

Cerebral palsy research news

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Interventions and Management

1. Safety and Feasibility of 1-Repetition Maximum (1-RM) Testing in Children and Adolescents With Bilateral Spastic **Cerebral Palsy**

Mattie Pontiff, Noelle G Moreau

Pediatr Phys Ther. 2022 Aug 12. doi: 10.1097/PEP.000000000000941. Online ahead of print.

Purpose: The purpose of this study was to standardize 1-repetition maximum (1-RM) testing procedures and evaluate the safety and feasibility of these procedures in youth with cerebral palsy (CP). Methods: Youth with CP completed 1-RM testing on a leg press. Results: Mean absolute, adjusted, and normalized 1-RM loads were 262.4 ± 161.3 lb, 127.0 ± 80.2 lb, and 1.28 ± 0.51 , respectively, and 67% were able to successfully lift the same or heavier load after a single failure. Cessation of testing after 1 failed attempt resulted in a 19.0% underestimation of the 1-RM. Conclusions: 1-RM testing in youth with CP is safe and feasible. Multiple attempts at a failed load should be provided to prevent underestimation in strength. The 1-RM test provides a more accurate strength assessment, which will improve the dosing for resistance training in youth with CP.

PMID: 35960137

2. Parent-therapist partnership to ELEVATE gross motor function in children with perinatal stroke: protocol for a mixed methods randomized controlled trial

Caitlin L Hurd, Michelle Barnes, Christa M Diot, Elizabeth G Condliffe, Hana Alazem, Lesley Pritchard, Jennifer D Zwicker, Anna McCormick, Man-Joe Watt, John Andersen, Adam Kirton, Jaynie F Yang

BMC Pediatr. 2022 Aug 10;22(1):480. doi: 10.1186/s12887-022-03525-6.

Background: There is increasing evidence for early, active rehabilitation to enhance motor function following early brain injury. This is clear for interventions targeting the upper extremity, whereas passive treatment approaches for the lower extremity persist. The purpose of this trial is to evaluate the effectiveness of early, intensive rehabilitation targeting the lower extremity and delivered in a parent-therapist partnership model for children with perinatal stroke. Methods: We describe a protocol for a waitlist-control, single-blind, mixed methods effectiveness randomized controlled trial, with an embedded qualitative study using interpretative description. Participants are children with perinatal stroke aged eight months to three years with signs of hemiparesis. Participants will be randomly allocated to an immediate ELEVATE (Engaging the Lower Extremity Via Active Therapy Early) intervention group, or a waitlist-control group, who will receive usual care for six months. The ELEVATE intervention involves one hour of training four days per week for 12 weeks, with a pediatric therapist and a parent or guardian each delivering two sessions per week. The intervention targets the affected lower extremity by progressively challenging the child while standing and walking. The primary outcome measure is the Gross Motor Function Measure-66. Secondary outcomes include the Pediatric Quality of Life Inventory™, Young Children's Participation and

Environment Measure, and an instrumented measure of spasticity. A cost-effectiveness analysis and qualitative component will explore benefit to costs ratios and parents' perspectives of early, intensive rehabilitation, and their role as a partner in the rehabilitation, respectively. Discussion: This study has the potential to change current rehabilitation for young children with perinatal stroke if the ELEVATE intervention is effective. The parent interviews will provide further insight into benefits and challenges of a partnership model of rehabilitation. The mixed methods design will enable optimization for transfer of this collaborative approach into physical therapy practice. Trial registration: ClinicalTrials.gov NCT03672864. Registered 17 September 2018.

PMID: 35948896

3. Swallowing and Motor Speech Skills in Unilateral Cerebral Palsy: Novel Findings From a Preliminary Cross-Sectional Study

Georgia A Malandraki, Samantha S Mitchell, Rachel E Hahn Arkenberg, Barbara Brown, Bruce A Craig, Wendy Burdo-Hartman, Jennifer P Lundine, Meghan Darling-White, Lisa Goffman

J Speech Lang Hear Res. 2022 Aug 11;1-16. doi: 10.1044/2022 JSLHR-22-00091. Online ahead of print.

Purpose: Our purpose was to start examining clinical swallowing and motor speech skills of school-age children with unilateral cerebral palsy (UCP) compared to typically developing children (TDC), how these skills relate to each other, and whether they are predicted by clinical/demographic data (age, birth history, lesion type, etc.). Method: Seventeen children with UCP and 17 TDC (7-12 years old) participated in this cross-sectional study. Feeding/swallowing skills were evaluated using the Dysphagia Disorder Survey (DDS) and a normalized measure of mealtime efficiency (normalized mealtime duration, i.e., nMD). Motor speech was assessed via speech intelligibility and speech rate measures using the Test of Children's Speech Plus. Analyses included nonparametric bootstrapping, correlation analysis, and multiple regression. Results: Children with UCP exhibited more severe (higher) DDS scores (p = .0096, Part 1; p = .0132, Part 2) and reduced speech rate than TDC (p = .0120). Furthermore, in children with UCP, total DDS scores were moderately negatively correlated with speech intelligibility (words: r = .6162, p = .0086; sentences: r = .60792, p = .0096). Expressive language scores were the only significant predictor of feeding and swallowing performance, and receptive language scores were the only significant predictor of motor speech skills. Conclusions: Swallowing and motor speech skills can be affected in school-age children with UCP, with wide variability of performance also noted. Preliminary cross-system interactions between swallowing, speech, and language are observed and might support the complex relationships between these domains. Further understanding these relationships in this population could have prognostic and/or therapeutic value and warrants further study.

PMID: 35952392

4. Psychometric properties of the Persian version of the oral motor assessment scale in children and adolescents with cerebral palsy

Omid Mohamadi, Farhad Torabinezhad, Abbas Ebadi

Int J Dev Disabil. 2020 Sep 17;68(4):511-517. doi: 10.1080/20473869.2020.1819944. eCollection 2022.

The Oral Motor Assessment Scale (OMAS) is a diagnostic tool used to assess the oral motor skills in individuals with neurological and neuromuscular disorders. This assessment was developed by Brazilian researchers and for the first time, its validity and reliability was examined in Brazil. The purpose of the present study was to examine the validity and reliability of the adopted Persian version of the OMAS (OMAS-P) to assess the oral skills of Iranian individuals with cerebral palsy (CP). In this non-experimental descriptive-analytical study 120 people (60 children and adolescents with CP) aged 3 to 15 years and 60 healthy subjects) participated. The research was carried out in number of stages including translation and adaptation of the OMAS to Persian (OMAS-P) in a forward-backward way. The oral motor skills functionality of the 120 people was examined using the OMAS-P. To assess the repeatability and reliability of the OMAS-P the assessments was repeated on the participants with CP disorder after two weeks. Results corresponding to this study indicated a reasonable agreement (Kappa >0.7) for all the OMAS-P items. The mean values of the OMAS-P items were appreciably different between the two groups (p < 0.001). The Persian version of the OMAS (OMAS-P) indicated consistent psychometric properties and can be used as a reliable tool for oral motor skills assessment in people with CP. However, it seems that by specifying factors such as the time frame for the OMAS, the position of the child during assessment, and whether or not parents use facilitating techniques, the comprehensiveness and efficiency of the OMAS data will also upgrade.

5. Chronic Pain in Young People With Cerebral Palsy: Activity Limitations and Coping Strategies Letisha Carozza, Ella Anderson-Mackay, A Marie Blackmore, Helen Alison Kirkman, Jin Ou, Nadine Smith, Sarah Love

Pediatr Phys Ther. 2022 Aug 2. doi: 10.1097/PEP.00000000000943. Online ahead of print.

Purpose: To describe the effect of chronic pain on the activities of children and adolescents with cerebral palsy, to describe coping strategies, and to examine associations between effect of pain on activities, coping strategies, and level of pain. Methods: Using an online survey, 27, 8- to 18-year-olds with cerebral palsy and chronic pain or their parents reported pain intensity, distribution, activity limitations (using the Child Activity Limitations Interview-21), and coping strategies (using the Pediatric Pain Coping Inventory). Results: Pain intensity ranged from 3 to 10, and 89% reported pain in multiple areas, principally the lower limbs. Individuals reporting higher pain intensity had more activity limitations and were more likely to use catastrophizing coping strategies. Conclusions: Coping strategies may be an important mediator between pain and its effect on activities in children with cerebral palsy. Individualized pain management should be based on routine pain assessment.

PMID: 35943391

6. Quality of life beyond diagnosis in intellectual disability - Latent profiling

Helen Leonard, Andrew Whitehouse, Peter Jacoby, Tim Benke, Scott Demarest, Jacinta Saldaris, Kingsley Wong, Dinah Reddihough, Katrina Williams, Jenny Downs

Res Dev Disabil. 2022 Aug 5;129:104322. doi: 10.1016/j.ridd.2022.104322. Online ahead of print.

Objective: To compare quality of life (QOL) across diagnoses associated with intellectual disability, construct QOL profiles and evaluate membership by diagnostic group, function and comorbidities. Method: Primary caregivers of 526 children with intellectual disability (age 5-18 years) and a diagnosis of cerebral palsy, autism spectrum disorder, Down syndrome, CDKL5 deficiency disorder or Rett syndrome completed the Quality of Life Inventory-Disability (QI-Disability) questionnaire. Latent profile analysis of the QI-Disability domain scores was conducted. Results: The mean (SD) total QOL score was 67.8 (13.4), ranging from 60.3 (14.6) for CDD to 77.5 (11.7) for Down syndrome. Three classes describing domain scores were identified: Class 1 was characterised by higher domain scores overall but poorer negative emotions scores; Class 2 by average to high scores for most domains but low independence scores; and Class 3 was characterised by low positive emotions, social interaction, and leisure and the outdoors scores, and extremely low independence scores. The majority of individuals with autism spectrum disorder and Down syndrome belonged to Class 1 and the majority with CDKL5 deficiency disorder belonged to Class 3. Those with better functional abilities (verbal communication and independent walking were predominately members of Class 1 and those with frequent seizures were more often members of Class 2 and 3. Conclusion: The profiles illustrated variation in QOL across a diverse group of children. QOL evaluations illustrate areas where interventions could improve QOL and provide advice to families as to where efforts may be best directed.

PMID: 35939908

7. Intervention Mapping of a Gamified Therapy Prescription App for Children With Disabilities: User-Centered Design Approach

Rowan W Johnson, Becky K White, Daniel F Gucciardi, Noula Gibson, Sian A Williams

JMIR Pediatr Parent. 2022 Aug 9;5(3):e34588. doi: 10.2196/34588.

Background: Mobile health (mHealth) apps for children are increasing in availability and scope. Therapy (physiotherapy, speech pathology, and occupational therapy) prescription apps to improve home or school program adherence work best when developed to be highly engaging for children and when they incorporate behavior change techniques (BCTs) within their design. Objective: The aim of this study was to describe the development of a user-centered therapy prescription app for children (aged 6-12 years) with neurodevelopmental disabilities (eg, cerebral palsy, autism spectrum disorder, and intellectual disability) incorporating intervention mapping (IM) and gamified design. Methods: We used an iterative, user-centered app development model incorporating the first 3 steps of IM. We conducted a needs analysis with user feedback from our previous mHealth app study, a literature review, and a market audit. Change objectives were then specified in alignment with the

psychological needs of autonomy, competence, and relatedness identified in self-determination theory. From these objectives, we then selected BCTs, stipulating parameters for effectiveness and how each BCT would be operationalized. A gamification design was planned and implemented focusing on maximizing engagement in children. In total, 2 rounds of consultations with parents, teachers, and therapists and 1 round of prototype app testing with children were conducted to inform app development, with a final iteration developed for further testing. Results: The IM process resulted in the specification of app elements, selfdetermination theory-informed BCTs, that were embedded into the app design. The gamification design yielded the selection of a digital pet avatar with a fantasy anime visual theme and multiple layers of incentives earned by completing prescribed therapy activities. Consultation groups with professionals working with children with disabilities (4 therapists and 3 teachers) and parents of children with disabilities (n=3) provided insights into the motivation of children and the pragmatics of implementing app-delivered therapy programs that informed the app development. User testing with children with disabilities (n=4) highlighted their enthusiasm for the app and the need for support in the initial phase of learning the app. App quality testing (Mobile Application Rating Scale-user version) with the children yielded means (out of 5) of 4.5 (SD 0.8) for engagement, 3.3 (SD 1.6) for function, 3.3 (SD 1.7) for aesthetics, and 4.3 (SD 1.1) for subjective quality. Conclusions: mHealth apps designed for children can be greatly enhanced with a systematic yet flexible development process considering the specific contextual needs of the children with user-centered design, addressing the need for behavior change using the IM process, and maximizing engagement with gamification and strong visual design.

PMID: 35943782

8. Standing power wheelchairs and their use by children and youth with mobility limitations: an interrupted time series Debra A Field, Jaimie Borisoff, Franco H N Chan, Roslyn W Livingstone, William C Miller

Disabil Rehabil Assist Technol. 2022 Aug 9;1-11. doi: 10.1080/17483107.2022.2096933. Online ahead of print.

Standing power wheelchairs (PWSDs) expand positioning and mobility options for individuals with motor impairments. Although more available, little is known about how PWSDs are used in everyday life. Purpose: to describe children's use of PWSDs in the first three months post-wheelchair delivery and the impacts on satisfaction with participation in daily life. Materials and methods: An interrupted time series of purposefully sampled children aged 5-18 years who were receiving a PWSD. The Wheelchair Outcome Measure for Young People (WhOM-YP) documented satisfaction with patient-reported meaningful participation outcomes. Data loggers objectively measured wheelchair mobility outcomes including distance travelled, bouts of mobility, and duration. Data were measured over two sessions pre-wheelchair-delivery and at one week, one month and three months post-wheelchair-delivery. Results: Six children aged 7-18 years participated, four diagnosed with cerebral palsy, two with spina bifida. Analyses of individual data illustrated positive change in overall WhOM-YP satisfaction scores after PWSD provision though change varied across time, as did, distance, bouts of mobility and duration of use. Participants identified 14 in-home and 16 out-of-home unique participation outcomes, although several commonalities existed. Conclusion: PWSDs hold promise for increasing children's satisfaction with participation in daily life, in addition to possibly increasing mobility outcomes. IMPLICATIONS FOR REHABILITATION: For children with mobility limitations, PWSDs may promote participation in daily life and increased mobility. Data logger technology provides valuable information about children's PWSD use and how this varies over time. Benefits and challenges exist with implementing PWSD and data logger technologies. When implementing PWSD use, it is critical to consider context, training and support needs of clients and caregivers.

PMID: 35943726

9. Visual feedback in Augmented Reality to walk at predefined speed. Cross-sectional study including children with cerebral palsy

Anne-Laure Guinet, Guillaume Bouyer, Samir Otmane, Eric Desailly

IEEE Trans Neural Syst Rehabil Eng. 2022 Aug 11; PP. doi: 10.1109/TNSRE.2022.3198243. Online ahead of print.

In an augmented reality environment, the range of possible real-time visual feedback is extensive. This study aimed to compare the impact of six scenarios in augmented reality combining four visual feedback characteristics on achieving a target walking speed. The six scenarios have been developed for Microsoft Hololens augmented reality headset. The four feedback characteristics that we have varied were: Color; Spatial anchoring; Speed of the feedback, and Persistence. Each characteristic could have different values (for example, the color could be unicolor, bicolor, or gradient). Participants had to walk for two consecutive walking trials for each scenario: at their maximal speed and an intermediate speed. Mean speed, percentage of time spent above or around target speed, and time to reach target speed were compared between scenarios using mixed linear models. A total of 25 children with disabilities have been included. The feasibility and user experience were excellent. Mean speed during scenario 6, which displayed feedback with gradient color, attached to the world, with a speed relative to the player equal to his speed, and that disappeared over time, was significantly higher than other scenarios and control (p=0.003). Participants spent 80.98% of time above target speed during scenario 6. This scenario mixed the best combination of feedback characteristics to exceed the target walking speed (p=0.0058). Scenarios 5 and 6, which shared the same feedback characteristics for spatial anchoring (world-locked) and feedback speed (equal to the player speed), decreased the time to reach the target speed (p=0.019). Delivering multi-modal feedback has been recognized as more effective for improving motor performance. Therefore, our results showed that not all visual feedback had the same impact on performance. Further studies are required to test the weight of each feedback characteristic and their possible interactions inside each scenario. This study was registered in the ClinicalTrials.gov database (NCT04460833).

PMID: 35951576

10. Control of a Wheelchair-Mounted 6DOF Assistive Robot With Chin and Finger Joysticks

Ivan Rulik, Md Samiul Haque Sunny, Javier Dario Sanjuan De Caro, Md Ishrak Islam Zarif, Brahim Brahmi, Sheikh Iqbal Ahamed, Katie Schultz, Inga Wang, Tony Leheng, Jason Peng Longxiang, Mohammad H Rahman

Front Robot AI. 2022 Jul 22;9:885610. doi: 10.3389/frobt.2022.885610. eCollection 2022.

Throughout the last decade, many assistive robots for people with disabilities have been developed; however, researchers have not fully utilized these robotic technologies to entirely create independent living conditions for people with disabilities, particularly in relation to activities of daily living (ADLs). An assistive system can help satisfy the demands of regular ADLs for people with disabilities. With an increasing shortage of caregivers and a growing number of individuals with impairments and the elderly, assistive robots can help meet future healthcare demands. One of the critical aspects of designing these assistive devices is to improve functional independence while providing an excellent human-machine interface. People with limited upper limb function due to stroke, spinal cord injury, cerebral palsy, amyotrophic lateral sclerosis, and other conditions find the controls of assistive devices such as power wheelchairs difficult to use. Thus, the objective of this research was to design a multimodal control method for robotic self-assistance that could assist individuals with disabilities in performing selfcare tasks on a daily basis. In this research, a control framework for two interchangeable operating modes with a finger joystick and a chin joystick is developed where joysticks seamlessly control a wheelchair and a wheelchair-mounted robotic arm. Custom circuitry was developed to complete the control architecture. A user study was conducted to test the robotic system. Ten healthy individuals agreed to perform three tasks using both (chin and finger) joysticks for a total of six tasks with 10 repetitions each. The control method has been tested rigorously, maneuvering the robot at different velocities and under varying payload (1-3.5 lb) conditions. The absolute position accuracy was experimentally found to be approximately 5 mm. The round-trip delay we observed between the commands while controlling the xArm was 4 ms. Tests performed showed that the proposed control system allowed individuals to perform some ADLs such as picking up and placing items with a completion time of less than 1 min for each task and 100% success.

PMID: 35937617

11. Global prevalence of cerebral palsy: A systematic analysis

Sarah McIntyre, Shona Goldsmith, Annabel Webb, Virginie Ehlinger, Sandra Julsen Hollung, Karen McConnell, Catherine Arnaud, Hayley Smithers-Sheedy, Maryam Oskoui, Gulam Khandaker, Kate Himmelmann, Global CP Prevalence Group*

Dev Med Child Neurol. 2022 Aug 11. doi: 10.1111/dmcn.15346. Online ahead of print.

Aim: To determine trends and current estimates in regional and global prevalence of cerebral palsy (CP). Method: A systematic analysis of data from participating CP registers/surveillance systems and population-based prevalence studies (from birth year 1995) was performed. Quality and risk of bias were assessed for both data sources. Analyses were conducted for pre-/perinatal, postnatal, neonatal, and overall CP. For each region, trends were statistically classified as increasing, decreasing, heterogeneous, or no change, and most recent prevalence estimates with 95% confidence intervals (CI) were calculated. Meta-analyses were conducted to determine current birth prevalence estimates (from birth year 2010). Results: Forty-one regions from 27 countries across five continents were represented. Pre-/perinatal birth prevalence declined significantly across Europe and Australia (11 out of 14 regions), with no change in postneonatal CP. From the limited but increasing data available from regions in low- and middle-income countries (LMICs), birth prevalence for pre-/perinatal CP was as high as 3.4 per 1000 (95%)

CI 3.0-3.9) live births. Following meta-analyses, birth prevalence for pre-/perinatal CP in regions from high-income countries (HICs) was 1.5 per 1000 (95% CI 1.4-1.6) live births, and 1.6 per 1000 (95% CI 1.5-1.7) live births when postneonatal CP was included. Interpretation: The birth prevalence estimate of CP in HICs declined to 1.6 per 1000 live births. Data available from LMICs indicated markedly higher birth prevalence.

PMID: 35952356

12. Describing functional skills in children with cerebral palsy close to age 5 years matters Catherine Arnaud

Dev Med Child Neurol. 2022 Aug 11. doi: 10.1111/dmcn.15372. Online ahead of print.

No abstract available

PMID: 35950892

13. Research on Children With Cerebral Palsy in Low- and Middle-Income Countries Hércules Ribeiro Leite, Pranay Jindal, Sandra Abdel Malek, Peter Rosenbaum

Pediatr Phys Ther. 2022 Aug 12. doi: 10.1097/PEP.000000000000949. Online ahead of print.

The purpose of this special communication is to present ideas and thoughts from a symposium at the 75th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine. These included perspectives and lessons from 3 previously published review studies regarding cerebral palsy (CP) research in Brazil, India, and African countries, which explored the literature through the lens of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework. Using this common lens, first we present the main findings of each of these articles, as well as the similarities and differences in CP research across these low- and middle-income countries (LMICs). Second, considering current evidence, lessons from other LMICs and based on our experiences, we raise recommendations of critical areas to be addressed such as ICF framework implementation and best evidence practice on CP, focusing on prevention, early diagnosis, and intervention (see Supplemental Digital Abstract, available at: http://links.lww.com/PPT/A413).

PMID: 35960038

14. Prevalence, Types, and Outcomes of Cerebral Palsy at a Tertiary Center in Jeddah, Saudi Arabia Basma A Al-Jabri, Alia S Al-Amri, Abdulkarim A Jawhari, Raghad M Sait, Reham Y Talb

Cureus. 2022 Aug 5;14(8):e27716. doi: 10.7759/cureus.27716. eCollection 2022 Aug.

Background: In developed countries, cerebral palsy (CP) is the most common neurological disorder in children. It is defined as a non-progressive disturbance to the developing brain leading to motor impairment that affects the child's activity. CP is classified into three main subtypes: ataxic, spastic, and mixed. Objectives: This study aimed to estimate the prevalence of CP and its subtypes in a single tertiary center located in Jeddah, Saudi Arabia. Method: This retrospective record review study included 98 patients diagnosed with CP from 2004 to 2019. Data were extracted from the hospital medical record and assessed using various tools. Result: The total number of patients was 98, with an estimated CP prevalence of 1.6 per 1000 lives. Most of the patients (74.8%) had spastic CP subtype, and 54.8% had quadriplegia. The mean age of the live children was 7.45 \pm 3.76 years. Moreover, gastrostomy was the most favorable feeding method. Conclusion: The prevalence of CP is almost equivalent to the national and worldwide figures. Spastic CP has the highest rates. Furthermore, the male gender has been identified as a significant risk factor for CP in the local community.

PMID: <u>35935114</u>

15. Current Profile of Physical Impairments in Children with Cerebral Palsy in Inclusive Education Settings: A Cross-Sectional Study

Pardeep K Pahwa, Suresh Mani

J Neurosci Rural Pract. 2022 Jul 1;13(3):424-430. doi: 10.1055/s-0042-1744556. eCollection 2022 Jul.

Introduction: Cerebral palsy (CP) excerpts a heterogeneous corral of neurological disorders occurring due to injury to the developing brain leading to motor dysfunctions. The CP children enjoy success and progress in normal school education and curriculum program. The principle of inclusive education has been acknowledged over recent decades in all countries supporting the schooling of children with disabilities into mainstream settings for constructing an inclusive society. Objective: The objective of this study was to determine the current status of physical impairments in children with CP in inclusive education settings in district Mandi, Himachal Pradesh. Materials and Methods: A survey using the physical examination of all CP children (n = 20) between the age group of 6 and 12 years in inclusive education settings with an organized interview of special educators in school settings was conducted. Descriptive analysis was conducted by using SPSS IBM 22. Results: A total of 20 CP children (11 boys and 9 girls, with the mean age of 9.8 ± 1.69) were enrolled in the study. Mean and standard deviation of Visual Analog Scale (6.5 ± 0.82), Pediatric Balance Scale (21.4 ± 17.1), Gross Motor Function Classification System, Expanded and Revised (2.8 ± 1.46), Manual Ability Classification System (2.5 ± 1.1), Gross Motor Function Measurement-88 (36.40 ± 22.94), and Goal Attainment Scale (35.9 ± 0.40) with the total WeeFIM score (75.7 ± 3.4) were analyzed as the score of all outcome measures. Conclusion: Right to Education act promotes the compulsory education of such children, and limiting disability by knowing the current profile of impairments could help in improving physical and functional status in children.

PMID: 35946009

16. Neurological diseases at the Pediatric Neurology Clinic in a semi-urban Nigerian tertiary hospital Olufemi Samuel Akodu, Tinuade Adetutu Ogunlesi, Abiodun Folashade Adekanmbi, Fatai Adekunle Gbadebo

Sudan J Paediatr. 2022;22(1):83-89. doi: 10.24911/SJP.106-1588669565.

Neurological diseases in children may be associated with mortality and long-term morbidity when they recover from acute ailments. The pattern of neurological disorders in an outpatient service may highlight the burden of these diseases. The objective of the present study is to describe the pattern of neurological disorders at the Pediatric Neurology Clinic of Olabisi Onabanjo University Teaching Hospital (OOUTH), Sagamu, Nigeria. A retrospective analysis of consecutive patients in a Pediatric Neurology Clinic of OOUTH, from 1st January 2011 till 31st December 2014, was carried out. A total of 4,476 patients attended the pediatric outpatient unit. Of these, 433 children had neurological disorders with a prevalence of 9.67%. The most frequent pediatric neurological disorders included seizure disorders (37.7%), cerebral palsy (37.7%), and central nervous system infections with complications (6.2%). The subjects with cerebral palsy were the youngest, while the subjects with seizures were the oldest. This study emphasizes that neurological disease contributes substantially to childhood morbidity in a semi-urban African tertiary hospital.

PMID: 35958080

17. Child disability and family-centred care in East Africa: Perspectives from a workshop with stakeholders and health practitioners

Pauline Samia, Susan Wamithi, Amina Kassam, Melissa Tirkha, Edward Kija, Ayalew Moges, Arnab Seal, Peter Rosenbaum, Robert Armstrong

Afr J Disabil. 2022 Jul 29;11:931. doi: 10.4102/ajod.v11i0.931. eCollection 2022.

Background: Our understanding of child disability has undergone major changes over the last three decades transforming our approach to assessment and management. Globally there are significant gaps in the application of these 21st century models of care. There is recognition that economic, cultural, and social factors influence transitions in care and there is need to consider contextual factors. Objectives: A two-day workshop brought together key stakeholders to discuss current models of care and

their application in the East African context. This article summarises workshop proceedings and identifies a broadly supported set of recommendations that serve to set a direction for health professionals, families, family-based disability organisations, communities and government. Method: Presentations followed by facilitated round-table sessions explored specific themes with participants reporting their responses communally. Future actions were agreed upon by relevant stakeholders. Results: Many barriers exist to care for children with disabilities in East Africa, including stigma and a lack of human and infrastructural resources. In addition, significant disparities exist with regard to access to medication and specialist care. The International Classification of Functioning framework needs to be translated to clinical practice within East Africa, with due recognition of the importance of family-centred care and emphasis on the life course theory for disability care. Family-centred care, educational initiatives, advocacy on the part of stakeholders and involvement of government policymakers are important avenues to improve outcomes. Conclusion: Further education and data are needed to inform family-centred care and multidisciplinary team implementation across East African care contexts for children with disabilities.

PMID: 35936923

18. Life births with cerebral palsy at a tertiary maternity hospital: incidence and associated risk factors over a 17-year period

Tamás Kobezda, Andreas Rehm

J Obstet Gynaecol. 2022 Aug 8;1-8. doi: 10.1080/01443615.2022.2109137. Online ahead of print.

The aim of this retrospective study was to establish the incidence and associated risk factors for cerebral palsy (CP) at a tertiary maternity hospital in the UK between 2000-2016. We identified CP patients from our electronic coding system using ICD codes. Multiple independent variables for all live births born during this period were included in a univariate and multivariate logistic regression (LR) to identify associations between these and CP. We identified 130 CP children out of 87318 live births. Univariate LR determined male sex, birth weight <2500 g, gestational age of ≤36 weeks, Small-for-gestational-age, 1-and 5minute Apgar score <9, neonatal intensive care unit (NICU) admission, multiple births, breech, emergency Caesarean section and delivery between 16.00-20.00 as significant risk factors. In the multivariate LG male sex, 1-minute Apgar <9, 5-minute Apgar <5 and admission to NICU remained as significant risk factors. The risk for delivery between 16.00-19.59 was nearly significant. There was a significant association between NICU admission and moderate-severe CP. Our CP incidence of 0.149% is at the lower end of the incidence spectrum of international comparisons. Impact Statement: What is already known on this subject? The historic reported incidence of cerebral palsy (CP) ranges from 1.1 to 3.6 cases per 1000 live births, with birth weight <2500g, birth <28 weeks of gestation, Apgar scores ≤ 4 and male sex having been associated with an increased incidence. What do the results of this study add? This is a large series of live births from a tertiary maternity hospital with a comparative low CP incidence of 0.149%, despite the hospital dealing with many complex pregnancies and deliveries. We identified that already an Apgar score of <9 at 1 minute (significant) and births between 16.00-20.00 (non-significant) were associated with an increased risk to develop CP but not with a specific day of the week. What are the implications of these findings for clinical practice and/or future research? Our significant association between a 1-minute Apgar score of <9 and CP stresses the importance of immediate efficient resuscitation already for babies with a 1-minute score as high as 8. The increased CP risk for deliveries between 16.00-19.59 may be linked to staffing issues and needs further exploration. What this paper adds: New data from a single maternity hospital, Analysis of risk factors, GMFCS distribution.

PMID: <u>35938283</u>

19. Stability of the Gross Motor Function Classification System over time in children with cerebral palsy Menal Huroy, Tarannum Behlim, John Andersen, David Buckley, Darcy Fehlings, Adam Kirton, Nicole Pigeon, Ram A Mishaal, Ellen Wood, Michael Shevell, Maryam Oskoui

Dev Med Child Neurol. 2022 Aug 8. doi: 10.1111/dmcn.15375. Online ahead of print.

Aim: To assess the stability of the Gross Motor Functional Classification System (GMFCS) in children with cerebral palsy (CP) from time of preliminary diagnosis (~2 years of age) to time of diagnosis (~5 years of age), and to examine factors associated with reclassification. Method: We conducted a longitudinal study using a sample from the Canadian CP Registry. Stability was analysed by using the percentage of agreement between timepoints and a weighted prevalence and bias adjusted kappa statistic. Univariate and multivariate logistic regressions were performed to identify variables associated with reclassification. Results: The study included 1670 children (857 males, 713 females) with a mean age of 11 years 4 months (SD 4 years, range 3 years 5 months-20 years 1 month) at time of data extraction (3rd September 2019), of which 1435 (85.9%)

maintained a stable GMFCS, with a weighted kappa of 0.91 (95% confidence interval 0.89-0.92). Univariate logistic regression showed that initial GMFCS level, CP subtype, and the presence of cognitive impairment were associated with the likelihood of change in the GMFCS level (p < 0.1). In the multivariate analysis, however, the likelihood was associated with initial GMFCS level only (odds ratio 7.10-8.88, p < 0.00). Interpretation: The GMFCS has good stability in early childhood. For the majority of children, it is predictive of their long-term motor function.

PMID: 35941090

20. Underrepresentation of the term cerebral palsy in clinical genetics databases Siddharth Srivastava, Sara A Lewis, Michael C Kruer, Annapurna Poduri

Am J Med Genet A. 2022 Aug 12. doi: 10.1002/ajmg.a.62930. Online ahead of print.

No abstract available

PMID: <u>35959765</u>

21. Impact of assisted reproduction techniques on the neuro-psycho-motor outcome of newborns: a critical appraisal Giuseppe Gullo, Marco Scaglione, Gaspare Cucinella, Antonino Perino, Vito Chiantera, Rosario D'Anna, Antonio Simone Laganà, Giovanni Buzzaccarini

J Obstet Gynaecol. 2022 Aug 12;1-5. doi: 10.1080/01443615.2022.2109953. Online ahead of print.

Subfertility and infertility are common problems among couples of reproductive age, and they increasingly require the use of assisted reproductive techniques (ART). Understandably, doubts about the safety of such methods are increasing among future parents. The purpose of this review is to analyse the real impact of ART, such as in vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI), on the health of the unborn baby; in particular, this work is focussed on the problems related to the neuro-psycho-motor area. Twenty-four studies were reviewed and outcomes investigated were: risk of the onset of neurodevelopmental diseases, worsening of school cognitive performance and risk of developing infantile cerebral palsy (CP) or neurological sequelae. For the first two outcomes, we did not find a correlation with ART; nevertheless, the results of the included studies about risk of CP are discordant and influenced by various confounding factors, such as pre-term birth and multiple pregnancies. IMPACT STATEMENT: What is already known on this subject? Assisted reproductive techniques (ART) are the main answer for achieving pregnancy in infertile couples. However, a wide number of studies have tried to focus on possible different outcomes in terms of maternal and foetal/new-born health. Regarding this scenario, a peculiar importance is given to diseases affecting the neuro-psycho-motor area of the new-born. Since this group of detrimental pathologies could heavily affect the new-born's quality of life and require costly social facilities, different studies have tried to focus on possible outcomes after ART. What do the results of this study add? This manuscript provides a review of the literature regarding ART procedures and neuro-psycho-motor implication. A review is strongly required due to the importance of collecting evidence from studies with different methodologies. What are the implications of these findings for clinical practice and/or further research? This manuscript provides evidence about the need for wider and more congruent studies regarding neurodevelopment disorders in new-borns after ART procedures. Data are prone to suggest a slight correlation, but several confounding factors can heavily hamper the possibility to draw a firm conclusion about the topic.

PMID: 35959847

22. Multisystem inflammatory syndrome in a newborn (MIS-N): clinical evidence and neurodevelopmental outcome Zahra Jamali, Reza Sinaei, Leyla Razi

Case Reports Curr Pediatr Rev. 2022 Aug 6. doi: 10.2174/1573396318666220806143047. Online ahead of print.

Background: Although coronavirus disease-2019 (COVID-19) seems to be milder in children than in adults, children may

exhibit severe multisystemic involvement, supported by growing evidence of this incidence in neonates. This case report aimed to demonstrate an inflammatory response syndrome in a full-term neonate born from a 35-year-old woman infected with severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2). Case presentation: A full-term neonate girl with uneventful perinatal history was admitted with mild tachypnea at the first hour of birth and getting worse gradually, resulting in subsequent ventilator support on the second day. The nasal SARS-CoV-2 real-time polymerase chain reaction (RT-PCR) test was positive in several cessations from the time of admission until the tenth day. She revealed cardiomegaly, a diffuse opacification of lungs in the chest radiograph, both side ventricular hypertrophy, valvular regurgitation, and severe pulmonary hypertension on echocardiography. She underwent treatment with surfactant, antibiotics, paracetamol, inotropes, and sildenafil, with beneficial effects. In the lack of a positive fluid culture, she developed necrotizing enterocolitis, transaminitis, and a generalized rash on day six. Furthermore, her mild brain edema that occurred on the second day developed into hydrocephaly. The patient was considered MIS-N and successfully treated with methylprednisolone pulse and intravenous immunoglobulin. She was discharged after 29-days and followed for eight months with persistent mild hydrocephalous and possible evidence of cerebral palsy. Conclusions: We conclude that maternal exposure to COVID-19 may potentially be associated with multisystem inflammation in the early neonatal period. However, this condition is relatively rare. Immunomodulatory agents may be beneficial in this condition.

PMID: 35946103

23. Different corticosteroids and regimens for accelerating fetal lung maturation for babies at risk of preterm birth Myfanwy J Williams, Jenny A Ramson, Fiona C Brownfoot

Review Cochrane Database Syst Rev. 2022 Aug 9;8(8):CD006764. doi: 10.1002/14651858.CD006764.pub4.

Background: Despite the widespread use of antenatal corticosteroids to prevent respiratory distress syndrome (RDS) in preterm infants, there is currently no consensus as to the type of corticosteroid to use, dose, frequency, timing of use or the route of administration. OBJECTIVES: To assess the effects on fetal and neonatal morbidity and mortality, on maternal morbidity and mortality, and on the child and adult in later life, of administering different types of corticosteroids (dexamethasone or betamethasone), or different corticosteroid dose regimens, including timing, frequency and mode of administration. Search methods: For this update, we searched Cochrane Pregnancy and Childbirth Group's Trials Register, ClinicalTrials.gov, the WHO International Clinical Trials Registry Platform (ICTRP) (9 May 2022) and reference lists of retrieved studies. Selection criteria: We included all identified published and unpublished randomised controlled trials or quasi-randomised controlled trials comparing any two corticosteroids (dexamethasone or betamethasone or any other corticosteroid that can cross the placenta), comparing different dose regimens (including frequency and timing of administration) in women at risk of preterm birth. We planned to exclude cross-over trials and cluster-randomised trials. We planned to include studies published as abstracts only along with studies published as full-text manuscripts. Data collection and analysis: At least two review authors independently assessed study eligibility, extracted data and assessed the risk of bias of included studies. Data were checked for accuracy. We assessed the certainty of the evidence using GRADE. Main results: We included 11 trials (2494 women and 2762 infants) in this update, all of which recruited women who were at increased risk of preterm birth or had a medical indication for preterm birth. All trials were conducted in high-income countries. Dexamethasone versus betamethasone Nine trials (2096 women and 2319 infants) compared dexamethasone versus betamethasone. All trials administered both drugs intramuscularly, and the total dose in the course was consistent (22.8 mg or 24 mg), but the regimen varied. We assessed one new study to have no serious risk of bias concerns for most outcomes, but other studies were at moderate (six trials) or high (two trials) risk of bias due to selection, detection and attrition bias. Our GRADE assessments ranged between high- and low-certainty, with downgrades due to risk of bias and imprecision. Maternal outcomes The only maternal primary outcome reported was chorioamnionitis (death and puerperal sepsis were not reported). Although the rate of chorioamnionitis was lower with dexamethasone, we did not find conclusive evidence of a difference between the two drugs (risk ratio (RR) 0.71, 95% confidence interval (CI) 0.48 to 1.06; 1 trial, 1346 women; moderate-certainty evidence). The proportion of women experiencing maternal adverse effects of therapy was lower with dexamethasone; however, there was not conclusive evidence of a difference between interventions (RR 0.63, 95% CI 0.35 to 1.13; 2 trials, 1705 women; moderate-certainty evidence). Infant outcomes We are unsure whether the choice of drug makes a difference to the risk of any known death after randomisation, because the 95% CI was compatible with both appreciable benefit and harm with dexamethasone (RR 1.03, 95% CI 0.66 to 1.63; 5 trials, 2105 infants; moderate-certainty evidence). The choice of drug may make little or no difference to the risk of RDS (RR 1.06, 95% CI 0.91 to 1.22; 5 trials, 2105 infants; high-certainty evidence). While there may be little or no difference in the risk of intraventricular haemorrhage (IVH), there was substantial unexplained statistical heterogeneity in this result (average (a) RR 0.71, 95% CI 0.28 to 1.81; 4 trials, 1902 infants; $I^2 = 62\%$; low-certainty evidence). We found no evidence of a difference between the two drugs for chronic lung disease (RR 0.92, 95% CI 0.64 to 1.34; 1 trial, 1509 infants; moderate-certainty evidence), and we are unsure of the effects on necrotising enterocolitis, because there were few events in the studies reporting this outcome (RR 5.08, 95% CI 0.25 to 105.15; 2 studies, 441 infants; low-certainty evidence). Longerterm child outcomes Only one trial consistently followed up children longer term, reporting at two years' adjusted age. There is probably little or no difference between dexamethasone and betamethasone in the risk of neurodevelopmental disability at follow-up (RR 1.02, 95% CI 0.85 to 1.22; 2 trials, 1151 infants; moderate-certainty evidence). It is unclear whether the choice

of drug makes a difference to the risk of visual impairment (RR 0.33, 95% CI 0.01 to 8.15; 1 trial, 1227 children; low-certainty evidence). There may be little or no difference between the drugs for hearing impairment (RR 1.16, 95% CI 0.63 to 2.16; 1 trial, 1227 children; moderate-certainty evidence), motor developmental delay (RR 0.89, 95% CI 0.66 to 1.20; 1 trial, 1166 children; moderate-certainty evidence) or intellectual impairment (RR 0.97, 95% CI 0.79 to 1.20; 1 trial, 1161 children; moderate-certainty evidence). However, the effect estimate for cerebral palsy is compatible with both an important increase in risk with dexamethasone, and no difference between interventions (RR 2.50, 95% Cl 0.97 to 6.39; 1 trial, 1223 children; lowcertainty evidence). No trials followed the children beyond early childhood. Comparisons of different preparations and regimens of corticosteroids We found three studies that included a comparison of a different regimen or preparation of either dexamethasone or betamethasone (oral dexamethasone 32 mg versus intramuscular dexamethasone 24 mg; betamethasone acetate plus phosphate versus betamethasone phosphate; 12-hourly betamethasone versus 24-hourly betamethasone). The certainty of the evidence for the main outcomes from all three studies was very low, due to small sample size and risk of bias. Therefore, we were limited in our ability to draw conclusions from any of these studies. Authors' conclusions: Overall, it remains unclear whether there are important differences between dexamethasone and betamethasone, or between one regimen and another. Most trials compared dexamethasone versus betamethasone. While for most infant and early childhood outcomes there may be no difference between these drugs, for several important outcomes for the mother, infant and child the evidence was inconclusive and did not rule out significant benefits or harms. The evidence on different antenatal corticosteroid regimens was sparse, and does not support the use of one particular corticosteroid regimen over another.

PMID: 35943347

24. Neurodevelopmental outcomes in a cohort of children with congenital Zika syndrome at one and two years of age Fernanda J P Marques, Claret Amarante, Renata Klein, Marco Aurelio C Elias, Osvaldo J M Nascimento, Marcio Leyser

Child Care Health Dev. 2022 Aug 12. doi: 10.1111/cch.13044. Online ahead of print.

Background: Early child development is a critical stage of life that influences social, educational, and health outcomes worldwide. A few years after Zika epidemic, families of children born with congenital Zika syndrome (CZS) continue to face uncertainties when it comes to the development of their children. The present study sought to analyze the developmental trajectories of a subset of children born with CZS in the first 24 months of life. Methods: Thirty-five children with CZS were assessed with the Bayley-III Scales at 12 and 24 months of age from November 2016 to December 2018 in a rehabilitation center in Brazil. Inclusion criteria included children with established diagnosis of CZS. Exclusion criteria included the presence of arthrogryposis, prematurity, irregular follow-up, clinical complications, or other causes of microcephaly. Children born with CZS who evolved with cerebral palsy (CP) were classified according to the Gross Motor Function Classification System (GMFCS) at two years of age. Results: At 12 months of age mean composite scores on the Bayley cognitive, communication and motor scores were 57.71 (SD 7.11), 57.94 (SD 14.34) and 49.26 (7.20), respectively. At 24 months of age composite scores were 57.43 (SD 7.11), 53.60 (SD 12.29) and 48.83 (7.76). In addition, 31 (88.57%) out of 34 children diagnosed with CP were classified as GMFCS levels IV and V. Conclusion: Zika virus congenital infection is a risk factor for functional impairments across all developmental domains having a direct and substantial negative impact in early child development.

PMID: 35959569

25. Outcome at 4.5 years after dextrose gel treatment of hypoglycaemia: follow-up of the Sugar Babies randomised trial Deborah L Harris, Greg D Gamble, Jane E Harding, CHYLD Study Group

Arch Dis Child Fetal Neonatal Ed. 2022 Aug 8; fetalneonatal-2022-324148. doi: 10.1136/archdischild-2022-324148. Online ahead of print.

Objective: Dextrose gel is used to treat neonatal hypoglycaemia, but later effects are unknown. Design and setting: Follow-up of participants in a randomised trial recruited in a tertiary centre and assessed in a research clinic. Patients: Children who were hypoglycaemic (<2.6 mmol/L) recruited to the Sugar Babies Study (>35 weeks, <48 hours old) and randomised to treatment with 40% dextrose or placebo gel. Interventions: Assessment of neurological status, cognitive ability (Weschler Preschool and Primary Scale of Intelligence), executive function (five tasks), motor function (Movement Assessment Battery for Children-2 (MABC-2)), vision, visual processing (Beery-Buktenica Development Test of Visual Motor Integration (Beery VMI) and motion coherence thresholds) and growth at 2 years. Main outcome measures: Neurosensory impairment (cerebral palsy; visual impairment; deafness; intelligence quotient <85; Beery VMI <85; MABC-2 score <15th centile; low performance on executive function or motion coherence). Results: Of 237 babies randomised, 185 (78%) were assessed; 96 randomised to dextrose and

89 to placebo gel. Neurosensory impairment was similar in both groups (dextrose 36/96 (38%) vs placebo 34/87 (39%), relative risk 0.96, 95% CI 0.66 to 1.34, p=0.83). Secondary outcomes were also similar, except children randomised to dextrose had worse visual processing scores (mean (SD) 94.5 (15.9) vs 99.8 (15.9), p=0.02) but no differences in the proportion with visual processing scores <85 or other visual test scores. Children randomised to dextrose gel were taller (z-scores 0.18 (0.97) vs -0.17 (1.01), p=0.001) and heavier (0.57 (1.07) vs 0.29 (0.92), p=0.01). Conclusions: Treatment of neonatal hypoglycaemia (<2.6 mol/L) with dextrose gel does not alter neurosensory impairment at 4.5 years. However, further assessment of visual processing and growth may be warranted. Trial registration number: ACTRN1260800062392.

PMID: <u>35940872</u>

26. Preterm General Movements in Prediction of Neurodevelopmental Disability and Cerebral Palsy at Two Years: A Prospective Cohort Study

Hima B John, Samuel P Oommen, T O Swathi, Manish Kumar, Ragnhild Stoen, Lars Adde

Indian Pediatr. 2022 Aug 10;S097475591600443. Online ahead of print.

Background: A neurological assessment before discharge from the NICU would enable early targeted intervention to mitigate the risk and severity of cerebral palsy (CP) and neurodevelopmental disability. Objective: To assess the accuracy of general movements (GM) in the preterm and fidgety movement periods in predicting neurodevelopmental disability and cerebral palsy in very preterm infants (\leq 32 weeks gestational age) at 18-24 months corrected gestational age. Study design: Prospective cohort study. Participants: One hundred and seventy very preterm infants, mean (SD) gestation 29.8 (1.32) weeks, and birthweight 1215 (226) g. Outcomes: Infants underwent GM assessments in the preterm period (31-36 weeks post-conception age and fidgety movement period (8-18 weeks post term age). Neurodevelopmental outcomes were assessed in 127 children using the Griffiths Mental Developmental delay. The relative risk (95% CI) for neurodevelopmental disability was 1.46 (0.31-6.89) with preterm movements and 6.07 (0.97 - 38.05) with fidgety movements. Sensitivity and specificity values for the prediction of neurodevelopmental disability were 33% and 64% in the preterm period and 25% and 92% in the fidgety movement period, respectively. The sensitivity and specificity values for prediction of CP were 50% and 63% in the preterm period and 100% and 93% in the fidgety movement period, respectively. Conclusion: Preterm movements showed lower sensitivity and specificity than fidgety movements in predicting later CP and neurodevelopmental disability in preterm infants.

PMID: 35959757

27. Spasticity Measurement Tools and Their Psychometric Properties Among Children and Adolescents With Cerebral Palsy: A Systematic Review

Saleh M Aloraini, Amnah M Alassaf, Mada M Alrezgan, Mishal M Aldaihan

Pediatr Phys Ther. 2022 Aug 2. doi: 10.1097/PEP.000000000000938. Online ahead of print.

Purpose: To identify and appraise the literature on the psychometric properties of spasticity measures that have been used among children and adolescents with cerebral palsy (CP). Methods: A comprehensive literature search was conducted in 5 databases. Two independent reviewers screened the literature search results for relevant studies. Reviewers extracted the data using a standardized form and study quality was assessed using a critical appraisal tool. Results: A total of 44 studies met the selection criteria and were included. We identified 22 different spasticity assessment tools, with different levels of evidence regarding their psychometric properties. Conclusion: The findings of the current review indicate that there is limited evidence to recommend 1 spasticity assessment method for children and adolescents with CP. Spasticity assessment in its current state lacks a method that possesses the necessary psychometric properties and is easily used in the clinical setting.

PMID: 35943394

28. Stress and Coping among Caregivers of Differently Able Children

Sharada Sharma, Jaya Subedi

J Nepal Health Res Counc. 2022 Jun 2;20(1):186-193. doi: 10.33314/jnhrc.v20i01.4069.

Background: Caring differently able children can cause stress in the caregivers. They employ a variety of coping mechanisms to deal with stress. The aim of this study is to identify stress and different coping styles among caregivers of differently able children. Methods: A cross-sectional study was carried out in three organizations that accommodated differently abled children. A non-probability purposive sampling technique was used to recruit primary caregivers of children with developmental disabilities. This study examined caregiver stress and different coping styles by using the Parent Stress Scale and Brief COPE Inventory. Face-to-face interviews were used to collect data, which was then analyzed using SPSS. Results: Among the total of 102 caregivers, mothers accounted for 60.8 percent, 57.8 percent child were boys whereas, 49 percent were the child with cerebral palsy. Total mean stress score was 57.17 ± 8.808 . High level of stress was reported by 58.8 percent of caregivers. Education and family income showed the statistically significant association with stress score P-value<0.05. Total mean coping score was 67.83 ± 5.812 . Caregivers' stress had significant positive correlation with different coping styles; active coping, denial, behavioral disengagement, humor, acceptance religion and self-blame (P-value<0.05). Conclusions: More than half of the caregivers' stress had significant positive correlation with different coping styles, health professionals and service providers should focus on stress reduction and positive coping technique to help family adaptation.

PMID: <u>35945874</u>

29. Transition program: Initial implementation with adults with neuromuscular conditions

Eduardo Del Rosario, Adella Bodden, Debra A Sala, Aline Goodman, Connie Lam, Mara Karamitopoulos

J Pediatr Nurs. 2022 Aug 5;67:52-56. doi: 10.1016/j.pedn.2022.06.012. Online ahead of print.

Purpose: To identify current medical and psychosocial needs and to examine the effectiveness of healthcare transition program for adult-aged patients with neuromuscular conditions transitioning from pediatric to adult services. Design and methods: At Neuromuscular Transition Clinic visit, 46 patients were evaluated and referred to adult-based providers, if did not currently have one, from an acquired list of interested clinicians. At mean follow-up of 22 months, 42 were interviewed by phone regarding referrals for Core Services (primary care, physiatry, dental care and gynecology), Medical Specialties and Rehabilitation Services. Mean age was 30 years with 62% males. Majority (74%) had cerebral palsy. Sixty percent were nonambulatory. Results: As per protocol, all were indicated to need Core Services. Eighty-three percent already had adult primary care provider. Most referrals were given for physiatry (62%), vocational training (100%), and occupational therapy (88%). At follow-up, visits were completed most frequently with adult provider for primary care (100%), occupational therapy (78%), and neurology (75%). Referred provider was seen 100% for physiatry, neurology, physical therapy, occupational therapy and vocational training. Of the total 125 referrals given across all services, 73 (58%) participants had completed a visit with an adult provider. Conclusions: As only about 60% transitioned to adult-based services after referral, healthcare transition remains challenging and requires tailoring of services according to patients' needs, staff and willing-and-available adult-based providers. Practice implications: Transitioning healthcare of patients with neuromuscular conditions from pediatric- to adultbased providers remains challenging. This clinical specialty requires tailoring of services based on patient's needs, and availability of adult-based providers and resources.

PMID: 35939953

30. A Review on Recent Advances of Cerebral Palsy

Sudip Paul , Anjuman Nahar, Mrinalini Bhagawati, Ajaya Jang Kunwar

Review Oxid Med Cell Longev. 2022 Jul 30;2022:2622310. doi: 10.1155/2022/2622310. eCollection 2022.

This narrative review summarizes the latest advances in cerebral palsy and identifies where more research is required. Several studies on cerebral palsy were analyzed to generate a general idea of the prevalence of, risk factors associated with, and classification of cerebral palsy (CP). Different classification systems used for the classification of CP on a functional basis

were also analyzed. Diagnosis systems used along with the prevention techniques were discussed. State-of-the-art treatment strategies for CP were also analyzed. Statistical distribution was performed based on the selected studies. Prevalence was found to be 2-3/1000 lives; the factors that can be correlated are gestational age and birth weight. The risk factors identified were preconception, prenatal, perinatal, and postnatal categories. According to the evidence, CP is classified into spastic (80%), dyskinetic (15%), and ataxic (5%) forms. Diagnosis approaches were based on clinical investigation and neurological examinations that include magnetic resonance imaging (MRI), biomarkers, and cranial ultrasound. The treatment procedures found were medical and surgical interventions, physiotherapy, occupational therapy, umbilical milking, nanomedicine, and stem cell therapy. Technological advancements in CP were also discussed. CP is the most common neuromotor disability with a prevalence of 2-3/1000 lives. The highest contributing risk factor is prematurity and being underweight. Several preventions and diagnostic techniques like MRI and ultrasound were being used. Treatment like cord blood treatment nanomedicine and stem cell therapy needs to be investigated further in the future to apply in clinical practice. Future studies are indicated in the context of technological advancements among cerebral palsy children.

PMID: 35941906