

Cerebral palsy research news

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Interventions and Management

1. Cognitive approaches in the rehabilitation of upper limbs function in children with cerebral palsy: a systematic review and meta-analysis

Andrea Demeco, Anna Molinaro, Martina Ambroggi, Antonio Frizziero, Elisa Fazzi, Cosimo Costantino, Giovanni Buccino

Eur J Phys Rehabil Med. 2024 Mar 21. doi: 10.23736/S1973-9087.24.08288-1. Online ahead of print.

Introduction: Cerebral palsy (CP) is the predominant cause of children disability. It is characterized by motor, sensory, and postural deficits due to a non-progressive injury to the developing central nervous system. In recent years, new rehabilitation techniques targeting the central representations of motor patterns have been introduced: the most used are action observation therapy (AOT), motor imagery (MI), and mirror therapy (MT). Aim of this study is to assess the effectiveness of these cognitive strategies on the recovery of upper limb motor functions in children with CP. Evidence acquisition: This study was designed as a systematic review and meta-analysis, registered in PROSPERO (CRD42023403794). For the report and methodological definitions of this study, the recommendations of the PRISMA protocol and the Cochrane collaboration, were followed. A total of 3 electronic databases (PubMed, Scopus, and Web of Science) were searched for relevant Randomized Control Trials (RCT) using the combinations of terms "cerebral palsy" AND "action observation" OR "motor imagery" OR "mirror therapy" OR "cognitive therapy." A meta-analysis was carried out to compare cognitive and conventional approaches and combine direct and indirect effects. A random-effects meta-analysis model was used to derive pooled effect estimates. Evidence synthesis: Out of 328 records, 12 RCTs were analyzed in this systematic review published from 2012 to 2022, and included 375 children, of whom 195 received cognitive therapies, and 180 underwent conventional rehabilitation. AOT was the most investigated (RCTs N.=7), and showed significant results in the recovery of upper limb motor functions, albeit the meta-analysis demonstrated a non-significant difference in Melbourne Unilateral Upper limb Scale (MUUL) (95% CI: -7.34, 12); in Assisting Hand Assessment (AHA) (95% CI: -4.84, 10.74), and in AbilHand-Kids Questionnaire (95% CI: -1.12, 1.45). Five RCTs investigated MT showing significant improvements in grip and dexterity; none used MI as intervention therapy. Conclusions: Cognitive therapies provided with encouraging results in the recovery of upper limb motor functions, although not a clinical effect in bimanual or unimanual performance; they could represent a valid therapeutic solution integrated to conventional rehabilitation in the treatment of upper limb motor impairment in children with CP.

PMID: <u>38512713</u>

2. Incidence and sequence of scoliosis and windswept hip deformity: which comes first in 4148 children with cerebral palsy? A longitudinal cohort study

Jackie Casey, Andreas Rosenblad, Atli Agustsson, Henrik Lauge-Pedersen, Elisabet Rodby-Bousquet

BMC Musculoskelet Disord. 2024 Mar 19;25(1):222. doi: 10.1186/s12891-024-07350-z.

Background: The aim was to analyse whether scoliosis or windswept hip deformity (WSH) occurs first for children with cerebral palsy (CP). Methods: This longitudinal cohort study using data from 1994 - 2020 (26 years) involved 41,600 measurements of 4148 children (2419 [58.3%] boys) with CP born 1990 - 2018 and registered into the Swedish CP follow-up program. Children were followed from a mean age of 2.8 [SD 1.4] years, until they developed either scoliosis or WSH or were

removed at surgery. Results: WSH developed first in 16.6% of the children (mean age 8.1 [SD 5.0] years), and scoliosis in 8.1% (mean age 8.1 [SD 4.9] years). The incidence of WSH was higher than scoliosis across all levels I-V of the Gross Motor Function Classification System (GMFCS), both sexes, and for those with dyskinetic (20.0%) or spastic (17.0%) CP. The incidence of scoliosis was highest (19.8%) and developed earliest in children with GMFCS level V (mean age 5.5 [SD 3.5] years), and in children with dyskinetic (17.9%) CP (mean age 7.0 [SD 4.7] years). Conclusions: WSH presents earlier than scoliosis in most children with CP. Children with higher GMFCS level or dyskinetic CP are more likely to develop these deformities at a younger age.

PMID: 38504256

3. Endoscopic lithotripsy for upper urinary tract stones in a patient with cerebral palsy and severe scoliosis: A case report

Hao Sun, Min Kong, Hai-Jun Li, Jun Chen

Asian J Surg. 2024 Mar 16:S1015-9584(24)00450-0. doi: 10.1016/j.asjsur.2024.03.023. Online ahead of print.

No abstract available

PMID: 38494353

4. Distal femoral osteotomy and patellar tendon advancement for the treatment of crouch gait in patients with bilateral spastic cerebral palsy

Mohammad Hossein Nabian, Shayan Abdollah Zadegan, Cindy Mallet, Yamile Neder, Brice Ilharreborde, Anne Laure Simon, Ana Presedo

Gait Posture. 2024 Mar 2:110:53-58. doi: 10.1016/j.gaitpost.2024.02.019. Online ahead of print.

Background: Crouch gait, or flexed knee gait, represents a common gait pattern in patients with spastic bilateral cerebral palsy (CP). Distal femoral extension and/or shortening osteotomy (DFEO/DFSO) and patellar tendon advancement (PTA) can be considered as viable options when knee flexion contractures are involved. Better outcomes have been reported after a combination of both, independently of the presence of knee extensor lag. In this study, we evaluated the clinical and kinematic outcomes of these procedures. Patients and methods: We reviewed a cohort of 52 limbs (28 patients) who were treated for crouch gait by DFEO/DFSO alone (group 1, n = 15) or DFEO/DFSO + PTA (group 2, n = 37) as a part of single event multilevel surgery (SEMLS). The mean age at surgery was 14 years, and the mean follow-up time was 18 months. The physical examination data and three-dimensional standardized gait analysis were collected and analyzed before the surgery and postoperatively. Results: Overall knee range of motion improved in all limbs. The knee flexion decreased significantly in both groups at initial, mid, and terminal stance. Hip flexion significantly decreased in mid-stance for limbs in group 2. Both clinical and gait parameters were most improved in limbs who underwent DFEO/DFSO + PTA. Increased pelvic tilt was observed in both groups after surgery. Conclusion: Although DFEO/DFSO alone was successful in correcting knee flexion contractures, PTA has helped to improve knee extensor lag and knee extension during gait. Level of evidence: Therapeutic level IV.

PMID: 38492261

5. Are tactile function and body awareness of the foot related to motor outcomes in children with upper motor neuron lesions?

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Front Rehabil Sci. 2024 Mar 1:5:1348327. doi: 10.3389/fresc.2024.1348327. eCollection 2024.

Introduction: Somatosensory function can be reduced in children with Upper Motor Neuron (UMN) lesions. Therefore, we investigated relationships between somatosensory functions of the foot and motor outcomes in children with UMN lesions. Method: In this cross-sectional study, we assessed the Tactile Threshold (TT) with monofilaments and body awareness with Tactile Localisation Tasks for spatial-related action (TLTaction) and structural-related perception (TLTperception) body representation at the foot sole. Furthermore, we assessed four motor outcomes: the Selective Control Assessment of the Lower Extremity (SCALE), the modified Timed Up and Go test (mTUG), the Gillette Functional Assessment Questionnaire (FAQ), and the Functional Mobility Scale (FMS). Spearman's correlations (ρ) were applied to assess relationships between the somatosensory function of the foot sole and the applied motor outcomes. Results: Thirty-five children with UMN lesions, on average 11.7 ± 3.4 years old, participated. TLTperception correlated significantly with all lower limb motor outcomes ($|\rho|=0.36$ -0.57; p < 0.05), but TLTaction ($|\rho|=0.00-0.27$; p = 0.15-0.97, and TT did not ($|\rho|=0.01-0.83$; p = 0.73-0.94). TLTperception correlated strongly with the Gross Motor Function Classification System ($|\rho|=0.62$; p = 0.001) in children with cerebral palsy (n = 24). Discussion: Assessing structural body representation of the foot sole should be considered when addressing lower limb motor impairments, including gait, in children with upper motor neuron lesions. Our results suggest that the assessment of

tactile function and spatial body representation may be less related to lower limb motor function.

PMID: 38496778

6. Comparison between prefabricated ankle-foot orthoses, Dyna Ankle and UD Flex, in patients with hemiplegia

Su Ji Lee, Tae Yong Kim, Kyung Min Kim, Sung-Rae Cho

J Int Med Res. 2024 Mar;52(3):3000605241233514. doi: 10.1177/03000605241233514.

Objective: To compare the kinematic effects of two widely-used prefabricated ankle-foot orthoses (AFOs), the Dyna Ankle (DA) and UD Flex (UD), on the gait cycle of patients with hemiplegia due to cerebral palsy or acquired brain injury. Methods: This was a retrospective cohort study involving 29 patients. Gait analysis results were assessed under three conditions: barefoot, with the DA, and with the UD. Friedman tests and post hoc analysis with Bonferroni correction were performed to assess differences between the three conditions. Results: The DA significantly improved ankle dorsiflexion during the mid-swing phase, making it more effective in correcting foot drop compared with the UD (DA: 2.28°, UD: 0.44°). Conversely, the UD was more effective in preventing knee flexion during the loading response (DA: 28.11°, UD: 26.72°). Conclusions: The DA improved ankle dorsiflexion during the swing phase significantly more than that with the UD in patients with hemiplegia. Compared with the DA, the UD more effectively prevented increased knee flexion during the loading response. The choice to prescribe these orthoses should consider individual patient characteristics.

PMID: 38501996

7. Foot drop after gastrocsoleus lengthening for equinus deformity in children with cerebral palsy

Erich Rutz, Nicholas Sclavos, Pam Thomason, Elyse Passmore, Kerr Graham

Gait Posture. 2024 Mar 9:S0966-6362(24)00079-1. doi: 10.1016/j.gaitpost.2024.03.005. Online ahead of print.

No abstract available

PMID: <u>38503577</u>

8. Does Size Really Matter? Incidence of Periprosthetic Fractures After Femoral Osteotomy in Patients With Cerebral Palsy

Sam P Wimmer, Tishya A L Wren, Susan A Rethlefsen, Oussama N Abousamra, Robert M Kay

J Pediatr Orthop. 2024 Mar 20. doi: 10.1097/BPO.00000000002663. Online ahead of print.

Objective: Of children, 30% to 35% with cerebral palsy (CP) develop hip subluxation or dislocation and often require reconstructive hip surgery, including varus derotation osteotomy (VDRO). A recent literature review identified postoperative fractures as the most common complication (9.4%) of VDROs. This study aimed to assess risk factors for periprosthetic fracture after VDRO in children with CP. Methods: A total of 347 patients (644 hips, 526 bilateral hips) with CP and hip subluxation or dislocation (129 females; mean age at index VDRO: 8.6 y, SD 3.4, range: 1.5 to 17.7; 2 Gross Motor Function Classification System (GMFCS) I, 35 GMFCS II, 39 GMFCS III, 119 GMFCS IV, 133 GMFCS V, 21 unavailable) were included in this retrospective, single-group intervention (VDRO) study at a tertiary referral center. Imaging and clinical documentation for patients age 18 years or younger at index surgery, treated with VDRO were reviewed to determine demographic data, GMFCS level, surgeon, type of hardware implanted, use of anticonvulsants and steroids, type of postoperative immobilization, presence of periprosthetic fractures, fracture location and mechanism, and time from surgery to fracture. Potential determinants of periprosthetic fractures were assessed using mixed effects logistic regression. Results: Of 644 hips, 14 (2.2%, 95% CI: 1.3%, 3.6%) sustained a periprosthetic fracture, at a median of 2.1 years postoperatively (interquartile range: 4.6 y, range: 1.2 mo to 7.8 y). Patients with a fracture had a median age at index surgery of 7.3 years (interquartile range: 4.3, range: 2.8 to 17.8; 1 GMFCS II, 6 GMFCS IV, 7 GMFCS V). Periprosthetic fractures were not significantly related to age at index surgery (P= 0.18), sex (P= 0.30), body mass index percentile (P= 0.87), surgery side (P= 0.16), anticonvulsant use (P= 0.35), type of postoperative immobilization (P= 0.40), GMFCS level (P= 0.31), or blade plate size (P= 0.17). Only surgeon volume significantly related to periprosthetic fracture (odds ratio = 5.03, 95% CI: 1.53, 16.56, P= 0.008), with the highest-volume surgeon also using smaller blade plates (P<0.01). Conclusions: Periprosthetic fractures after VDRO surgery in children with CP are uncommon, and routine hardware removal appears unnecessary. The data suggest that the common dogma of putting in the largest blade plate possible to maximize fixation may increase the risk of periprosthetic fracture. Due to the overall low fracture rate, especially when contextualized relative to the risk of hardware removal, a reactive approach to hardware removal appears warranted. Level of evidence: Level III-retrospective study (targeting varus derotational osteotomies in children with cerebral palsy).

PMID: 38506352

9. Content Validity of a Collaborative Goal-Setting Pictorial Tool for Children Who Wear Ankle-Foot Orthoses: A Modified Delphi Consensus Study

Elaine Owen, Mary Rahlin, Kyra Janine Kane

Journal of Prosthetics and Orthotics 36(2):p 89-98, April 2024. | DOI: 10.1097/JPO.000000000000462

Introduction. To determine the optimum prescription and dosage for an ankle-foot orthosis and footwear, clinicians and families need to agree on goals for intervention. To facilitate family-centered collaborative goal setting, a table of potential goals and its pictorial representation had been developed previously. These tools incorporated the International Classification of Functioning, Disability, and Health (ICF) and International Organization for Standardization (ISO) clinical objectives for orthoses and were structured in an approach understandable to families. This study aimed to obtain consensus on the content validity of the Table and Pictorial Tools. Methods. Seventeen experts from seven countries (orthotists, physical therapists, physicians, surgeons, and engineers) were invited. A modified Delphi technique was used to evaluate and refine the Table Tool (rounds 1 and 2) and Pictorial Tool (rounds 3 and 4). Participants rated their agreement with overall tool structure, content, and feasibility of use on a 4-point Likert scale, and provided open-ended feedback. Consensus was defined as a median score ≥ 3 (agree) with 75% of responses \geq 3. Data were collected using REDCap. After each round, thematic analysis guided document revisions and anonymized feedback. Results. Ten experts from four countries completed the study. Round 1 (Table Tool): median ratings were all 3: consensus was achieved for 3/5 questions. Round 2: full consensus was achieved. Round 3 (Pictorial Tool): median ratings were ≥ 3 for 10/11 questions; consensus was achieved for 4/11 questions. Round 4: full consensus was achieved. Conclusions. The content validity for the Table and Pictorial Tools was established by modified Delphi consensus. These tools represent a comprehensive selection of goals across all ICF components. Clinical Relevance. These novel tools have the potential to facilitate collaborative goal setting between families and clinicians and aid clinical education. A goalsetting framework specific to orthotic management may improve outcomes within the context of family-centered care.

Article Link

10. Efficacy of Early Intervention for Infants With Cerebral Palsy in an LMIC: An RCT

Katherine A Benfer, Koa Whittingham, Robert S Ware, Asis Kumar Ghosh, Sayak Chowdhury, Golam Moula, Sandip Samanta, Naila Zaman Khan, Kristie L Bell, Stina Oftedal, Sasaka Bandaranayake, Alison T Salt, Anjan Bhattacharya, Pradip Maiti, Santanu K Tripathi, Cathy Morgan, Iona Novak, Roslyn N Boyd

Pediatrics. 2024 Mar 22:e2023063854. doi: 10.1542/peds.2023-063854. Online ahead of print.

Objective: To test efficacy of a parent-delivered multidomain early intervention (Learning through Everyday Activities with Parents [LEAP-CP]) for infants with cerebral palsy (CP) compared with equal-dose of health advice (HA), on (1) infant development; and (2) caregiver mental health. It was hypothesized that infants receiving LEAP-CP would have better motor function, and caregivers better mental health. Methods: This was a multisite single-blind randomized control trial of infants aged 12 to 40 weeks corrected age (CA) at risk for CP (General Movements or Hammersmith Infant Neurologic Examination). Both LEAP-CP and HA groups received 15 fortnightly home-visits by a peer trainer. LEAP-CP is a multidomain active goaldirected intervention. HA is based on Key Family Practices, World Health Organization. Primary outcomes: (1) infants at 18 months CA: Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT mobility); and (2) caregiver: Depression Anxiety and Stress Scale. Results: Of eligible infants, 153 of 165 (92.7%) were recruited (86 males, mean age 7.1±2.7 months CA, Gross Motor Function Classification System at 18 m CA: I = 12, II = 25, III = 9, IV = 18, V = 32). Final data were available for 118 (77.1%). Primary (PEDI-CAT mobility mean difference = 0.8 (95% CI - 1.9 to 3.6) P = .54) and secondary outcomes were similar between-groups. Modified-Intention-To-Treat analysis on n = 96 infants with confirmed CP showed Gross Motor Function Classification System I and IIs allocated to LEAP-CP had significantly better scores on PEDI-CAT mobility domain (mean difference 4.0 (95% CI = 1.4 to 6.5), P = .003) compared with HA. Conclusions: Although there was no overall effect of LEAP-CP compared with dose-matched HA, LEAP-CP lead to superior improvements in motor skills in ambulant children with CP, consistent with what is known about targeted goal-directed training.

PMID: <u>38516717</u>

11. Botulinum neurotoxin type A responders among children with spastic cerebral palsy: Pattern-specific effects

E Papageorgiou, N Peeters, L Staut, G Molenaers, E Ortibus, A Van Campenhout, K Desloovere

Eur J Paediatr Neurol. 2024 Mar 1:49:131-140. doi: 10.1016/j.ejpn.2024.02.017. Online ahead of print.

Aim: To identify short-term effects of botulinum neurotoxin type A (BoNT) injections on gait and clinical impairments, in children with spastic cerebral palsy (CP), based on baseline gait pattern-specific subgroups. Method: Short-term effects of

BoNT injections in the medial hamstrings and gastrocnemius were defined in a retrospective convenience sample of 117 children with CP (median age: 6 years 4 months; GMFCS I/II/III: 70/31/16; unilateral/bilateral: 56/61) who had received gait analyses before and 2 months post-BoNT. First, baseline gait patterns were classified. Statistical and meaningful changes were calculated between pre- and post-BoNT lower limb sagittal plane kinematic waveforms, the gait profile score, and non-dimensional spatiotemporal parameters for the entire sample and for pattern-specific subgroups. These gait waveforms per CP subgroup at pre- and post-BoNT were also compared to typically developing gait and composite scores for spasticity, weakness, and selectivity were compared between the two conditions. Results: Kinematic improvements post-BoNT were identified at the ankle and knee for the entire sample, and for subgroups with apparent equinus and jump gait. Limbs with baseline patterns of dropfoot and to a lesser extent true equinus showed clear improvements only at the ankle. In apparent equinus, jump gait, and dropfoot, spasticity improved post-BoNT, without leading to increased weakness or diminished selectivity. Compared to typical gait, knee and hip motion improved in the crouch gait subgroup post-BoNT. Conclusion: This comprehensive analysis highlighted the importance of investigating BoNT effects on gait and clinical impairments according to baseline gait patterns. These findings may help identify good treatment responders.

PMID: 38518417

12. Visual-motor integration in children with unilateral cerebral palsy: application of the computer-aided measure of visual-motor integration

Wen-Feng Huang, Ren-Yu Chen, Tien-Ni Wang, Po-Ya Chuang, Jeng-Yi Shieh, Hao-Ling Chen

J Neuroeng Rehabil. 2024 Mar 19;21(1):37. doi: 10.1186/s12984-024-01335-8.

Background: Children with unilateral cerebral palsy (UCP) are encouraged to participate in the regular school curriculum. However, even when using the less-affected hand for handwriting, children with UCP still experience handwriting difficulties. Visual-motor integration (VMI) is a predictor of handwriting quality. Investigating VMI in children with UCP is important but still lacking. Conventional paper-based VMI assessments is subjective and use all-or-nothing scoring procedures, which may compromise the fidelity of VMI assessments. Moreover, identifying important shapes that are predictive of VMI performance might benefit clinical decision-making because different geometric shapes represent different developmental stepping stones of VMI. Therefore, a new computer-aided measure of VMI (the CAM-VMI) was developed to investigate VMI performance in children with UCP and to identify shapes important for predicting their VMI performance. Methods: Twenty-eight children with UCP and 28 typically-developing (TD) children were recruited. All participants were instructed to complete the CAM-VMI and Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery-VMI). The test items of the CAM-VMI consisted of nine simple geometric shapes related to writing readiness. Two scores of the CAM-VMI, namely, Error and Effort, were obtained by image registration technique. The performances on the Beery-VMI and the CAM-VMI of children with UCP and TD children were compared by independent t-test. A series of stepwise regression analyses were used to identify shapes important for predicting VMI performance in children with UCP. Results: Significant group differences were found in both the CAM-VMI and the Beery-VMI results. Furthermore, Error was identified as a significant aspect for predicting VMI performance in children with UCP. Specifically, the square item was the only significant predictor of VMI performance in children with UCP. Conclusions: This study was a large-scale study that provided direct evidence of impaired VMI in schoolaged children with UCP. Even when using the less-affected hand, children with UCP could not copy the geometric shapes as well as TD children did. The copied products of children with UCP demonstrated poor constructional accuracy and inappropriate alignment. Furthermore, the predictive model suggested that the constructional accuracy of a copied square is an important predictor of VMI performance in children with UCP.

PMID: 38504351

13. Estimate the burden of malnutrition among children with cerebral palsy in Sub-Saharan Africa: a systematic review with meta-analysis

Ermias Sisay Chanie, Natnael Moges, Fikadie Dagnew Baye, Gebrehiwot Berie Mekonnen, Mengistu Melak Fekadie, Lakachew Yismaw Bazezew, Denekew Tenaw Anley, Melkamu Aderajew Zemene, Natnael Atnafu Gebeyehu, Getachew Asmare Adella, Gizachew Ambaw Kassie, Misganaw Asmamaw Mengstie, Mohammed Abdu Seid, Endeshaw Chekol Abebe, Molalegn Mesele Gesese, Kirubel Dagnaw Tegegne, Yenealem Solomon Kebede, Berihun Bantie, Sefineh Fenta Feleke, Tadesse Asmamaw Dejenie, Wubet Alebachew Bayih, Amare Kassaw, Anteneh Mengist Dessie, Melkalem Mamuye Azanaw, Sewunt Sisay Chanie

Meta-Analysis Sci Rep. 2024 Mar 18;14(1):6494. doi: 10.1038/s41598-024-55730-1.

Malnutrition is more prevalent among children with cerebral palsy and a major factor for child morbidity and mortality in children with different co-morbidity, especially in Sub-Saharan Africa: The main aim of this systematic review and metaanalysis was to estimate the burden of malnutrition among children with cerebral palsy in Sub-Saharan Africa. We searched PubMed, Web of Science, Google Scholar, Research Gate, and institutional repositories for papers that reported the proportion of malnutrition among children with cerebral palsy that were published between December 2010 and September 2023. Data were retrieved using the standardized JBI data extraction checklist through Microsoft Excel, and then exported to STATA 17 for further analysis. DerSimonian and Laird's estimator was used to calculate the pooled effect size in the random-effects model. Statistics such as the Cochran Q test and I2 test were employed to measure heterogeneity. Egger's test and the funnel plot were used to look for publication bias. This systematic review and meta-analysis used 16 studies from Sub-Saharan Africa to estimate the proportion of malnutrition among 2,120 children with cerebral palsy. The pooled proportion of malnutrition among children with cerebral palsy in Sub-Saharan Africa by using random-effects model analysis was found to be 59.7% (95% CI; 49.8-69.6). The proportion of malnutrition was also estimated by sample sizes categorized as ≤ 120 and > 120, and the proportion of malnutrition was found to be 54.0 (95% CI: 44.7-63.3) and 64.5 (95% CI: 50.5-78.5). Moreover, the proportion of malnutrition was estimated by accounting for the difference in the year of publication. In this regard, the study classified before ≤ 2017 and > 2017, and the proportion of malnutrition among children with cerebral in Sub-Saharan Africa was found to be 53.7 (95% CI: 49.7-75.3) in Sub-Saharan Africa respectively. Malnutrition among children with cerebral in Sub-Saharan Africa was found to be very high. Hence, enhancing and developing strategic guidelines for malnutrition screening, prevention, and nutritional support are crucial among children with cerebral palsy. Furthermore, systematic review, randomized control trials, and qualitative studies are recommended to understand the burden more among children with cerebral palsy in the continent.

PMID: <u>38499717</u>

14. Amyotrophic Lateral Sclerosis due to ALS2 Pathogenic Variant Masquerading as Cerebral Palsy: Authors' Reply

Vykuntaraju K Gowda, Sharath Babu, Uddhava Kinhal, Varunvenkat M Srinivasan

Indian J Pediatr. 2024 Mar 23. doi: 10.1007/s12098-024-05107-z. Online ahead of print.

No abstract available

PMID: 38519722

15. Genetic and Congenital Anomalies in Infants With Hypoxic-Ischemic Encephalopathy

Adriana S Morell, Sarah E Monsell, Marie-Coralie Cornet, Jessica L Wisnowski, Robert C McKinstry, Amit M Mathur, Yi Li, Hannah C Glass, Fernando F Gonzalez, Dennis E Mayock, Kristen L Benninger, Krisa P Van Meurs, Andrea L Lampland, Tai-Wei Wu, David Riley, Ulrike Mietzsch, Lina Chalak, John Flibotte, Joern-Hendrick Weitkamp, Kaashif A Ahmad, Toby D Yanowitz, Mariana Baserga, Stephanie Merhar, Rakesh Rao, Gregory M Sokol, Bryan A Comstock, Patrick J Heagerty, Sandra E Juul, Yvonne W Wu

Pediatr Neurol. 2024 Feb 20:154:44-50. doi: 10.1016/j.pediatrneurol.2024.02.007. Online ahead of print.

Background: Infants with hypoxic ischemic encephalopathy (HIE) may have underlying conditions predisposing them to hypoxic-ischemic injury during labor and delivery. It is unclear how genetic and congenital anomalies impact outcomes of HIE. Methods: Infants with HIE enrolled in a phase III trial underwent genetic testing when clinically indicated. Infants with known genetic or congenital anomalies were excluded. The primary outcome, i.e., death or neurodevelopmental impairment (NDI), was determined at age two years by a standardized neurological examination, Bayley Scales of Infant Development, Third Edition (BSID-III), and the Gross Motor Function Classification Scales. Secondary outcomes included cerebral palsy and BSID-III motor, cognitive, and language scores at age two years. Results: Of 500 infants with HIE, 24 (5%, 95% confidence interval 3% to 7%) were diagnosed with a genetic (n = 15) or congenital (n = 14) anomaly. Infants with and without genetic or congenital anomalies had similar rates of severe encephalopathy and findings on brain magnetic resonance imaging. However, infants with genetic or congenital anomalies were more likely to be diagnosed with cerebral palsy (32% vs 13%, P = 0.02), and had lower BSID-III scores in all three domains than HIE survivors without such anomalies. Conclusions: Among infants with HIE, 5% were diagnosed with a genetic or congenital anomaly had worse neurodevelopmental outcomes than infants with HIE alone.

PMID: 38518503

16. Exploring the sexual experiences and challenges of individuals with cerebral palsy

Amber Newell, Neal Liang, Jan Moskowitz, Nancy Lee, Xiaoyu Norman Pan, Heakyung Kim

J Pediatr Rehabil Med. 2024 Mar 22. doi: 10.3233/PRM-240006. Online ahead of print.

Purpose: Cerebral palsy (CP) is a prevalent motor disorder affecting children, with evolving demographics indicating an increasing survival into adulthood. This shift necessitates a broader perspective on CP care, particularly in addressing the often overlooked aspect of sexuality. The purpose of this study was to investigate experiences of, challenges with, and related factors of sexuality and intimacy that people with CP are facing. Methods: This was a descriptive and cross-sectional single institution survey among individuals with CP, ages 18 to 65, who had the ability to independently complete an online survey. Results: A total of 40 respondents participated in the survey (Gross Motor Function Classification System [GMFCS] level I/II, 32.5%; III,

35% ; IV, 32.5%). Of those, 45% were partnered, 60% had past sexual experience, 47.5% were currently sexually active at the time of submitting the survey, 80% had masturbation experience, and 45.8% believed it had positive effect on their self-esteem. Only 10% received sex education tailored for people with disability, whereas school (72.5%) and internet (35%) were the most common sources of sex education. Muscle spasms, positioning difficulty, and pain/discomfort were the most common physical challenges experienced during intimate activity amongst all function stratifications. Stratification analysis showed that, compared to higher functioning respondents, a smaller proportion of lower functioning respondents were partnered (GMFCS IV, 23.1%; quadriplegic, 31.6%), had past or current sexual experience (GMFCS IV, 44.4%, 36.4%; quadriplegic, 42.1%, 26.3%, respectively), and had masturbation experience (GMFCS IV, 61.5%); Also, they had worse Quality of Life Scale scores on average (GMFCS IV, 88.4; quadriplegic, 88.3) and a higher rate of reported positive effects of sexual experiences on self-esteem than negative (GMFCS IV, 38.5%; quadriplegic, 35%).

PMID: <u>38517807</u>

17. "From All, To All": Implementing a collaborative online conference to reflect on the daily living of individuals with cerebral palsy

Beatriz S Vieira, Marina J Airoldi, Deborah Chalfun, Rafael G A S Bonfim, Rachel Teplicky, Peter Rosenbaum, Marisa C Mancini, Marina B Brandão

Child Care Health Dev. 2024 Mar;50(2):e13254. doi: 10.1111/cch.13254.

Background: Translating knowledge to improve paediatric rehabilitation has become a research area of interest. This study describes the development and evaluation of an online conference that brought together perspectives of individuals with cerebral palsy (CP), families, health care professionals, and researchers to discuss the daily living of individuals with CP. Methods: We anchored the development and implementation of the online conference in the action cycle of the Knowledge to Action Framework. To develop the meeting, we included representatives from each stakeholder group in the programme committee. The conference programme was designed having the lifespan perspective of individuals with CP, from birth to adulthood, as its central core, with themes related to daily living (e.g., self-care, mobility, and continuing education). Participants' satisfaction with the conference was assessed using an anonymized online survey sent to all participants. Results: The conference (i.e., quality of the technical support, audio and video, and online platform) and discussed topics (i.e., relevance, content, discussion, speakers, and available time) positively. Conclusion: Collaborative conferences that include stakeholders throughout the planning and implementation are a viable, effective knowledge translation strategy that allows for sharing experiences and disseminating knowledge among families and individuals with CP, health care professionals, and researchers.

PMID: 38517156

18. Evaluating the impact of movement tracking feedback on engagement with home exercise programmes of children with cerebral palsy using a new therapy app: a protocol for a mixed-methods single-case experimental design with alternating treatments

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Introduction: Children with cerebral palsy (CP) are prescribed home exercise programmes (HEPs) to increase the frequency of movement practice, yet adherence to HEPs can be low. This paper outlines the protocol for a single-case experimental design (SCED) with alternating treatments, using a new home therapy exercise application, Bootle Boot Camp (BBCamp), offered with and without movement tracking feedback. This study will explore the impact of feedback on engagement, movement quality, lower limb function and family experiences to help understand how technology-supported HEPs should be translated and the added value, if any, of movement tracking technology. Methods and analysis: In this explanatory sequential mixedmethods study using a SCED, 16 children with CP (aged 6-12 years, Gross Motor Function Classification System levels I-II) will set lower limb goals and be prescribed an individualised HEP by their physiotherapist to complete using BBCamp on their home television equipped with a three-dimensional camera-computer system. Children will complete four weekly exercise sessions over 6 weeks. Children will be randomised to 1 of 16 alternating treatment schedules where BBCamp will provide or withhold feedback during the first 4 weeks. The version of BBCamp that results in the most therapeutic benefit will be continued for 2 final weeks. Goals will be re-evaluated and families interviewed. The primary outcome is adherence (proportion of prescribed exercise repetitions attempted) as a measure of behavioural engagement. Secondary outcomes are affective and cognitive engagement (smiley face ratings), exercise fidelity, lower limb function, goal achievement and participant experiences. SCED data will be analysed using visual and statistical methods. Quantitative and qualitative data will be integrated using joint displays. Ethics and dissemination: Ethical approval was obtained from the Research Ethics Boards at Bloorview Research Institute and the University of Toronto. Results will be distributed through peer-reviewed journals and scientific conferences. Trial registration number: NCT05998239; pre-results.

PMID: 38503423

19. A scoping review on muscle cramps and spasms in upper motor neuron disorder-two sides of the same coin?

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Background: Muscle cramps are typically regarded as benign muscle overactivity in healthy individuals, whereas spasms are linked to spasticity resulting from central motor lesions. However, their striking similarities made us hypothesize that cramping is an under-recognized and potentially misidentified aspect of spasticity. Methods: A systematic search on spasms and cramps in patients with Upper Motor Neuron Disorder (spinal cord injury, cerebral palsy, traumatic brain injury, and stroke) was carried out in Embase/Medline, aiming to describe the definitions, characteristics, and measures of spasms and cramps that are used in the scientific literature. Results: The search identified 4,202 studies, of which 253 were reviewed: 217 studies documented only muscle spasms, 7 studies reported only cramps, and 29 encompassed both. Most studies (n = 216) lacked explicit definitions for either term. One-half omitted any description and when present, the clinical resemblance was significant. Various methods quantified cramp/spasm frequency, with self-reports being the most common approach. Conclusion: Muscle cramps and spasms probably represent related symptoms with a shared pathophysiological component. When considering future treatment strategies, it is important to recognize that part of the patient's spasms may be attributed to cramps.

PMID: 38497037

20. The role of animal-assisted programs in physical health improvement of children and adolescents with special education needs - a systematic review

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Programs involving animals in therapeutic programs are becoming increasingly prevalent. These programs can vary greatly in their approach, scope, and objectives, and they can significantly impact the development of healthy children and those with various disorders. In this systematic review, we sought to investigate the psychological ramifications of animal-assisted activities (AAA), therapies (AAT), and interventions (AAI). We searched for relevant studies using the EBSCO Discovery Service search engine across 85 databases, utilising appropriate keywords. Our search generated 262 results, of which 21 were selected for inclusion after title and abstract screening, as well as full-text analysis. Our findings indicate that dogs and horses are animal-assisted programs' most commonly used animals. Additionally, autism, cerebral palsy, and ADHD were found to be overrepresented in these programs. Furthermore, the length of sessions and overall program duration exhibited considerable variation, regardless of patient age or disease type. The principal measures centred on the physiological variables related to the nervous system and motorium-related indicators. The studies were generally of exceptional methodological soundness. Frequently, the studies narrowed their scope to a single segment or just the child or adolescent, but the outcomes lacked contextual interpretation. Expanding the range of studies by comparing psychological and physiological indicators and conducting follow-up analysis with a longitudinal design would be beneficial.

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