Models of transitional care for young people with complex health needs: a scoping review.

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Background: Young people with complex healthcare needs (CHNs) face the challenge of transferring from child to adult health services. This study sought to identify successful models of transitional care for young people with CHNs. Three conditions were used as exemplars: cerebral palsy, autism spectrum disorders and diabetes.

Methods: Scoping review: using search terms concerning transitional care, four databases were systematically searched for papers published in English between 1980 and April 2010. Additional informal search methods included recommendations from colleagues working with young people with each of the three conditions and making contact with clinical and research teams with expertise in transitional care. Inclusion and exclusion criteria were applied to define the papers selected for review. A separate review of policy documents, adolescent health and transition literature was also undertaken; 10 common summary categories for the components of high-quality services were identified. All papers were coded using a framework analysis which evaluated the data in two ways using the 10 transition categories and four elements of Normalization Process Theory that are important for successful implementation and integration of healthcare interventions. Results: Nineteen papers were selected for review. A very limited literature of models of service provision was identified for young people with cerebral palsy and diabetes. No models were identified for young people with autism spectrum disorders. Furthermore most publications were either descriptions of new service provision or time-limited pilot studies with little service evaluation or consideration of key elements of effective implementation. Conclusions: Despite agreement about the importance of effective transitional care, there is a paucity of evidence to inform best practice about both the process of and what constitutes effective transitional care. There is therefore an urgent need for research to evaluate current transitional care practices for young people with CHNs.

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Using the Gross Motor Function Classification System to describe patterns of motor severity in cerebral palsy.

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Aim: The aim of this study was to describe the distribution of motor severity levels and temporal trends in an Australian population cohort and to review the distribution of Gross Motor Function Classification System (GMFCS) levels across cerebral palsy (CP) registries worldwide. Methods: Data were extracted from the Victorian Cerebral Palsy Register for 3312 individuals (1852 males, 1460 females; mean age 21y 2mo [SD 9y 6mo]) with non-postneonatally acquired CP, born between 1970 and 2003. The proportions of each motor severity level were calculated and logistic regression analyses were used to assess trends over time. A systematic review of the literature was undertaken and GMFCS data were extracted based on previously devised criteria. The proportions were plotted and the degree of heterogeneity was assessed for each level. Results: Population data from Victoria suggested a proportional increase in mild motor impairment (GMFCS levels I/II) from 54% of all cases of CP in the 1970s to 61% in the 2000s. For nine CP registries worldwide, the mean proportions of each GMFCS level, from level I to V, were 34.2%, 25.6%, 11.5%, 13.7%, and 15.6% respectively. There was substantial heterogeneity between registries for all levels except level III. Interpretation: Despite the usefulness and reported reliability of the GMFCS, substantial variability was found in the distribution of GMFCS levels between population registries, particularly between levels I and II, suggesting greater classification uncertainty between these levels. Further research would be useful to determine whether routine collection of extra clinical information may facilitate more reliable classification.


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Reliability of GMFCS family report questionnaire.

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Purpose: To examine the reliability of the web-based GMFCS Family Report Questionnaire (GMFCS-FR) between 8 and 11 years old children, compared with the GMFCS-Expanded and Revised (GMFCS-E&R). Method: The GMFCS-FR was translated from the English GMFCS-FR into Danish after the CanChild guidelines; only the order of levels was chosen like in the GMFCS-E&R. Families of 30 children with spastic and dystonic cerebral palsy (age from 8 to 11 years, randomly selected from a cerebral palsy register) answered the GMFCS-FR and were later interviewed by two physiotherapists. Participants and non-responders were compared on basic parameters available from the Danish CP register. Inter-rater agreement and weighted $\kappa$ was calculated in order to compare the translated GMFCS-FR with physiotherapist's applied GMFCS-E&R. Results: The inter-rater agreement between the GMFCS-FR in Danish and the GMFCS-E&R was high (76%) and misclassification was minimal. There was a good agreement on the same or nearby levels (weighted $\kappa = 0.76$ and 0.81). The family rated the same or less ability, when compared with trained physiotherapists. Conclusion: The GMFCS-FR is a reliable tool for GMFCS evaluation among 8-11 years old Danish children with CP. The tendency for less-ability rating by families is important when performing and comparing results from epidemiological studies based on GMFCS-FR and GMFCS-E&R.

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The use of the Gross Motor Function Classification System in cerebral palsy registers: quo vadis?

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From 'one size fits all' to tailor-made physical intervention for cerebral palsy.

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Characteristics of recurrent musculoskeletal pain in children with cerebral palsy aged 8 to 18 years.

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Aim: The aim of this study was to explore the prevalence, predictors, severity, and impact of recurrent musculoskeletal pain in children and adolescents with cerebral palsy (CP). Method: One hundred and fifty-three participants (81 males, 72 females) aged 8 to 18 years were assessed by clinical examination, interview, and questionnaires. CP type distribution was 38% unilateral spastic, 55% bilateral spastic, 6% dyskinetic, and 1% ataxic. Gross Motor Function Classification System (GMFCS) levels were as follows: level I, 54; level II, 56; level III, 20; level IV, 8; and level V, 15. Sixty-four children and 89 parents recorded pain on the Child Health Questionnaire, 56 children and 85 parents indicated impact of pain on 0 to 10 numeric rating scales, and 72 children indicated pain intensity on the Faces Pain Scale-Revised. Results: Ninety-five (62%) children across all GMFCS levels experienced recurrent musculoskeletal pain. Age above 14 years was the only significant predictor (OR 2.90, 95% CI 1.22-7.80, p=0.02, adjusted for sex, CP type, gross motor function and mother's education). Children reported recurrent musculoskeletal pain to be moderate. Parents reported pain to be more severe and with higher impact on sleep than their children did. Children and parents reported similar impact of pain on general activity and walking. Interpretation: Recurrent musculoskeletal pain is the dominating pain problem in children and adolescents with CP. Monitoring of musculoskeletal pain should be part of the medical follow-up across the whole range of motor impairment.


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Mechanical implant failure in posterior cervical spine fusion.

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PURPOSE: The aim of this study was to determine whether the recent refinement and downsizing of the implants for posterior cervical fusion increase the occurrence of implant failure. METHODS: One hundred forty-two consecutive cases of cervical fusion, using either cannulated Magerl screws or a multiaxial pedicle screw-rod system, were reviewed retrospectively after an average follow-up period of more than 3 years, and the rate and characteristics of the failure of these implants were evaluated. RESULTS: Implant failure occurred in six (4.2%) patients: five with rheumatoid arthritis and one with athetoid cerebral palsy. Occipital plate fracture occurred in two patients, Magerl screw breakage in one patient, cervical pedicle screw fracture in two patients, and disassembly of the pedicle screw and rod in two patients (one with an occipital plate fracture). There was no rod fracture. The implant failures were asymptomatic, except in one patient. Disassembly of the pedicle screw and rod was observed immediately after another surgical procedure under general anesthesia in two patients. CONCLUSIONS: The failure rate of 4.2% was similar to the rates reported in the literature for posterior lumbar spinal fusion, confirming the reliability of the recent cervical screw-rod system.

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Assisting people with multiple disabilities by actively keeping the head in an upright position with a Nintendo Wii Remote Controller through the control of an environmental stimulation.

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The latest researches have adopted software technology by applying the Nintendo Wii Remote Controller to the correction of hyperactive limb behavior. This study extended Wii Remote Controller functionality for improper head position (posture) correction (i.e. actively adjusting abnormal head posture) to assess whether two people with multiple disabilities would be able to actively keep the upright head position by controlling their favorite stimulation using a Wii Remote Controller with a newly developed active head position correcting program (AHPCP). The study was performed according to an ABAB design, in which A represented the baseline and B represented intervention phases. Results showed that both participants significantly increased their time duration of maintaining upright head position (TDMUHP) to obtain the desired environmental stimulation during the intervention phases. Practical and developmental implications of the findings were discussed.

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Effect of load carriage on chronic low back pain in adults with cerebral palsy.

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Background: Chronic low back pain (LBP) is a common secondary musculoskeletal problem among adults with cerebral palsy (CP). This study investigated the feasibility of incorporating backpack carriage with daily production activities for relieving chronic LBP among adults with CP. Objectives: The effects of backpack carriage in relieving chronic LBP for adults with CP. Study Design: A multiple bivariate approach with convenience sampling. Methods: Nine adults with CP suffering from chronic LBP were scheduled to carry a 4 lb backpack at work for 60 minutes on weekdays for four consecutive weeks. The pain level was rated by the participants on an 11-point scale. Muscle activity of erector spinae was measured by surface electromyography. Results: Significant improvement in back pain was found immediately after the backpack carriage with no adverse effect reported. It was accompanied with significantly reduced erector spinae activity. Although the overall change in pain ratings across the study period was...
not significant, a decreasing trend with time was observed. Conclusions: The loaded backpack has the potential to serve as an 'orthosis' for immediate back pain relief among adults with CP. Its underlying mechanism can be attributed to a reduction in back muscle tension during the load carriage.

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The Mini Nutritional Assessment (MNA) is useful for assessing the risk of malnutrition in adults with intellectual disabilities.

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Aim. The study was aimed to examine the appropriateness of using the Mini Nutritional Assessment to screen for risk of under- and over-nutrition in adults with intellectual disabilities. Background. Persons with intellectual disabilities are at increased risk of malnutrition, but routine monitoring of their nutritional conditions are not widely done. Design. The study purposively recruited 104 institutionalised adults (≥19 years old) with intellectual disabilities to serve as participants. Methods. Participants were interviewed with a structured questionnaire to elicit personal data, health-related information and answers to items in the Activities of Daily Living and the Mini Nutritional Assessment scales and measured for anthropometrics. Biochemical data were taken from their routine medical measurements. Each subject was graded with the Mini Nutritional Assessment that adopted Taiwanese-specific anthropometric cut-off points (T1) and an alternative version that omitted the body mass index item (T2). Results. Both Mini Nutritional Assessment versions were able identifying individuals at risk of malnutrition among adults with intellectual disabilities and rated comparable proportions of patients malnourished (6.7 and 5.8% for Mini Nutritional Assessment-T1 and Mini Nutritional Assessment-T2, respectively) or at risk of malnutrition (14.4 and 17.3%, respectively). Persons with cerebral palsy were at greater risk of malnourishment than persons with other disabilities. Conclusion. The Mini Nutritional Assessment is appropriate for screening for under- and over-nutrition in adults with intellectual disabilities. The Mini Nutritional Assessment (especially the version without body mass index) can make routine monitoring of nutritional status of these patients an easier task. However, further studies are needed to develop subtype-specific versions (tools) as various subtypes of intellectual disability are associated with different nutritional problems. Relevance to clinical practice. The Mini Nutritional Assessment can serve as a tool for routine screening for under- and over-nutrition in persons with intellectual disabilities.

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Development and Validation of a Model for Predicting Inpatient Hospitalization.

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BACKGROUND: Hospitalizations are costly for health insurers and society. OBJECTIVES: To develop and validate a predictive model for acute care hospitalization from administrative claims for a population including all age groups. RESEARCH DESIGN: We constructed a retrospective cohort study using a US health plan claims database, including annual person-level files with demographic markers, and morbidity and utilization measures. We developed and validated the model using separate data. PARTICIPANTS: The validation sample included 4.7 million persons enrolled for at least 6 months in 2006 and 1 or more months in 2007. MEASURES: Risk factors and
outcome variables were obtained from administrative claims data using the Adjusted Clinical Group (ACG) system. Utilization variables were added, and models were fitted with multivariate logistic regression. RESULTS: A 3.2% of patients had a hospitalization during a 1-year period, and 20% of patients who had been hospitalized during the previous year were rehospitalized. Effect sizes of risk factors were modest with odds ratios <1.5. Odds ratios were greater than 1.5 for age ≥80 years, 3+ prior hospitalizations, 3+ emergency room visits, 20 ACG morbidity categories, and 40 diseases including high impact neoplasms, bipolar disorder, cerebral palsy, chromosomal anomalies, cystic fibrosis, and hemolytic anemia. Model performance of ACG hospitalization models was good (AUC=0.80) and superior to a prior hospitalization model (AUC=0.75) and a Charlson comorbidity hospitalization model (AUC=0.78). CONCLUSIONS: A validated population-based predictive model for hospital risk estimates individual risk for future hospitalization. The model could be useful to health plans and care managers.

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Effect of a clown’s presence at botulinum toxin injections in children: a randomized, prospective study.

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BACKGROUND: The effect of the presence of a hospital clown during pediatric procedures has rarely been evaluated. In a pediatric ward, botulinum toxin injection is a painful procedure and a stressful experience for the child. We undertook a study of the effect of the presence of a hospital clown on children treated with botulinum toxin in an outpatient setting. METHODS: In total, 60 children, the majority of whom had spastic cerebral palsy, were subjected to a total of 121 botulinum toxin treatment sessions. Thirty-two children were being treated for the first time. During a 2-year period, we enrolled 121 treatment sessions prospectively, and the children were randomized to either the presence of a female clown during treatment or to no presence of a clown. The duration of the child's crying during the procedure was used as an indicator of the effect of the presence of a clown. RESULTS: The effect of the clown was significantly related to patient gender. Girls were found to have a significantly shorter period of crying when the clown was present. For children younger than 8 years, the effect on boys was negative. Children treated for the first time did not appear to benefit from the presence of the clown, and showed no difference in effect between genders. CONCLUSION: No effect of the clown was documented for children being treated for the first time. At repeat treatments, we saw a positive effect of the female clown in relation to girls, and a negative effect on boys younger than 8 years of age.

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Background: Each of the 4 randomized clinical trials (RCTs) hosted by the Physical Therapy Clinical Research Network (PTClinResNet) targeted a different disability group (low back disorder in the Muscle-Specific Strength Training Effectiveness After Lumbar Microdiscectomy [MUSSEL] trial, chronic spinal cord injury in the Strengthening and Optimal Movements for Painful Shoulders in Chronic Spinal Cord Injury [STOMPS] trial, adult stroke in the Strength Training Effectiveness Post-Stroke [STEPS] trial, and pediatric cerebral palsy in the Pediatric Endurance and Limb Strengthening [PEDALS] trial for children with spastic diplegic cerebral palsy) and tested the effectiveness of a muscle-specific or functional activity-based intervention on primary outcomes that captured pain (STOMPS, MUSSEL) or locomotor function (STEPS, PEDALS). ObjectiveThe focus of these secondary analyses...
was to determine causal relationships among outcomes across levels of the International Classification of Functioning, Disability and Health (ICF) framework for the 4 RCTs. Method and Design: With the database from PTClinResNet, we used 2 separate secondary statistical approaches-mediation analysis for the MUSSEL and STOMPS trials and regression analysis for the STEPS and PEDALS trials-to test relationships among muscle performance, primary outcomes (pain related and locomotor related), activity and participation measures, and overall quality of life. RESULTS: Predictive models were stronger for the 2 studies with pain-related primary outcomes. Change in muscle performance mediated or predicted reductions in pain for the MUSSEL and STOMPS trials and, to some extent, walking speed for the STEPS trial. Changes in primary outcome variables were significantly related to changes in activity and participation variables for all 4 trials. Improvement in activity and participation outcomes mediated or predicted increases in overall quality of life for the 3 trials with adult populations. Limitations: Variables included in the statistical models were limited to those measured in the 4 RCTs. It is possible that other variables also mediated or predicted the changes in outcomes. The relatively small sample size in the PEDALS trial limited statistical power for those analyses. CONCLUSIONS: Evaluating the mediators or predictors of change between each ICF level and for 2 fundamentally different outcome variables (pain versus walking) provided insights into the complexities inherent across 4 prevalent disability groups.

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Prevention and Cure


Neonatal white matter abnormality predicts childhood motor impairment in very preterm children.


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Aim: Children born very preterm are at risk for impaired motor performance ranging from cerebral palsy (CP) to milder abnormalities, such as developmental coordination disorder. White matter abnormalities (WMA) at term have been associated with CP in very preterm children; however, little is known about the impact of WMA on the range of motor impairments. The aim of this study was to assess whether WMA were predictive of all levels of motor impairments in very preterm children. Method: Two hundred and twenty-seven very preterm infants (<30wks gestational age or birthweight <1250g) had brain magnetic resonance imaging at term-equivalent age to assess for WMA, which were categorized as nil, mild, or moderate to severe. At 5 years of age children were classified as having a moderate to severe motor impairment if they were below the 5th centile or mild to severe motor impairment if their score placed them no higher than the 15th centile on the Movement Assessment Battery for Children (MABC). WMA (nil vs mild and nil vs moderate-severe) were explored as predictors of motor impairment using logistic regression. Analyses were repeated adjusting for the effects of other perinatal variables and excluding children with CP. Results: Of the 193 very preterm children (97 males, 96 females) assessed with the MABC, 53 (27%) were classified as having a moderate to severe motor impairment and 96 (50%) a mild to severe motor impairment if their score placed them no higher than the 15th centile on the Movement Assessment Battery for Children (MABC). WMA (nil vs mild and nil vs moderate-severe) were explored as predictors of motor impairment using logistic regression. Analyses were repeated adjusting for the effects of other perinatal variables and excluding children with CP. Results: Of the 193 very preterm children (97 males, 96 females) assessed with the MABC, 53 (27%) were classified as having a moderate to severe motor impairment and 96 (50%) a mild to severe motor impairment. WMA were predictive of motor impairment in very preterm children, with mild versus no WMA increasing the odds of moderate to severe motor impairment by over fivefold (odds ratio [OR] 5.6; 95% confidence interval [CI] 1.9-16.1; p=0.002) and mild to severe impairment by twofold (OR 2.2; 95% CI 1.1-4.2; p=0.02). Compared with no WMA, moderate to severe WMA increased the odds for moderate to severe impairment 19-fold (OR 19.4; 95% CI 5.6-66.7; p<0.001) and for mild to severe motor impairment ninefold (OR 9.4; 95% CI 3.2-28.1; p<0.001). Results remained similar after controlling for several potential confounders and after excluding 14 children who had CP at age 2 years. Interpretation: WMA predict motor impairment at 5 years, with rates of impairment increasing with more severe WMA. Very preterm children with any WMA at term require follow-up throughout childhood.

Magnesium sulfate therapy for the prevention of cerebral palsy in preterm infants: a decision-analytic and economic analysis.

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OBJECTIVE: We sought to estimate the cost-effectiveness of magnesium neuroprophylaxis for all women at risk for preterm birth <32 weeks. STUDY DESIGN: A decision analytic and cost-effectiveness model was designed to compare use of magnesium for neuroprophylaxis vs no treatment for women at risk for preterm birth <32 weeks due to preterm premature rupture of membranes or preterm labor from 24-32 weeks. Outcomes included neonatal death and moderate-severe cerebral palsy. Effectiveness was reported in quality-adjusted life years. RESULTS: Magnesium for neuroprophylaxis led to lower costs ($1739 vs $1917) and better outcomes (56.684 vs 56.678 quality-adjusted life years). However, sensitivity analysis revealed the model to be sensitive to estimates of effect of magnesium on risk of moderate or severe cerebral palsy as well as neonatal death. CONCLUSION: Based on currently published evidence for efficacy, magnesium for neuroprophylaxis in women at risk to deliver preterm is cost-effective.


Cerebral palsy and assisted conception.

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Assisted reproductive technologies have been widely used over the past 30 years, and 1% to 4% of births worldwide are products of these technologies. However, adverse health outcomes related to assisted reproductive technologies, including cerebral palsy, have been reported. We extracted and reviewed all relevant studies cited by Medline from 1996 to 2010 evaluating the role of assisted reproductive technologies as a causative factor for cerebral palsy and poor long-term neurologic outcome. The research suggests that multiple pregnancy, preterm delivery, and babies small for gestational age are factors in the development of cerebral palsy. The vanishing embryo syndrome may also play a role. We review the evidence for these potentially causative factors, as well as their implications for embryo transfer policies.


When the womb is no longer safe: chorioamnionitis.

Hall V.

Intraterine infections are a leading cause of preterm birth, cerebral palsy and neonatal sepsis. This article investigates current ideas about prevention, diagnosis and treatment from a midwifery point of view.

Neurodevelopmental outcomes after laser therapy for twin-twin transfusion syndrome: a systematic review and meta-analysis.

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OBJECTIVE: To perform a systematic review of the literature regarding the occurrence of neurologic morbidity, neurologic impairment, or neurologic morbidity and impairment of patients treated with laser therapy for twin-twin transfusion syndrome. DATA SOURCES: The PubMed, MEDLINE, EMBASE databases and reference lists were searched up to December 2010 for studies describing outcomes in laser-treated twin-twin transfusion syndrome pregnancies. METHODS FOR STUDY SELECTION:: Inclusion criteria were twin-twin transfusion syndrome diagnosed with standard criteria and treated by laser therapy and neurologic morbidity and neurologic impairment collected at birth or 28 days after birth. Exclusion criteria were omission of at least one criterion; data in graphs or percentage; and non-English publications, letters, personal communications. TABULATION, INTEGRATION AND RESULTS:: Data recorded were rates and length of successful follow-up, age at diagnosis and type of neurologic morbidity, affected donors and recipients, prevalence of neurologic morbidity, and neurologic impairment for twin sets. From 15 articles, the incidence of neurologic morbidity at birth was 55 out of 895 (6.1%), without differences between donors and recipients (19/249, 7.6% compared with 16/273, 5.8%; odds ratio [OR] 1.36; 95% confidence interval [CI] 0.68-2.70). At follow-up, the incidence of neurologic impairment was 140 out of 1,255 (11.1%), with cerebral palsy the most frequent (60/151, 39.7%). Neurologic impairment was identified equally between donors and recipients (48/330, 14.5% compared with 54/364, 14.8%; OR 1.02; 95% CI 0.66-1.57), and between one survivor and two survivors for twin sets (24/139, 17.3% compared with 88/489, 18.0%; OR 0.67; 95% CI 0.18-2.49).

CONCLUSION: A small number (11.1%) of cases of twin-twin transfusion syndrome treated with laser therapy are affected with neurologic impairment that manifests during infancy. A strict follow-up of apparently healthy neonates is warranted.

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A small-molecule smoothened agonist prevents glucocorticoid-induced neonatal cerebellar injury.

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Glucocorticoids are used for treating preterm neonatal infants suffering from life-threatening lung, airway, and cardiovascular conditions. However, several studies have raised concerns about detrimental effects of postnatal glucocorticoid administration on the developing brain leading to cognitive impairment, cerebral palsy, and hypoplasia of the cerebellum, a brain region critical for coordination of movement and higher-order neurological functions. Previously, we showed that glucocorticoids inhibit Sonic hedgehog-Smoothed (Shh-Smo) signaling, the major mitogenic pathway for cerebellar granule neuron precursors. Conversely, activation of Shh-Smo in transgenic mice protects against glucocorticoid-induced neurotoxic effects through induction of the 11β-hydroxysteroid dehydrogenase type 2 (11β-HSD2) pathway. Here, we show that systemic administration of a small-molecule agonist of the Shh-Smo pathway (SAG) prevented the neurotoxic effects of glucocorticoids. SAG did not interfere with the beneficial effects of glucocorticoids on lung maturation, and despite the known associations of the Shh pathway with neoplasia, we found that transient (1-week-long) SAG treatment of neonatal animals was well tolerated and did not promote tumor formation. These findings suggest that a small-molecule agonist of Smo has potential as a neuroprotective agent in neonates at risk for glucocorticoid-induced neonatal cerebellar injury.

Progress in encephalopathy of prematurity [Article in Chinese]

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The preterm birth has been increasing for the last decade. With the development of neonatal intensive care techniques, the survival rate of preterm infants is increased markedly. However, the brain of preterm infants is so vulnerable to injury that preterm brain injury has become an enormous public health problem. Hypoxia-ischemia and infection/inflammation are two main perinatal risk factors causing premyelinating oligodendrocyte and cortical neuron injury. Encephalopathy of prematurity is characterized by diffuse white matter injury and neuronal/axonal disruption, leading to neurological disabilities such as cognitive impairment and cerebral palsy. The advancement in imaging techniques, especially magnetic resonance imaging, provides more information for preterm brain injury and brain development, which contributes to the diagnosis and follow-up of the preterm infants. This article reviews the progress in encephalopathy of prematurity in order to open a new window to prophylaxis and management of this disease.

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