

Cerebral palsy research news

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Interventions and Management

1. The Screening Hand Assessment for Infants for detecting the risk of unilateral cerebral palsy: Item selection and development

Ulrike C Ryll, Johanna Kembe, Cornelia H Verhage, Giuseppina Sgandurra, Lena Krumlinde-Sundholm, Ann-Christin Eliasson

Dev Med Child Neurol. 2024 Jul 8. doi: 10.1111/dmcn.16004. Online ahead of print.

Aim: To develop a screening tool (the screening Hand Assessment for Infants [s-HAI]) for infants aged from 3.5 months that can identify a high risk of developing unilateral cerebral palsy (CP) based on a selection of items from the HAI. Method: Receiver operating characteristic curve analysis was performed on previously collected HAI assessments from 212 infants (104 females, 108 males) aged from 3.5 to 8.5 months, to select items suitable for screening. The area under the curve (AUC), sensitivity, specificity, and cut-off values were derived for the suggested item combination. The clinical outcome (unilateral CP yes or no) at 24 months or older served as the external criterion. Results: About half of the infants developed unilateral CP. The AUC across the items ranged from 0.63 to 0.80, and from 0.85 to 0.87 for different item combinations. Sensitivity for the selected 6-item set was 91% for 8 points or less and 88% for 7 points or less on the contralesional score of each hand, while specificity was 60% and 73% respectively. Interpretation: The s-HAI, designed from six HAI items, has the potential to be used to screen infants at risk of unilateral CP from 3.5 months of age. It is easy to administer, time-efficient, and can be used in different settings. Its measurement properties and feasibility need to be tested in a new data set.

PMID: <u>38978330</u>

2. Infant Modified Constraint-Induced Movement Therapy Paired With Neuromuscular Electrical Stimulation: A Feasibility Study

Kathy Grinde, Jayne Myhre, Amanda Nickel, Michael D Finch

Pediatr Phys Ther. 2024 Jul 8. doi: 10.1097/PEP.000000000001124. Online ahead of print.

Purpose: To determine the feasibility of modified constraint-induced movement therapy (mCIMT) paired with neuromuscular electrical stimulation (NMES) for infants with asymmetrical hand function (AHF). Methods: Five infants received an experimental ABA design: (A1) 3 weeks of our Standard AHF Care, (B) 3 weeks mCIMT-NMES, and (A2) 3 weeks of our Standard AHF Care. Parents tracked key data in a daily log, and infants were assessed 4 times using the Hand Assessment for Infants and Peabody Developmental Motor Scale-2. Results: There was a high level of participant enrollment, visit frequency adherence, and compliance with the treatment protocol. No adverse events were reported. Mean Hand Assessment for Infants Both Hands measure scores changed more after mCIMT-NMES than after our Standard AHF Care. Conclusions: mCIMT-NMES is a feasible early intervention for infants with AHF at risk for unilateral cerebral palsy. A future study in a larger sample should examine the efficacy of mCIMT-NMES in this population.

PMID: <u>38985945</u>

3. The Impact of Neurological Disorders on Clinical and Functional Outcomes after Shoulder Arthroplasty: A Systematic Review

Eddie Afetse, Olivia M Jochl, Ajay C Kanakamedala, Lucas Minas, Maximilian Hinz, Joseph Ruzbarsky, Peter J Millett, Matthew T Provencher

Review J Shoulder Elbow Surg. 2024 Jul 9:S1058-2746(24)00469-5. doi: 10.1016/j.jse.2024.05.023. Online ahead of print.

Background: Patients with pre-existing neurologic disorders present a unique set of challenges for shoulder arthroplasty (SA) surgeons due to the presence of concomitant contractures, muscle weakness, and spasticity, which may affect outcomes and complication rates after shoulder arthroplasty. The goal of this systematic review was to evaluate the clinical and functional outcomes after SA in patients pre-existing with neurologic disorders, focusing on complication and reoperation rates. Methods: This systematic review was performed in adherence to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines outlined by Cochrane Collaboration. A search of PubMed, the Medline Library, and EMBASE from inception until September 2023 was conducted to obtain studies reporting on outcomes after SA in patients with neurological disorders. Study demographics and information on outcomes including patient-reported outcomes and complication rates were collected. The methodological quality of included primary studies was appraised using the MINORS scoring system. Results: Twenty articles published between 1997 and 2023 met inclusion criteria. In total, 13,126 patients with neurological conditions with 7 different neurological disorders (Parkinson's disease (PD), epilepsy and seizures, cerebral palsy (CP), poliomyelitis, Charcot neuropathy (CN), cerebrovascular disease (CVD) and multiple sclerosis (MS)) were included. The mean patient age was 64.3 years (range, 33.0 - 75.8 years), 51.4% of patients were male, and the mean postoperative follow-up time was 5.1 years (range, 1.4 - 9.9 years). PD was the most reported neurological disorder (9 studies, 8,033 patients), followed by epilepsy (4 studies, 3,783 patients), and MS (1 study, 1,077 patients). While these patients did experience improvements in outcomes following SA, high complication and revision rates were noted. Conclusions: Patients with neurologic disorders demonstrate improvements in pain and function after SA but have higher reported complication and revision rates when compared with patients without neurologic conditions. This systematic review offers valuable data for both the surgeon and patient regarding anticipated clinical results and possible complications from SA in patients with neurologic disorders that may aid in shared decision-making when considering SA.

PMID: 38992413

4. Design, Development, and Functional Validation of a 3D-Printed Passive Upper Limb Exoskeleton

E Urendes, C Sanchez, S Lerma-Lara, A Rojo, V Costa, R Raya

IEEE Trans Neural Syst Rehabil Eng. 2024:32:2503-2512. doi: 10.1109/TNSRE.2024.3424537. Epub 2024 Jul 12.

Motor disability in children is evident in diagnoses such as cerebral palsy, muscular dystrophy, multiple sclerosis, or spinal muscular atrophy, among others, due to altered movement and postural patterns. This becomes more evident as the child grows and can be treated with physical therapy. The effectiveness of early interventions in facilitating an improvement in daily life activities varies depending on the child's condition. In this context, the use of exoskeletons has emerged in recent years as a valuable resource for conducting more efficient therapy processes. This work describes the design (both structural and functional) and preliminary usability and functional validation of a 3D-printed passive upper limb exoskeleton. The goal is to provide clinicians with an efficient, low-cost device that is both easy to manufacture and assemble and, in a gamified environment, serves as an assistive device to physical therapy. The device features 5 degrees of freedom, enabling both a progravity and an anti-gravity mode, controlled by a series of elastic bands. This gives rise to a dual operating mode, offering assistance or resistance to different arm, forearm, and shoulder-dependent movements. Usability validation conducted by exoskeleton users showed average results in all aspects rated above 3.8 out of 5, which implies levels of satisfaction between "quite satisfied" and "very satisfied". The analysis of metrics recorded during therapy, such as the Hand Path Ratio and Success Rate (capturing user movements using an inertial sensor in the gamified environment), as well as the range of motion, reveals quantifiable improvements which can be attributed to the use of the exoskeleton: the Hand Path Ratio tended to approach 1 throughout sessions in almost all the users, the Success Rate remained stable (as users consistently were capable of completing the assigned tasks), and the range of motion showed that all patients achieved improvements of more than 10 degrees in some of the tested movements). These functional validation processes involved the participation of 7 children with varying levels of upper limb neuro-motor impairments.

PMID: 38980787

5. Methods of muscle spasticity assessment in children with cerebral palsy: a scoping review

Mehdi Nourizadeh, Babak Shadgan, Samin Abbasidezfouli, Maria Juricic, Kishore Mulpuri

Review J Orthop Surg Res. 2024 Jul 11;19(1):401. doi: 10.1186/s13018-024-04894-7.

Background: Evaluating muscle spasticity in children with cerebral palsy (CP) is essential for determining the most effective

treatment strategies. This scoping review assesses the current methods used to evaluate muscle spasticity, highlighting both traditional and innovative technologies, and their respective advantages and limitations. Methods: A search (to April 2024) used keywords such as muscle spasticity, cerebral palsy, and assessment methods. Selection criteria included articles involving CP children, assessing spasticity objectively/subjectively, comparing methods, or evaluating method effectiveness. Results: From an initial pool of 1971 articles, 30 met our inclusion criteria. These studies collectively appraised a variety of techniques ranging from well-established clinical scales like the modified Ashworth Scale and Tardieu Scale, to cutting-edge technologies such as real-time sonoelastography and inertial sensors. Notably, innovative methods such as the dynamic evaluation of range of motion scale and the stiffness tool were highlighted for their potential to provide more nuanced and precise assessments of spasticity. The review unveiled a critical insight: while traditional methods are convenient and widely used, they often fall short in reliability and objectivity. Conclusion: The review discussed the strengths and limitations of each method and concluded that more reliable methods are needed to measure the level of muscle spasticity more accurately.

PMID: 38992701

6. Quantitative ultrasound of submental and masticatory muscles in children with cerebral palsy

Marloes L J Lagarde, Karen van Hulst, Corrie E Erasmus, Lenie van den Engel-Hoek, Alexander C H Geurts, Nens van Alfen

J Pediatr Rehabil Med. 2024 Jul 2. doi: 10.3233/PRM-230029. Online ahead of print.

Purpose: Quantitative muscle ultrasound (QMUS) is potentially valuable as a diagnostic tool in central neurological disorders, as it provides information about changes in muscle architecture. This study aimed to investigate whether ultrasound images of the submental and masticatory muscles in children with spastic cerebral palsy (CP) differ from those obtained in a reference group, and whether observed ultrasound abnormalities differ between subgroups of children with different Eating and Drinking Ability Classification System (EDACS) levels to support its construct validity. Methods: A prospective cohort study was conducted in 25 children with spastic CP aged 3-18 years. QMUS of selected muscles was performed. Muscle thickness and echogenicity in the CP group were compared to previously collected reference values, and between different EDACS levels within the CP group. Results: Median echogenicity of all muscles was significantly higher in children with CP than in healthy controls. The temporalis muscle was significantly thinner in the CP group. There were no differences in muscle thickness or echogenicity between EDACS levels. Conclusion: QMUS is able to detect abnormal architecture of submental and masticatory muscles in children with spastic CP, but the interpretation of abnormalities in relation to the severity of mastication and swallowing problems needs further investigation.

PMID: 38995809

7. The everydayness of falling: consequences and management for adults with cerebral palsy across the life course

Sonali Shah, Anthony Avery, Ruth Bailey, Brian Bell, Neil Coulson, Richard Luke, Janice McLaughlin, Pip Logan

Disabil Rehabil. 2024 Jul 12:1-9. doi: 10.1080/09638288.2024.2376346. Online ahead of print.

Purpose: To explore the cause, influences and consequences of falling for adults with cerebral palsy (CP) across their life course, and how this is managed. Materials and methods: We used interview data from a multimethod UK study exploring the effects of ageing with CP and healthcare across the life course. Twenty-six participants were recruited and interviewed using various digital platforms to maximise inclusive participation in the UK. Follow-up email semi-structured interviews were conducted to further explore experiences of falls. Transcribed interviews were analysed thematically. Results: Falling and fear of falling (FoF) is problematic for over half of the participants in the sample. They perceived falls and FoF as limiting their participation, autonomy and independence in employment, social and cultural activities. Participants used their own management strategies, due to limited specialist interventions or practitioner knowledge to manage or prevent falls. Practices, such as the use of a wheelchair or avoiding activities prompted changes to relationships and identity. Conclusions: Falling for adults with CP happens earlier in life compared to the general population. Adults with CP may benefit from specialist falls prevention services to help maintain muscle strength and balance. Research is needed to evaluate effective interventions for people with CP.

PMID: 38994847

8. When to use lower limb orthoses in cerebral palsy

Elaine Owen

J Paediatr Child Health. 2024 July 25. https://doi.org/10.1016/j.paed.2024.06.002. In Press, Corrected Proof.

Healthcare practitioners will encounter children who use orthoses to improve or maintain body structures and functions, activities and participation. Orthotic interventions involve complex science and the benefits need to outweigh the burden.

Interdisciplinary collaborative family centred goal setting, from birth to adulthood is essential. An understanding of why and when orthoses are helpful allows a deeper discussion with families and can improve adherence. This article presents a systematic 'Inside-Out Approach' incorporating the International Classification of Functioning, Disability and Health and the International Organization for Standardization objectives for orthotic interventions. Pictorial and Table Tools identify potential goals for bones and joints, muscles, motor control of standing and walking, activities and participation, and prevention of pain which is an indicator of quality of life. Achieving short and long term goals requires early intervention. The design, alignments and dosage, the duration and frequency the child needs to wear the orthosis, required to achieve goals will be determined by an understanding of natural history and prognosis, the agreed goals and the child's schedule of activities. A Dosage Tool is presented. Recent improved understanding of the contribution of the footwear, individualized and optimized joint and segment alignments and segment proportion is discussed.

Science Direct

9. Effects of robot rehabilitation on the motor function and gait in children with cerebral palsy: a systematic review and meta-analysis

Jae-Hyun Lim, Eun-Young Kang, Se-Ju Park, Byeong-Geun Kim

Review J Exerc Rehabil. 2024 Jun 30;20(3):92-99. doi: 10.12965/jer.2448186.093. eCollection 2024 Jun.

This study was to determine the effects of robot rehabilitation on motor function and gait in children with cerebral palsy (CP) and the effect of robot type. Inclusion criteria were children with any type of CP, robot rehabilitation studies, non-robot rehabilitation comparison groups, outcomes related to motor function and gait, and randomized controlled trials. PubMed, Embase, Cochrane Library, CINAHL, and Web of Science databases were searched. Risk of bias was assessed using physiotherapy evidence database. Seven studies with a total of 228 participants were selected. Motor function was significantly improved in three studies comparing robot rehabilitation and control groups (standard mean difference [SMD], 0.79; 95% confidence intervals [CIs], 0.34-1.24; I 2=73%). Gait was not significantly improved in five studies comparing robot rehabilitation and control groups (SMD, 0.27; 95% CI, -0.09 to 0.63; I 2=45%). When comparing effects by robot type, robotic -assisted gate training (RAGT) showed significant improvements in both motor function (SMD, 0.89; 95% CI, 0.36-1.43; I 2=77%) and gait (SMD, 0.62; 95% CI, 0.12-1.11; I 2=44%). Robot rehabilitation effectively improved motor function, and among the robot types, RAGT was found to be effective in improving motor function and gait.

PMID: 38973981

10. A randomized cross-over study protocol to evaluate long-term gait training with a pediatric robotic exoskeleton outside the clinical setting in children with movement disorders

Taylor M Devine, Katharine E Alter, Diane L Damiano, Thomas C Bulea

Randomized Controlled Trial PLoS One. 2024 Jul 8;19(7):e0304087. doi: 10.1371/journal.pone.0304087. eCollection 2024.

Individuals with neuromuscular disorders display a combination of motor control deficits and lower limb weakness contributing to knee extension deficiency characterized by exaggerated stance phase knee flexion. There is a lack of evidence for long-term improvement of knee extension deficiency with currently available clinical treatment programs. Our previous work testing a wearable robotic exoskeleton with precisely timed assistive torque applied at the knee showed immediate increases in knee extension during walking for children with cerebral palsy, which continued to improve over an acute practice period. When we applied interleaved assistance and resistance to knee extension, we observed improvements in knee extension and increased muscle activation indicating the potential for muscle strengthening when used over time. There is a need for additional, high-quality trials to assess the impact of dosage, intensity and volume of training necessary to see persistent improvement in lower limb function for these patient populations. This randomized crossover study (ClinicalTrials.gov: NCT05726591) was designed to determine whether 12 weeks of overground gait training with a robotic exoskeleton outside of the clinical setting, following an initial in clinic accommodation period, has a beneficial effect on walking ability, muscle activity and overall motor function. Participants will be randomized to either complete the exoskeleton intervention or continue their standard therapy for 12 weeks first, followed by a crossover to the other study component. The primary outcome measure is change in peak knee extension angle during walking; secondary outcome measures include gait speed, strength, and validated clinical scales of motor function and mobility. Assessments will be completed before and after the intervention and at 6 weeks post-intervention, and safety and compliance will be monitored throughout. We hypothesize that the 12-week exoskeleton intervention outside the clinical setting will show greater improvements in study outcome measures than the standard therapy.

PMID: 38976710

11. Estimates of functional muscle strength from a novel progressive lateral step-up test are feasible, reliable, and related to physical activity in children with cerebral palsy

Trevor Batson, Sydni V W Whitten, Harshvardhan Singh, Chuan Zhang, Gavin Colquitt, Christopher M Modlesky

PLoS One. 2024 Jul 10;19(7):e0306529. doi: 10.1371/journal.pone.0306529. eCollection 2024.

Objective: To determine if estimates of functional muscle strength from a novel progressive lateral-step-up test (LSUT) are feasible, reliable, and related to physical activity in children with cerebral palsy (CP). Design: Cross-sectional; test-retest reliability Subjects/Patients: Children with CP and typically developing control children (n = 45/group). Methods: An LSUT with 10, 15, and 20 cm step heights was completed. It was repeated 4 weeks later in 20 children with CP. A composite score of LSUT was calculated based on the step height and number of repetitions completed. Physical activity was assessed using monitors worn on the ankle and hip. Results: Only 4 (13%) of the children with CP were unable to complete a lateral step-up repetition without assistance. All children were able to complete at least 1 repetition with assistance, though more than twice as many children with CP required assistance at 15 and 20 cm step heights than at the 10 cm step height (p < 0.01). Children with CP had 59 to 63% lower LSUT performance, 37% lower physical activity assessed at the ankle, and 22% lower physical activity assessed at the hip than controls (all p < 0.01). The intra-class correlation coefficient ranged from 0.91 to 0.96 for LSUT performance at the different step heights and was 0.97 for the composite score. All LSUT performance measures were positively related to ankle physical activity in children with CP (r range = 0.43 to 0.47, all p < 0.01). Only performance at 20 cm and the composite score were positively related to hip physical activity (r = 0.33 and 0.31, respectively, both p < 0.05). The relationship between the LSUT performance and physical activity at both the ankle and hip increased when age and sex were statistically controlled (model r range = 0.55 to 0.60, all p < 0.001). Conclusion: Estimates of functional muscle strength from a novel progressive LSUT are feasible, reliable, and positively related to physical activity in children with CP.

PMID: 38985818

12. How Does Standing Anteroposterior Stability Limits Correlate to Foot/ankle Functions in Bilateral Spastic Cerebral Palsy?

Hidehito Tomita, Shuhei Takahashi, Daisuke Kawaguchi, Yumi Aoki, Yoshiji Yamamoto, Hitoshi Asai

Pediatr Phys Ther. 2024 Jul 15. doi: 10.1097/PEP.000000000001128. Online ahead of print.

Purpose: To determine whether foot and ankle functions are correlated with the limits of stability (LoS) while standing in individuals with bilateral spastic cerebral palsy (BSCP). Methods: Eighteen people who could walk and with BSCP and 18 people without disability participated. Anteroposterior LoS was measured using a force platform. To quantify ankle and foot functions, spasticity, isometric muscle strength, passive range of motion, and plantar light touch-pressure sensation were assessed. Results: In the BSCP group, anteroposterior LoS was significantly decreased, and anterior LoS reduction was correlated with decreases in plantar flexor and toe flexor strength and in sensitivity of the forefoot to light touch-pressure sensation, whereas the posterior LoS reduction was correlated with reduced dorsiflexor strength. Conclusions: The present findings suggest that improvement in these foot and ankle functions in BSCP may increase LoS while standing.

PMID: 38995638

13. Knee Angle Estimation from Surface EMG during Walking Using Attention-Based Deep Recurrent Neural Networks: Feasibility and Initial Demonstration in Cerebral Palsy

Mohamed Abdelhady, Diane L Damiano, Thomas C Bulea

Sensors (Basel). 2024 Jun 28;24(13):4217. doi: 10.3390/s24134217.

Accurately estimating knee joint angle during walking from surface electromyography (sEMG) signals can enable more natural control of wearable robotics like exoskeletons. However, challenges exist due to variability across individuals and sessions. This study evaluates an attention-based deep recurrent neural network combining gated recurrent units (GRUs) and an attention mechanism (AM) for knee angle estimation. Three experiments were conducted. First, the GRU-AM model was tested on four healthy adolescents, demonstrating improved estimation compared to GRU alone. A sensitivity analysis revealed that the key contributing muscles were the knee flexor and extensors, highlighting the ability of the AM to focus on the most salient inputs. Second, transfer learning was shown by pretraining the model on an open source dataset before additional training and testing on the four adolescents. Third, the model was progressively adapted over three sessions for one child with cerebral palsy (CP). The GRU-AM model demonstrated robust knee angle estimation accuracy improved by 14 degrees on average across successive sessions of walking in the child with CP. These results demonstrate the feasibility of using attention-based deep networks for joint angle estimation in adolescents and clinical populations and support their further development for deployment in wearable robotics.

PMID: 39000996

14. Anxiety, depression, and support needs of the mothers of children with cerebral palsy and determining their opinions: Mixed methods study

Abdullah Sarman, Suat Tuncay, Yusuf Budak, Eyyüp Demirpolat, İrem Bulut

J Pediatr Nurs. 2024 Jul 11:S0882-5963(24)00259-8. doi: 10.1016/j.pedn.2024.06.028. Online ahead of print.

Purpose: This study aimed to determine the level of anxiety, depression, support needs and opinions of mothers of children with cerebral palsy. Design and methods: The study used a descriptive qualitative design. The population of the study consisted of children with cerebral palsy who were educated in special education centers in a province of Eastern Turkey. All participants who volunteered for the study were accepted and the study was completed with 126 mothers. Results: Caregiver mothers with male cerebral palsy patients had higher carer support needs and anxiety total mean scores. The mean scores of depression and anxiety of the mothers who were older were statistically higher. This study found that mothers of children with diseases other than cerebral palsy had statistically higher mean depression scores. The mothers of child with cerebral palsy who had a high gross motor classification score had higher mean carer support needs, depression, and anxiety total scores. Conclusions: According to the study, depression and trait anxiety were linked to greater maternal support needs. Qualitative interviews revealed that mothers experienced issues such as stigmatization and withdrawal from social activities as a result of their children's illness. Practice implications: This study shows the relationship of need for support of mothers of children with cerebral palsy and mental problems such as depression and trait anxiety. Pediatric nurses should provide emotional support to mothers and guide them towards support groups and training programs.

PMID: <u>38997912</u>

15. Informing knowledge translation for selective dorsal rhizotomy: A survey of Australian clinicians and people with lived experience of cerebral palsy

Jennifer A Lewis, Simon P Paget, Neil Wimalasundera, Meredith Wynter, Lani Campbell, Olivia S Lee, Kirsty Stewart, R Shah, Marnee J McKay; Selective Dorsal Rhizotomy Knowledge Translation Advisory Team

J Paediatr Child Health. 2024 Jul 8. doi: 10.1111/jpc.16605. Online ahead of print.

Aim: Selective dorsal rhizotomy (SDR) is a neurosurgical intervention used to reduce spasticity in children with cerebral palsy (CP). There is minimal relevant, evidence-based information available for Australian families and clinicians. This study aims to investigate the knowledge of people with lived experience and clinicians regarding SDR, including how they currently access information and what information they seek. Methods: Adults with CP, carers of children with CP and clinicians treating children with CP were invited to complete an online survey. Data regarding participant demographics, current knowledge and confidence in knowledge about CP and SDR, information source/s used and participants level of trust in these sources are presented as counts and percentages. Comparisons in knowledge between groups were analysed. Results: A total of 114 surveys were completed: 63 clinicians, 48 carers, and 3 adults with CP. Eighty percent of clinicians were allied health professionals. People with lived experience were less confident in their knowledge about SDR compared to knowledge of CP (P < 0.001). Clinicians rated scientific research literature and the hospital team as the most useful and trustworthy information source. People with lived experience used a wider range of information sources including the internet, rating their community therapy team and other people with lived experience, likely due to a gap in accessible and readable evidence-based information. While both groups differed in how they access information, there was agreement that greater information about SDR is needed.

PMID: 38973618

16. Practices of Physical Therapists Who Assist People With Cerebral Palsy in Brazil: A National Survey

Michelle Alexandrina Dos Santos Furtado, Egmar Longo, Ana Carolina de Campos, Maiara Aparecida Tino da Silva, Ana Clara de Carvalho Silva, Kênnea Martins Almeida Ayupe, Ana Cristina Resende Camargos, Hércules Ribeiro Leite

Pediatr Phys Ther. 2024 Jul 8. doi: 10.1097/PEP.000000000001126. Online ahead of print.

Purpose: To describe the practices of pediatric physical therapists (PTs) working with children and adolescents with cerebral palsy (CP) in Brazil. Methods: PTs working with children and adolescents with CP were invited to participate via social media and email campaigns to complete an online survey containing 46 questions. Results: In total, 373 PTs participated. Most PTs reported searching in scientific databases (96.8%) and on social media (71%). The main barrier to information reported was limited access to full-text articles (44%). Among the PTs, 58.4% and 84% reported using the International Classification of Functioning, Disability and Health (ICF) and family centered practice models, respectively. Regarding tools and interventions,

there was little focus on the domains of contextual factors and participation. Conclusions: This survey points to some important advances. However, strategies are still needed to promote knowledge translation and evidence-based practices among pediatric PTs in Brazil.

PMID: 38985944

17. Implementation of remote general movement assessment using the in-motion instructions in a high-risk norwegian cohort

Lars Adde, Kristin Bjørnstad Åberg, Toril Fjørtoft, Kristine Hermansen Grunewaldt, Randi Lade, Siril Osland, Frank Piegsa, Per Gunnar Sandstrøm, Ragnhild Støen, Gunfrid V Størvold, Beate Horsberg Eriksen

Multicenter Study BMC Pediatr. 2024 Jul 10;24(1):442. doi: 10.1186/s12887-024-04927-4.

Background: General Movement Assessment (GMA) is recommended for early detection of risk for cerebral palsy but requires trained clinical experts. We aimed to implement home- and hospital-based filming for remote GMA in a Norwegian high-risk infant cohort, as well as evaluating parents' experiences in filming their infant at home. Methods: This knowledge translational study used a prospective cohort design including participants referred to neurodevelopmental follow-up across three sites in the Central Norway Regional Health Authority. Two home films of the fidgety type of general movements were collected between 12+1-14+6 and 15+1-17+6 weeks after term by parents. An additional film was collected at the hospital between 12+1 and 17+6 weeks after term. The instructional guide for all filming was the In-Motion App standards. Videos were transferred to a remote GMA team and classified as either "GMA scorable" or "GMA not scorable" based on Prechtl's GMA standards. Parents responded to an online survey using a 5-point Likert scale to collect information about their perspectives, experiences, and possible worries by filming their infant at home. Results: One-hundred-and-two infants from 95 families participated. Ninetytwo (96.8%) families transferred 177 home-based videos. Eighty-four (92%) of these had 95 videos taken in their local hospital. All 177 home-videos were "GMA scorable" and three (3,1%) out of 95 hospital-based videos were classified as "GMA not scorable". Eight families did not respond to the survey and two families did not receive the survey due to a technical error. Seventy-eight (91.7%) respondents agreed or strongly agreed that it was easy to perform home filming and five (5.9%) agreed that they were more worried about their child's development after filming at home. Almost 80% of respondents agreed that a video for GMA can be taken at home instead of in hospital. Conclusions: This study strengthens the clinical implementation of home filming by parents and remote GMA for early detection of CP in high-risk follow-up programs. The implementation of remote GMA has the potential to facilitate early intervention to improve function in children with CP in line with international recommendations. Trial registration: ClinicalTrials.gov ID: NCT04287166 Date of registration: 27/02/2020.

PMID: 38987721

18. Increasing prevalence of cerebral palsy in children born very preterm in Denmark

Martha Veber Fogh, Gorm Greisen, Tine Dalsgaard Clausen, Lone Krebs, Mads Langager Larsen, Christina Engel Hoei-Hansen

Dev Med Child Neurol. 2024 Jul 12. doi: 10.1111/dmcn.16020. Online ahead of print.

Aim: To analyse the rising prevalence of cerebral palsy (CP) in children born preterm in Denmark. Method: We included all live-born children born preterm in Denmark from 1997 to 2013. The prevalence of CP in children born preterm was categorized by gestational age and correlated with neonatal mortality and changes in clinical factors. Results: Among 70 876 children, 824 (1.2%) had CP. The overall CP prevalence in children born preterm decreased substantially until 2001, from when it increased annually by 2.8% (95% confidence interval 0.6-5.0). When categorized, the prevalence only increased significantly in children born very preterm (gestational weeks 28-31). Neonatal mortality rates decreased steadily at all gestational ages during the entire study period. Clinical factors that changed during the study period were increasing numbers of high-risk pregnancies, maternal obesity, emergency caesarean sections, neonatal admissions, and usage of assisted ventilation. Interpretation: The increasing prevalence of CP in children born preterm was driven by the subgroup born very preterm and matched their decrease in neonatal mortality. In similar population studies, decreased mortality was not followed by increased CP prevalence. An increase in clinical risk factors was unlikely to explain our findings, but more active neonatal life support may have played a role.

PMID: <u>38994777</u>

19. Perspectives of cerebral palsy experts on access to health care in Europe

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Eur J Paediatr Neurol. 2024 Jun 15:52:20-28. doi: 10.1016/j.ejpn.2024.06.002. Online ahead of print.

Aim: To explore the perspectives of cerebral palsy (CP) experts on access to healthcare and an analysis of socioeconomic and environmental determinants impacting young individuals with CP in Europe. Method: Cross-sectional survey designed by a convenience multi-disciplinary panel of invited experts and completed by clinicians, researchers and opinions leaders in the field of CP. Results: Fifty-eight experts (response rate 85 %) from 39 regions in 26 European countries completed the survey. All countries provide care and financing through public systems. Long waiting lists were reported (mean 3 mo, range 1-12 mo), depending on type of specialist care and place of residence. Although diagnostic and therapeutic services were available, access within countries/regions were unevenly distributed, with children receiving better care than adults. Most experts reported a lack of transition services, although improvement is expected (62 % of responses). Hip and malnutrition surveillance, as well as educational and recreational activities were variably available. Public transportation, accessible roads and pavements, and urban green spaces for persons with disabilities were more available in larger cities. Overall, only 57 % of responders felt that most patients had adequate access to healthcare. Conclusion: The survey of CP experts' perspectives from the majority of European countries indicates discrepancies in the availability and accessibility of healthcare needed by people with CP and nonuniform implementation of policies across Europe.

PMID: 38996558

20. A Cross-Sectional Study of Disparities in Healthcare Transition in Cerebral Palsy

Gavin Colquitt, Mario Keko, Haresh D Rochani, Christopher M Modlesky, Joshua Vova, Nathalie Linda Maitre

J Clin Med. 2024 Jun 27;13(13):3759. doi: 10.3390/jcm13133759.

Background: Cerebral palsy (CP) is the most common physical disability among children, affecting their lifespan. While CP is typically nonprogressive, symptoms can worsen over time. With advancements in healthcare, more children with CP are reaching adulthood, creating a greater demand for adult care. However, a significant lack of adult healthcare providers exists, as CP is predominantly considered a pediatric condition. This study compares the transition experiences of children with CP compared to those with other developmental disabilities (DDs) and typically developing children (TDC). Methods: This study utilizes cross-sectional data from the National Survey of Children's Health (NSCH) from 2016-2020, including 71,973 respondents aged 12-17. Children were categorized into three groups: CP (n = 263), DD (n = 9460), and TDC (n = 36,053). The analysis focused on the receipt of transition services and identified demographic and socioeconomic factors influencing these services. Results: Only 9.7% of children with CP received necessary transition services, compared to 19.7% of children with CP received necessary transition services, compared to 19.7% of children with CP were less likely to have private time with healthcare providers and receive skills development assistance compared to other groups. Conclusions: The findings highlight disparities and critical needs for targeted interventions and structured transition programs to improve the transition from pediatric to adult healthcare for children with CP. Addressing disparities in service receipt and ensuring coordinated, continuous care are essential for improving outcomes for children with CP.

PMID: 38999322

21. Respiratory Comorbidities and Complications of Cerebral Palsy

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Respiratory complications are the most frequent cause of morbidity, mortality, and poor quality of life in children with cerebral palsy (CP) and represent the leading cause of hospitalizations. Several factors negatively influence the respiratory status of these children: lung parenchymal alterations and factors modifying the pulmonary pump function of chest and respiratory muscles, as well as concomitant pathologies that indirectly affect the respiratory function, such as sleep disorder, malnutrition, epilepsy, and pharmacological treatments. Early management of respiratory complications can improve the global health of children with CP and enhance quality of life for them and their caregivers.

PMID: 38992903

22. 'There was nothing, just absolute darkness': Understanding the needs of those caring for children and young people with complex neurodisability in a diverse UK context: A qualitative exploration in the ENCOMPASS study

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Child Care Health Dev. 2024 Jul;50(4):e13303. doi: 10.1111/cch.13303.

Background: Children and young people (CYP) with complex neurodisability experience multiple physical, communication,

educational and social challenges, which require complex packages of multidisciplinary care. Part of the holistic care required includes supporting the families and parents/caregivers. The aim of the wider study was to introduce a new programme ('Ubuntu') to parents/caregivers and healthcare professionals (HCPs) in order to test the feasibility and acceptability of the concept and content, with the goal of potential adaptation for the UK in mind. Data collection and analysis uncovered rich data on caregiving journeys, navigation of health services, and perceived service gaps. This paper focuses solely on these topics. Further papers will report on the feasibility and adaptation data. Methods: Two rounds of semi-structured interviews were conducted with 12 caregivers of CYP with complex neurodisability and six HCPs from a variety of disciplines, recruited from a community child health service in London Borough of Newham, UK in 2020. The interviews included open-ended questions to explore caregiving journeys, experiences of navigating health services and perceived service gaps. Transcripts were analysed using a data-driven inductive thematic analysis. Results: Three themes were identified that related to the aim of understanding caregivers' experiences and unmet needs relating to current service provision. These were (1) Caregiver Mental Health, (2) The Information Gap and (3) The Need for Holistic Support. Mental health difficulties were reported, particularly around the period of diagnosis. Priority needs included the provision of clear information about the diagnosis and services offered, opportunities to forge peer support networks and for services across the community to collaborate. Conclusions: The delivery of health services for CYP with neurodisability should encompass the broad needs of the family as well as meeting the clinical needs of the CYP.

PMID: 38991712

23. Dyskinetic Cerebral Palsy in Children: Clinical Perspectives on Common Comorbidities and Health-Related Quality of Life

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Background: The data on specific comorbidities in children with dyskinetic cerebral palsy (DCP) is limited. We evaluated the pattern of comorbidities and health related quality of life (HRQOL) in these children and compared them between etiological and motor impairment subgroups. Methodology: This cross-sectional study was conducted over 18 months in children with DCP of both sex, and age between one and 14 years. Comorbidities were assessed using standardized scales such as gross motor functioning scale (GMFCS), developmental profile-3 (DP-3), developmental behaviour checklist, sleep behaviour questionnaire (SBQ), and caregiver questionnaire. Results: Sixty-five children with DCP were evaluated (hyperbilirubinemia n = 43, 66% and perinatal asphyxia n = 19, 29%). The majority of children were severely affected in gross motor functioning (level IV 29.2% and level V 53.8%). Epilepsy was seen in 21.5% of cases (19% in hyperbilirubinemia and 32% in asphyxia, p = 0.4). The mean age of onset of seizures was 15.4 + 20.6 months (range 2-72). Visual problems were seen in 54% of cases and included upgaze palsy, squint, refractive error, optic atrophy and cortical blindness. A significant proportion of children with hyperbilirubinemia had upgaze palsy as compared to those with perinatal asphyxia (70% vs. 32%, p 0.01). Rest of the visual problems were not significantly different between the two etiological subgroups. Drooling (87.6%), protein-energy malnutrition (66.6%), and reflux (57%) were the most common gastrointestinal problems in children with DCP. Children with DCP showed problems in social relating (33.8%), anxiety (26.2%), and self-absorbed behaviour (7.7%). However, there were no statistically significant differences between the etiological, motor impairment and age-based subgroups. Children with DCP had high scores on SBQ, suggesting sleep problems. Sleep scores were similar in the hyperbilirubinemia and perinatal asphyxia subgroups. Greater sleep problems were noted in children aged $< 4y (70.6 + 10.1 \text{ vs. } 56.5 + 11.3, p < 0.05 \text{ as compared to children above 4y of age) and severe motor impairments (68.2 + 11.3 vs. 57.2 + 13.1, p 0.008 as compared to mild-moderate$ motor impairment). Poor overall developmental scores were seen in 61.5% children and were significantly associated with GMFCS (p 0.04). The majority of children showed impairments in physical (58.5%), adaptive behaviour (58.5%), socialemotional (50.8%), cognitive (60%) and communication (52%) subscales of DP-3. Cognitive impairment was similar in the etiological (hyperbilirubinemia vs. perinatal asphyxia, p = 0.3), and motor impairment (mild-moderate vs. severe, p = 0.9) subgroups. HRQOL was significantly affected by motor impairment in positioning-transfer (p value 0.0001), and interactioncommunication domains (p value 0.0001), however, there was no difference based on the etiology of hyperbilirubinemia and asphyxia. Conclusion: Children with DCP demonstrate several comorbidities and impaired quality of life. These are similar in hyperbilirubinemia and perinatal asphyxia cohorts, expect for significant proportion of upgaze palsy in DCP secondary to hyperbilirubinemia. Younger children have more problematic behaviour and impaired sleep quality. Severe motor disability influences the developmental outcomes, cognition, sleep and HRQOL in children with DCP.

PMID: 38990371

24. Prenatal Exposure to Ambient Air Pollution and Cerebral Palsy

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JAMA Netw Open. 2024 Jul 1;7(7):e2420717. doi: 10.1001/jamanetworkopen.2024.20717.

Importance: Air pollution is associated with structural brain changes, disruption of neurogenesis, and neurodevelopmental

disorders. The association between prenatal exposure to ambient air pollution and risk of cerebral palsy (CP), which is the most common motor disability in childhood, has not been thoroughly investigated. Objective: To evaluate the associations between prenatal residential exposure to ambient air pollution and risk of CP among children born at term gestation in a population cohort in Ontario, Canada. Design, setting, and participants: Population-based cohort study in Ontario, Canada using linked, province-wide health administrative databases. Participants were singleton full term births (≥37 gestational weeks) born in Ontario hospitals between April 1, 2002, and March 31, 2017. Data were analyzed from January to December 2022. Exposures: Weekly average concentrations of ambient fine particulate matter with a diameter 2.5 µm (PM2.5) or smaller, nitrogen dioxide (NO2), and ozone (O3) during pregnancy assigned by maternal residence reported at delivery from satellite-based estimates and ground-level monitoring data. Main outcome and measures: CP cases were ascertained by a single inpatient hospitalization diagnosis or at least 2 outpatient diagnoses for children from birth to age 18 years. Results: The present study included 1 587 935 mother-child pairs who reached term gestation, among whom 3170 (0.2%) children were diagnosed with CP. The study population had a mean (SD) maternal age of 30.1 (5.6) years and 811 745 infants (51.1%) were male. A per IQR increase (2.7 µg/m3) in prenatal ambient PM2.5 concentration was associated with a cumulative hazard ratio (CHR) of 1.12 (95% CI, 1.03-1.21) for CP. The CHR in male infants (1.14; 95% CI, 1.02-1.26) was higher compared with the CHR in female infants (1.08; 95% CI, 0.96-1.22). No specific window of susceptibility was found for prenatal PM2.5 exposure and CP in the study population. No associations or windows of susceptibility were found for prenatal NO2 or O3 exposure and CP risk. Conclusions and relevance: In this large cohort study of singleton full term births in Canada, prenatal ambient PM2.5 exposure was associated with an increased risk of CP in offspring. Further studies are needed to explore this association and its potential biological pathways, which could advance the identification of environmental risk factors of CP in early life.

PMID: 38980674

25. Assessing aspects of early social communication in non-speaking children with bilateral cerebral palsy

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Purpose: Research suggests that rates for autism may be higher in cerebral palsy than in the general population. For those with severe bilateral physical impairment (GMFCS level IV and V) and little or no speech, describing a profile of social communication skills has been difficult because there are currently no assessments for early social communication specifically tailored for these children. Our aim was to explore the assessment of aspects of joint attention and social reciprocity in this group of children with CP. Methods: We compared the performance of children with bilateral CP on carefully designed assessments of joint attention and social responsiveness with groups of children with Down syndrome and autism. All three groups were matched for chronological age and mental age. Results: Approximately 30% of the children with bilateral CP had early social communication scores similar to the autistic children. The remaining 70% of children with CP had a range of early social communication skills in non-speaking children with bilateral motor disability. This could provide insights to help clinicians and caregivers as they discuss abilities and explore potential areas for intervention.

PMID: <u>38975724</u>

26. Potential clinical applications of advanced genomic analysis in cerebral palsy

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Cerebral palsy (CP) has historically been attributed to acquired insults, but emerging research suggests that genetic variations are also important causes of CP. While microarray and whole-exome sequencing based studies have been the primary methods for establishing new CP-gene relationships and providing a genetic etiology for individual patients, the cause of their condition remains unknown for many patients with CP. Recent advancements in genomic technologies offer additional opportunities to uncover variations in human genomes, transcriptomes, and epigenomes that have previously escaped detection. In this review, we outline the use of these state-of-the-art technologies to address the molecular diagnostic challenges experienced by individuals with CP. We also explore the importance of identifying a molecular etiology whenever possible, given the potential for genomic medicine to provide opportunities to treat patients with CP in new and more precise ways.

PMID: <u>38970919</u>