingly. The need for AAC was defined as Levels III-V on the CFCS, without simultaneous classification at VSS Level I, and/or Levels III-IV on VSS. Parents reported on child- and family-directed AAC interventions using the Habilitation Services Questionnaire. Of the 95 children (42 females) with CP (M = 39.4 months, SD = 10.3), 14 had communication aids. Of the 35 children (31.4%) defined as needing AAC, 11 had been provided with communication aids. Parents of children with a communication aid reported satisfaction with and frequent use of the aid. Children at MACS Level III-V (OR = 3.4, p = .02) or with epilepsy (OR = 8.9, p < .01) were most likely to have received an AAC intervention. The low proportion of children receiving communication aids indicates an unmet need for AAC interventions among preschool children with CP.

### PMID: 37212772

### 19. Early childhood outcomes of NICU graduates with cytomegalovirus infection in California

Tatiana M Lanzier, Tianyao Lu, Mihoko V Bennett, Susan R Hintz, David E Sugerman, Sheila C Dollard, Megan H Pesch, Maria A L Jocson, Henry C Lee

Birth Defects Res. 2023 May 25. doi: 10.1002/bdr2.2203. Online ahead of print.

Background: To assess demographics and outcomes up to 3 years of age among children with cytomegalovirus (CMV) infection in California neonatal intensive care units (NICUs) during 2010-2021. Methods: The California Perinatal Quality Care Collaborative (CPQCC) collects data on all very low birth weight (VLBW, birth weight  $\leq$  1500 g) and acutely ill infants with birth weight > 1500 g across 92% of NICUs in California. VLBW infants and those with neurological conditions are referred to a statewide high-risk infant follow-up (HRIF) program. CMV infection was defined as a positive culture or PCR identified during the NICU hospitalization. Results: During 2010-2021, CMV reporting rates averaged 3.5/1000 VLBW infants (n = 205) and 1.1/1000 infants >1500 g (n = 128). Among all 333 infants with CMV, 314 (94%) were discharged home alive, 271 (86%) were referred for HRIF and 205 (65%) had  $\geq$ 1 visit. Whereas infants born to mothers <20 years of age had highest CMV reporting rates and those born to Hispanic mothers comprised 49% of all infected infants, they had the highest loss of follow-up. At the 12-month visit (n = 152), 19 (13%) infants with CMV had bilateral blindness and 18 (12%) had hearing loss. At the 24-month visit, 5 (5%) of 103 had severe cerebral palsy. Conclusions: Among infants admitted to the NICU, those with CMV diagnoses may over represent infants with more severe CMV disease and outcomes. The CPQCC and HRIF program findings may help inform implementation of surveillance for congenital CMV infection in other U.S. states and guide strategies to reduce disparities in access to services.

# PMID: 37226857

# 20. Exploring the Influence of the Coronavirus Disease 2019 Pandemic on the Accessibility of Rehabilitation Services Provided to Children with Disabilities: A Cross-Sectional Study

Safaa Mostafa Elkholi, Monira I Aldhahi, Nisreen Naser Al Awaji

#### Medicina (Kaunas). 2023 Apr 26;59(5):837. doi: 10.3390/medicina59050837.

Background and Objectives: Children with disabilities (such as cerebral palsy, autistic spectrum disorder, and Down syndrome) are the most vulnerable and marginalized subset of the population, representing 2.7% of the total population of Saudi Arabia. The COVID-19 outbreak might have disproportionately affected children with disabilities, augmented their isolation, and induced severe disruptions to the services on which these children rely. Limited research has been conducted in Saudi Arabia to understand the impact of the COVID-19 pandemic on the rehabilitation services provided to children with disabilities and barriers. This study aimed to investigate the effect of the lockdown implemented as a result of the coronavirus disease-2019 (COVID-19) pandemic on the accessibility of rehabilitation services, including communication, occupational therapy, and physical therapy, in Riyadh, Kingdom of Saudi Arabia. Materials and Methods: In this cross-sectional study, a survey was conducted between June and September 2020 during the lockdown in Saudi Arabia. A total of 316 caregivers of children with disabilities from Riyadh participated in the study. The accessibility of rehabilitation services provided to children with disabilities was assessed by designing a valid questionnaire. Results: A total of 280 children with disabilities received rehabilitation services before the COVID-19 pandemic and showed improvement following therapeutic sessions. However, during the pandemic, most children stopped receiving therapeutic sessions because of lockdown, which deteriorated their condition. This shows a significant reduction in the accessibility of the rehabilitation services provided during the pandemic. Conclusions: The findings of this study revealed a drastic decline in services provided to children with disabilities. This caused a notable deterioration in the abilities of these children.

### PMID: 37241069

### 21. Mobile Solutions for Clinical Surveillance and Evaluation in Infancy-General Movement Apps

Peter B Marschik, Amanda K L Kwong, Nelson Silva, Joy E Olsen, Martin Schulte-Rüther, Sven Bölte, Maria Örtqvist, Abbey Eeles, Luise Poustka, Christa Einspieler, Karin Nielsen-Saines, Dajie Zhang, Alicia J Spittle

Review J Clin Med. 2023 May 20;12(10):3576. doi: 10.3390/jcm12103576.

The Prechtl General Movements Assessment (GMA) has become a clinician and researcher toolbox for evaluating neurodevelopment in early infancy. Given that it involves the observation of infant movements from video recordings, utilising smartphone applications to obtain these recordings seems like the natural progression for the field. In this review, we look back on the development of apps for acquiring general movement videos, describe the application and research studies of available apps, and discuss future directions of mobile solutions and their usability in research and clinical practice. We emphasise the importance of understanding the background that has led to these developments while introducing new technologies, including the barriers and facilitators along the pathway. The GMApp and Baby Moves apps were the first ones developed to increase accessibility of the GMA, with two further apps, NeuroMotion and InMotion, designed since. The Baby Moves app has been applied most frequently. For the mobile future of GMA, we advocate collaboration to boost the field's progression and to reduce research waste. We propose future collaborative solutions, including standardisation of cross-site data collection, adaptation to local context and privacy laws, employment of user feedback, and sustainable IT structures enabling continuous software updating.

## PMID: 37240681

### 22. Redefining Neurodevelopmental Impairment: Perspectives of Very Preterm Birth Stakeholders

Anne Synnes, Amarpreet Chera, Lindsay L Richter, Jeffrey N Bone, Claude Julie Bourque, Sofia Zhang-Jiang, Rebecca Pearce, Annie Janvier, Thuy Mai Luu

Children (Basel). 2023 May 14;10(5):880. doi: 10.3390/children10050880.

Children born very preterm are at risk of severe neurodevelopmental impairment, a composite endpoint that includes cerebral palsy, developmental delay, and hearing and visual impairment defined by medical professionals. We aimed to describe preterm birth stakeholders' perspectives on this classification. Ten clinical scenarios describing 18-month-old children with different components of severe neurodevelopmental impairment and one scenario of a typically developing child (control) were distributed to parents and stakeholders using a snowball sampling technique. For each scenario, participants rated health on a scale from 0 to 10 and whether the scenario represented a severe condition. Results were analyzed descriptively and mean differences from the control scenario were compared using a linear mixed-effects model. Stakeholders (number = 827) completed 4553 scenarios. Median health scores for each scenario varied from 6 to 10. The rating for the cerebral palsy and language delay scenario was significantly lower (mean difference -4.3; 95% confidence interval: -4.4, -4.1) than the control. The proportion of respondents rating a scenario as "severe" ranged from 5% for cognitive delay to 55% for cerebral palsy and language delay. Most participants disagreed with the rating used in research to describe severe neurodevelopmental impairment in preterm children. The term should be redefined to align with stakeholder perceptions.

### PMID: 37238428

# 23. The Role of Amplitude-Integrated Electroencephalography (aEEG) in Monitoring Infants with Neonatal Seizures and Predicting Their Neurodevelopmental Outcome

Florina Marinela Doandes, Aniko Maria Manea, Nicoleta Lungu, Timea Brandibur, Daniela Cioboata, Oana Cristina Costescu, Mihaela Zaharie, Marioara Boia

Children (Basel). 2023 May 3;10(5):833. doi: 10.3390/children10050833.

Newborn monitoring in neonatal intensive care units (NICU) is mandatory, but neurological and especially electroencephalographic (EEG) monitoring can be overlooked or delayed until the newborn is clinically stable. However, the neonatal period is associated with the highest risk of seizures in humans, and the clinical symptoms may often be discrete, but the evolution and long-term neurodevelopmental disorders in these patients may be important. In response to this issue, we conducted a study to evaluate newborns who experienced neonatal seizures (NS) in the NICU and monitored their long-term neurological development. We enrolled 73 term and preterm newborns who underwent EEG monitoring using amplitude-integrated electroencephalography (aEEG). We then followed their neurological development until around 18 months of age, with 59 patients remaining in the long-term study. A total of 22% of patients with NS developed epilepsy, 12% cerebral palsy, 19% severe neurodevelopmental disabilities, and 8.5% died within the first 18 months of life. Our findings indicate that aEEG background pattern is a strong predictor of unfavorable neurological outcomes, with an odds ratio of 20.4174 (p < 0.05). Additionally, higher Apgar scores were associated with better outcomes (p < 0.05), with the odds of unfavorable neurological outcomes (p = 0.0104). Our study highlights the importance of early EEG monitoring in the NICU and provides valuable insights into predictors of unfavorable neurological outcomes in newborns who experienced NS.

### PMID: 37238381

# 24. Serum Neurofilament light chain (NfL) levels in children with and without neurologic diseases

Tobias Geis, Svena Gutzeit, Sotiris Fouzas, Andreas Ambrosch, Pascal Benkert, Jens Kuhle, Sven Wellmann

Eur J Paediatr Neurol. 2023 May 6;45:9-13. doi: 10.1016/j.ejpn.2023.05.003. Online ahead of print.

Background/objective: Serum neurofilament light chain (sNfL) is a specific biomarker of neuronal damage. Elevated sNfL levels have been reported in numerous neurologic diseases in adults, whereas data on sNfL in the pediatric population are incomplete. The aim of this study was to investigate sNfL levels in children with various acute and chronic neurologic disorders and describe the age dependence of sNfL from infancy to adolescence. Methods: The total study cohort of this prospective cross-sectional study consisted of 222 children aged from 0 to 17 years. Patients' clinical data were reviewed and patients were assigned to the following groups: 101 (45.5%) controls, 34 (15.3%) febrile controls, 23 (10.4%) acute neurologic conditions (meningitis, facial nerve palsy, traumatic brain injury, or shunt dysfunction in hydrocephalus), 37 (16.7%) febrile seizures, 6 (2.7%) epileptic seizures, 18 (8.1%) chronic neurologic conditions (autism, cerebral palsy, inborn mitochondrial disorder, intracranial hypertension, spina bifida, or chromosomal abnormalities), and 3 (1.4%) severe systemic disease. sNfL

levels were measured using a sensitive single-molecule array assay. Results: There were no significant differences in sNfL levels between controls, febrile controls, febrile seizures, epileptic seizures, acute neurologic conditions, and chronic neurologic conditions. In children with severe systemic disorders, by far the highest NfL levels were found with an sNfL of 429 pg/ml in a patient with neuroblastoma, 126 pg/ml in a patient with cranial nerve palsy and pharyngeal Burkitt's lymphoma, and 42 pg/ml in a child with renal transplant rejection. The relationship between sNfL and age could be described by a second order polynomial with an R2 of 0.153 with a decrease of sNfL by 3.2% per year from birth to age 12 years and thereafter an increase by 2.7% per year until age 18 years. Conclusions: In this study cohort, sNfL levels were not elevated in children with febrile or epileptic seizures, or various other neurologic diseases. Strikingly high sNfL levels were detected in children with oncologic disease or transplant rejection. A biphasic sNfL age-dependency was documented, with highest levels in infancy and late adolescence and the lowest levels in middle school age.

# PMID: <u>37236127</u>

### 25. Linking cortex and contraction-Integrating models along the corticomuscular pathway

Lysea Haggie, Laura Schmid, Oliver Röhrle, Thor Besier, Angus McMorland, Harnoor Saini

Front Physiol. 2023 May 10;14:1095260. doi: 10.3389/fphys.2023.1095260. eCollection 2023.

Computational models of the neuromusculoskeletal system provide a deterministic approach to investigate input-output relationships in the human motor system. Neuromusculoskeletal models are typically used to estimate muscle activations and forces that are consistent with observed motion under healthy and pathological conditions. However, many movement pathologies originate in the brain, including stroke, cerebral palsy, and Parkinson's disease, while most neuromusculoskeletal models deal exclusively with the peripheral nervous system and do not incorporate models of the motor cortex, cerebellum, or spinal cord. An integrated understanding of motor control is necessary to reveal underlying neural-input and motor-output relationships. To facilitate the development of integrated corticomuscular motor pathway models, we provide an overview of the neuromusculoskeletal modelling landscape with a focus on integrating computational models of the motor cortex, spinal cord circuitry, α-motoneurons and skeletal muscle in regard to their role in generating voluntary muscle contraction. Further, we highlight the challenges and opportunities associated with an integrated corticomuscular pathway model, such as challenges in defining neuron connectivities, modelling standardisation, and opportunities in applying models to study emergent behaviour. Integrated corticomuscular pathway models have applications in brain-machine-interaction, education, and our understanding of neurological disease.

# PMID: 37234419

# 26. Preoperative Biopsychosocial Assessment and Length of Stay in Orthopaedic Surgery Admissions of Youth with Cerebral Palsy

Nancy Lennon, Carrie Sewell-Roberts, Tolulope Banjo, Denver B Kraft, Jose J Salazar-Torres, Chris Church, M Wade Shrader

Behav Sci (Basel). 2023 May 6;13(5):383. doi: 10.3390/bs13050383.

Caregivers of children with cerebral palsy (CP) experience stress surrounding orthopaedic surgery related to their child's pain and recovery needs. Social determinants of health can affect the severity of this stress and hinder health care delivery. A preoperative biopsychosocial assessment (BPSA) can identify risk factors and assist in alleviating psychosocial risk. This study examined the relationship between the completion of a BPSA, hospital length of stay (LOS), and 30-day readmission rates for children with CP who underwent hip reconstruction (HR) or posterior spinal fusion (PSF). Outcomes were compared with a matched group who did not have a preoperative BPSA. The BPSA involved meeting with a social worker to discuss support systems, financial needs, transportation, equipment, housing, and other services. A total of 92 children (28 HR pairs, 18 PSF pairs) were identified. Wilcoxon analysis was statistically significant (p = 0.000228) for shorter LOS in children who underwent PSF with preoperative BPSA (median = 7.0 days) vs. without (median = 12.5 days). Multivariate analysis showed that a BPSA, a lower Gross Motor Function Classification System level, and fewer comorbidities were associated with a shorter LOS after both PSF and HR (p < 0.05). Identifying and addressing the psychosocial needs of patients and caregivers prior to surgery can lead to more timely discharge postoperatively.

### PMID: <u>37232620</u>

# 27. Blood biomarkers in the fetally growth restricted and small for gestational age neonate: associations with brain injury

Hannah Musco, Kate Beecher, Kirat K Chand, Paul B Colditz, Julie A Wixey

Review Dev Neurosci. 2023 May 10;1. doi: 10.1159/000530492. Online ahead of print.

Fetal growth restriction (FGR) and small for gestational age (SGA) infants have increased risk of mortality and morbidity. Although both FGR and SGA infants have low birthweights for gestational age, a diagnosis of FGR also requires assessments of umbilical artery Doppler, physiological determinants, neonatal features of malnutrition and in utero growth retardation. Both FGR and SGA are associated with adverse neurodevelopmental outcomes ranging from learning and behavioural difficulties to cerebral palsy. Up to 50% of FGR newborns are not diagnosed until around the time of birth, yet this diagnosis lacks further indication of the risk of brain injury or adverse neurodevelopmental outcomes. Blood biomarkers may be a promising tool. Defining blood biomarkers indicating an infant's risk of brain injury would provide the opportunity for early detection and therefore earlier support. The aim of this review is to summarise the current literature to assist in guiding the future direction for the early detection of adverse brain outcomes in FGR and SGA neonates. The studies investigated potential diagnostic blood biomarkers from cord and neonatal blood or serum from FGR and SGA human neonates. Results were often conflicting with heterogeneity common in the biomarkers examined, timepoints, gestational age, and definitions of FGR and SGA used. Due to these variations, it was difficult to draw strong conclusions from the results. The search for blood biomarkers of brain injury in FGR and SGA neonates should continue as early detection and intervention is critical to improve outcomes for these neonates.

### PMID: 37231871

### 28. It's time to offer genetic testing to all individuals diagnosed with cerebral palsy

### Andrés Moreno-De-Luca

Editorial Parkinsonism Relat Disord. 2023 May 20;105449. doi: 10.1016/j.parkreldis.2023.105449. Online ahead of print.

#### No abstract available

## PMID: 37230823

#### 29. Rewarming rate of hypothermic neonates in a low-resource setting: a retrospective single-center study

Elisa Rossi, Donald Micah Maziku, Dionis Erasto Leluko, Chiara Guadagno, Luca Brasili, Gaetano Azzimonti, Giovanni Putoto, Andrea Pietravalle, Francesco Cavallin, Daniele Trevisanuto

Front Pediatr. 2023 May 9;11:1113897. doi: 10.3389/fped.2023.1113897. eCollection 2023.

Background: Hypothermic neonates need to be promptly rewarmed but there is no strong evidence to support a rapid or a slow pace of rewarming. This study aimed to investigate the rewarming rate and its associations with clinical outcomes in hypothermic neonates born in a low-resource setting. Methods: This retrospective study evaluated the rewarming rate of hypothermic inborn neonates admitted to the Special Care Unit of Tosamaganga Hospital (Tanzania) in 2019-2020. The rewarming rate was calculated as the difference between the first normothermic value (36.5-37.5°C) and the admission temperature, divided by the time elapsed. Neurodevelopmental status at 1 month of age was assessed using the Hammersmith Neonatal Neurological Examination. Results: Median rewarming rate was 0.22°C/h (IQR: 0.11-0.41) in 344/382 (90%) hypothermic inborn infants, and was inversely correlated to admission temperature (correlation coefficient -0.36, p < 0.001). Rewarming rate was not associated with hypoglycemia (p = 0.16), late onset sepsis (p = 0.10), jaundice (p = 0.85), respiratory distress (p = 0.83), seizures (p = 0.34), length of hospital stay (p = 0.22) or mortality (p = 0.17). In 102/307 survivors who returned at follow-up visit at 1 month of age, rewarming rate was not associated with a potential correlate of cerebral palsy risk. Conclusions: Our findings did not show any significant association between rewarming rate and mortality, selected complications or abnormal neurologic exam suggestive of cerebral palsy. However, further prospective studies with strong methodological approach are required to provide conclusive evidence on this topic.

### PMID: 37228438

# 30. Promoting peace of mind: The importance of wellness in children with disabilities and their families

M Wade Shrader

Dev Med Child Neurol. 2023 May 24. doi: 10.1111/dmcn.15661. Online ahead of print.

No abstract available

PMID: 37221990

### 31. Cannabidiol Use Patterns and Efficacy for Children Who Have Cerebral Palsy

Ryan A Seltzer, Joanna L Langner, Nadine M Javier, Japsimran Kaur, Abdul-Lateef Shafau, Teeto Ezeonu, Xochitl Bryson,

Katherine Hastings, Kali Tileston, John S Vorhies

Orthopedics. 2023 May 23;1-5. doi: 10.3928/01477447-20230517-06. Online ahead of print.

Cannabidiol (CBD)-containing supplements are used by children with cerebral palsy (CP), but the prevalence and efficacy of their use have not been studied. We sought to describe CBD use patterns and perceived efficacy in the pediatric population with CP, evaluating any association between CBD use and health-related quality of life. Patients with CP were prospectively enrolled, and caregivers were offered the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) Questionnaire and a survey assessing CBD use. Of 119 participants, 20 (16.8%) endorsed CBD use (CBD+) and 99 (83.2%) denied it (CBD-). Participants in the CBD+ group had worse functional status (85% Gross Motor Function Classification System level IV-V for CBD+ vs 37.4% for CBD-, P<.001) and lower health-related quality of life (mean CPCHILD score of 49.3 for CBD+ vs 62.2 for CBD-, P=.001). Spasticity was the rationale most cited for CBD use (29%), followed by pain and anxiety (both 22.6%). CBD was perceived to be most effective for improving emotional health, spasticity, and pain. Fifty percent of the patients in the CBD+ group underwent surgery in the previous 2 years and most endorsed a general benefit in the postoperative setting. The most common side effects noted were fatigue and increased appetite (both 12%). Most participants endorsed no side effects (60%). CBD may serve as a useful adjunct for some children with CP, especially those with worse disease severity. Caregivers perceive CBD as offering some benefits, particularly in the domains of emotional health, spasticity, and pain. We found no evidence of severe adverse events in our small cohort. [Orthopedics. 202x;4x(x):xx-xx.].

PMID: 37216564