Two sides of the mirror: parents' and service providers' view on the family-centredness of care for children with cerebral palsy.

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Background: In order to best meet the needs of both families and their children with cerebral palsy, many rehabilitation service providers have adopted a family-centred service (FCS) approach. In FCS parents are seen as experts on their child's needs, and the family and professionals collaborate in the rehabilitation process. However, parents and service providers might look at FCS from different points of view, i.e. look into the mirror from two different sides. The objective of this study was to explore the degree to which parents experience the service as being family-centred and to which extent the service providers experience their service provision as family-centred. Methods: A translated version of The Measure of Processes of Care 20 (MPOC-20) questionnaire was used to evaluate parents' experience of FCS, and a Measures of Processes of Care for Service Providers (MPOC-SP) questionnaire was used to evaluate the FCS provided by professionals. Parents visiting two university hospital neuropediatric wards (n= 67) during a 2-month period and who were willing to participate received the questionnaire. Also the service providers working on the same wards (n= 49) were invited to participate. Results: A total of 53 families and 29 service providers completed the questionnaires. Both parents and professionals generally rated the FCS positively. General information was rated lowest and respectful treatment the highest by both parents and professionals. The results revealed that written information about the child’s condition, the possibility to choose when to receive information, and contact with other families in the same situation are areas in need of improvement. Conclusions: The possibility to regularly evaluate services both from the families’ and the professionals’ perspectives should be part of quality development. Providing general information is a challenge for all service providers. The MPOC questionnaires can be used to highlight important areas of improvement in FCS.

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Grip force coordination during bimanual tasks in unilateral cerebral palsy.

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Aim: The aim of the study was to investigate coordination of fingertip forces during an asymmetrical bimanual task in children with unilateral cerebral palsy (CP). Method: Twelve participants (six males, six females; mean age 14y 4mo, SD 3.3y; range 9-20y;) with unilateral CP (eight right-sided, four left-sided) and 15 age-matched typically developing participants (five males, 10 females; mean age 14y 3mo, SD 2.9y; range 9-18y,) were included. Participants were instructed to hold custom-made grip devices in each hand and place one device on top of the other. The grip force and load force were recorded simultaneously in both hands. Results: Temporal coordination between the two hands was impaired in the participants with CP (compared with that in typically developing participants), that is they initiated the task by decreasing grip force in the releasing hand before increasing the force in the holding hand. The grip force increase in the holding hand was also smaller in participants with CP (involved hand/non-dominant hand releasing, p<0.001; non-involved hand/dominant hand releasing, p=0.007), indicating deficient scaling of force amplitude. The impairment was greater when participants with CP used their non-involved hand as the holding hand. Interpretation: Temporal coordination and scaling of fingertip forces were impaired in both hands in participants with CP. The non-involved hand was strongly affected by activity in the involved hand, which may explain why children with unilateral CP prefer to use only one hand during tasks that are typically performed with both hands.


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Spasticity of the gastrosoleus muscle is related to the development of reduced passive dorsiflexion of the ankle in children with cerebral palsy.

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Background and purpose: Spasticity and muscle contracture are two common manifestations of cerebral palsy (CP). A spastic muscle may inhibit growth in length of the muscle, but the importance of this relationship is not known. In 1994, a register and a healthcare program for children with CP in southern Sweden were initiated. The child's muscle tone according to the Ashworth scale and the ankle range of motion (ROM) is measured annually during the entire growth period. We have used these data to analyze the relationship between spasticity and ROM of the gastrosoleus muscle. Patients and methods: All measurements in the total population of children with CP aged 0-18 years during the period January 1995 through June 2008 were analyzed. The study was based on 2,796 examinations in 355 children. In the statistical analysis, the effect of muscle tone on ROM was estimated using a random effects model. Results: The range of dorsiflexion of the ankle joint decreased in the total material by mean 19 (95% CI: 14-24) degrees during the first 18 years of life. There was a statistically significant association between the ROM and the child's level of spasticity during the year preceding the ROM measurement. Interpretation: Spasticity is related to the development of muscle contracture. In the treatment of children with CP, the spasticity, contracture, and strength of the gastrosoleus muscle must be considered together.

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Motor Factors Associated with Health-Related Quality-of-Life in Ambulatory Children with Cerebral Palsy.

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OBJECTIVE: This study aimed to examine the relationship between fine and gross motor skills and cerebral palsy-specific quality-of-life in ambulatory children with cerebral palsy. DESIGN: Thirty-nine children with cerebral palsy (29 boys, 10 girls; mean age ± SD, 8.8 ± 2.3 yrs) classified under Gross Motor Function Classification System Level I or II were enrolled. Health-related quality-of-life was evaluated using the Cerebral Palsy Quality of Life Questionnaire for Children (parent-proxy version). Motor functions were measured using the Bruininks-Oseretsky Test of Motor Proficiency. RESULTS: Regression analysis for QOL revealed fine motor skills, including upper-limb speed and dexterity, which are positively correlated to functioning (r = 0.205, P < 0.01), and visual-motor control that is positively correlated to other domains, including social well-being and acceptance, participation and physical health, emotional well-being and self-esteem, and family health (r = 0.150-0.188, P < 0.05). CONCLUSIONS: Fine motor functions, including upper-limb speed and dexterity and visual-motor control, were the most important motor factors associated with health-related quality-of-life in ambulatory children with cerebral palsy.

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Motor preparation in unilateral cerebral palsy.

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PMID: 21896001 [PubMed - in process]


Reliability, Validity, and Precision of a Handheld Myometer for Assessing in Vivo Muscle Stiffness.

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Biomechanically, muscle stiffness is the ratio of force response that results from and resists mechanical stretch. The stiffness of the passive structures surrounding a joint contributes little to its biomechanical stability except at the end ranges of motion. Research has found, however, that the active stiffness properties of muscles are essential to dynamic stability. Optimal levels of musculotendinous stiffness are highly correlated to significant increases in muscle performance. This increased muscle stiffness surrounding a joint could limit the translation suffered by the joint after an injurious perturbation. This in turn would limit strain on the ligamentous structures, ultimately decreasing the incidence and severity of injury. Excessive amounts of stiffness, such as the spasticity associated with cerebral palsy, can be detrimental, however. Therefore, the ability to accurately quantify active muscle stiffness in an attempt to identify the optimal level of stiffness is integral for both clinicians and researchers.

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AIM: The aim of this paper was to evaluate the validity and reliability of a multisensor accelerometer, the Intelligent Device for Energy Expenditure and Activity (IDEEA, MiniSun, CA), for measuring energy expenditure in children with cerebral palsy (CP). Twenty-one children with CP, age range 4-10 years, with varying degrees of impairment, were recruited for the study. In addition, 7 children with normal development, age range 5.67-8.5 years, were also tested. METHODS: Children were connected to a portable metabolic cart (Cosmed, Rome, Italy) and to the IDEEA by five sensors. Children were asked to perform a series of activities simulating everyday activity, walk on a treadmill for 4 min and climb a staircase for 4 min. During all activities oxygen consumption values were measured and converted to energy units. Energy expenditure as measured by the IDEEA was also recorded. RESULTS: During the simulation of daily activities and during walking at a comfortable speed the IDEEA significantly overestimated the energy expenditure. However significant and relatively high positive correlations (0.70-0.97) were found between the two instruments. Inconsistent results were obtained during walking at increased speed. During a step test similar means were found by the two instruments for children with normal development and children with CP with good correlations between the values measured by the two instruments. Energy expenditure measurement in children with CP were found to be very reliable, with a correlation of 0.998 for repeated measurements during treadmill walking. CONCLUSION: It seems IDEEA, with its present conversion equations, is not suitable for exact evaluation of energy expenditure in children with CP or in young children with normal development. However, in light of the good correlation with the standard method of evaluating energy expenditure and the high test-retest reliability of the IDEEA's measurements, it is suggested that IDEEA may be a valuable tool for clinical follow-up of children with CP for quantitative evaluation of the efficacy of treatment interventions. The establishment of population specific conversion equations is expected to significantly increase the accuracy of energy expenditure evaluation by the IDEEA.

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Patella alta in cerebral palsy patients [Article in Czech]

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Ortopedická klinika 2. LF UK a FN Motol - Dětská a dospělá ortopedie a traumatologie.

PURPOSE OF THE STUDY: The absence of active knee extension in cerebral palsy patients is often due to elevation of the patellar ligament causing the patella to run outside the intercondylar groove. Distal patellar realignment can be achieved by either patellar ligament shortening or transposition of the patellar ligament distally. MATERIAL In the 1992-2008 period we indicated 95 knees for the distal realignment procedure involving a bone block in children 12 to 18 years old, and 46 knees in children aged between 8 and 16 years for shortening of the patellar ligament using the method of rafage in the early period, and modified plication from 2003. METHODS: Clinical and radiographic findings were evaluated pre-operatively and at 6 weeks, 6 months and 1 year after surgery. In the cases treated by patellar ligament shortening, the Insall-Salvati index was assessed post-operatively. Physical examination included local findings and the patient's ability to change locomotion. RESULTS Improved locomotion and maintenance of knee extension during standing and walking were recorded in 89 of the 95 knees with distal patellar realignment (93.68%) and in 40 of the 46 knees with patellar ligament shortening (86.96%). DISCUSSION: Distal realignment of the patellar ligament or its shortening should be indicated as a follow-up treatment after muscular balance has been gained at persistent knee joint flexion during standing and walking, and the inability of active extension. The distal realignment procedure with a bone block should be indicated only after growth cessation because otherwise genu recurvatum may develop. Concurrently with this procedure, it is necessary to carry out distal realignment of the proximal ligament of the rectus femoris muscle. CONCLUSIONS: Shortening of the patellar ligament using modified plication or its distal realignment involving a bone block are two options for the treatment of patella alta that is indicated in the absence of active knee extension.
in cerebral palsy patients. Key words: patella alta, distal patellar realignment, patellar ligament plication.

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A population-based study and systematic review of hearing loss in children with cerebral palsy.

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Aim: The aims of this study were to estimate the frequency of hearing loss in children with cerebral palsy (CP), to examine factors associated with hearing loss, and to describe aspects of hearing in a population sample of children with CP and hearing loss. Method: A systematic review of the international literature was undertaken, and data on the frequency of hearing loss or severe hearing loss were extracted from 14 data sets based on previously devised criteria. Six hundred and eight-five children with CP (406 males, 279 females) born in Victoria, Australia, between 1999 and 2004 were identified from the Victorian Cerebral Palsy Register. Children were included if they had an established post neonatal cause for their CP before the age of 2 years. Additional information was collected on 48 children with documented hearing loss based on a four-tone pure tone average in the better ear. Results: There was considerable variation in the definitions and proportions of hearing loss (range 4-13%) and severe hearing loss (range 2-12%) reported by CP registries in developed countries. In Victoria, 7% of individuals with CP had bilateral hearing loss of a moderate to profound degree, whereas the subgroup with a severe-profound degree of loss constituted 3% to 4% of the CP population. Interpretation: These population-based data are likely to more accurately reflect the true frequency of defined hearing loss in children with CP than previous reviews.


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Cochlear implantation in children with cerebral palsy.

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OBJECTIVE: Few studies have looked at the outcomes of children with complex needs following cochlear implantation. Increasing evidence supports the case for implantation in these children. To date there is very little evidence available evaluating the role of cochlear implantation in children with cerebral palsy. In this paper we look at the Manchester Cochlear Implant Programme's experience of implantation in 36 children with cerebral palsy.

METHODS: A retrospective review of prospectively collected data for all children with cerebral palsy was undertaken. Cognitive and physical disability was scored by members of the cochlear implant team. A modified version of Geers and Moog's 1987 Speech Reception Score was used to assess outcome. Data was analysed looking at the relationship between cognitive and physical impairment, age at implantation and the SRS outcomes.

RESULTS: This study demonstrated that children with cerebral palsy and a mild cognitive impairment do significantly better following implantation than those with a severe impairment (p=0.008). Children with mild physical impairment did not appear to do significantly better than those with moderate or severe impairments (mild versus severe p=0.13). Age at implantation was not a significant prognostic factor in this study group. CONCLUSIONS: Children with complex needs are increasingly being referred for consideration of cochlear implantation. Further research is required to help guide candidacy, but each case must be considered individually. Higher functioning does appear to be the most important prognostic indicator regarding outcome but the effect of modest improvement in sound perception should not be underestimated.

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Describing hearing in individuals with cerebral palsy.

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Botox® to reduce drooling in a paediatric population with neurological impairments: a Phase I study.

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Background: The treatment of drooling in a paediatric population with neurological impairments is clinically challenging. Surgery is considered invasive, while behaviour modification techniques, correction of situational factors and oral-motor therapy do not always produce sustained improvement. In recent years the use of Botox® to decrease drooling has been investigated. Aims: To review the clinical data from a Drooling Treatment Project for children with neurological impairments and to establish the validity of the drooling severity and frequency rating scales, establishing Phase I-level information about the therapeutic use of submandibular salivary gland injections of Botox® in various contexts. Method & Procedures: A retrospective, explanatory design was used to review the data. Nine children, seven with cerebral palsy and two with operculum syndrome, ranging in age from 5 to 17 years (mean = 9.3 years) were included. Drooling was assessed by qualified speech-language therapists using drooling rating scales, in five different situations and at different time points pre- and post-Botox® injection up to 6 months. Quantitative and qualitative analyses were computed. Parents'/primary caregivers' perceptions of drooling and treatment with Botox® were also considered using an interview form and a quality of life questionnaire. Outcomes & Results: Statistically significant reductions in drooling with large effect sizes were obtained in the communicating and general appearance situations. There was a difference in the pattern of response between the children with cerebral palsy and those with operculum syndrome. Discrepancies between the parents and the speech-language therapists regarding the context of drooling reduction were found. Most parents/primary caregivers felt their children's lives and their own had improved following the Botox® injection and would repeat the treatment. The drooling rating scales were a valid method to assess drooling in a clinical situation. Conclusions & Implications: In the clinical setting of the Drooling Treatment Project, the results indicated that the context in which drooling occurs is an important factor and suggested the value of considering the situational context when making drooling judgments. Further, there was a difference in the pattern of response between the children with cerebral palsy and those with operculum syndrome, suggesting that aetiology may be involved in the response to Botox®.

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Commentary on "Relationship of therapy to postsecondary education and employment in young adults with physical disabilities".

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Comment on


PMID: 21552084 [PubMed - indexed for MEDLINE]


Making progress.

Van Sant AF.

PMID: 21552072 [PubMed - indexed for MEDLINE]


Developmental Coordination Disorder in School-Aged Children Born Very Preterm and/or at Very Low Birth Weight: A Systematic Review.


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OBJECTIVE: To systematically review and synthesize the literature to document the association between infants born very preterm and/or very low birth weight (VLBW) and the presence of developmental coordination disorder (DCD) at school age. METHODS: Seven databases were systematically searched. Studies were included if they examined very preterm (<32 weeks) and/or VLBW (<1500 g) infants to school age (age, 5-18 years), had a full-term and/or normal birth weight comparison group, and used a formal measure of motor impairment. Studies that included only infants who were small for gestational age or diagnosed with cerebral palsy were excluded. Two independent reviewers completed full-text screening, data extraction, and quality assessment of included studies. RESULTS: Sixteen articles were included, with 7 studies incorporated into 2 meta-analyses using cutoff scores of either <5th or 5-15th percentile on the Movement Assessment Battery for Children. Both analyses showed a significant increase in the likelihood of DCD for children born very preterm and/or 1500 g or less, with odds ratios of 6.29 (95% confidence interval, 4.37-9.05, p < .00001) and 8.66 (95% confidence interval, 3.40-22.07, p < .00001) for <5th or 5-15th percentile scores, respectively. CONCLUSIONS: Consistent across studies, DCD is more prevalent in the VLBW/very preterm population than full-term/normal birth weight control children and the general school-age population, with significantly greater odds of developing the disorder. Clinical practice should focus on early identification of and intervention for children with DCD, while research should focus on determining the mechanisms underlying DCD in the preterm population.

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The motor repertoire of extremely low-birthweight infants at term in relation to their neurological outcome.

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Aim: The aim of this study was to assess the motor repertoire of extremely low-birthweight infants at term-equivalent age (TEA), in relation to their neurological outcome. Method: Using Prechtl's method, we assessed both the quality of general movements and a detailed motor optimality score in 13 extremely low-birthweight infants (four males; nine females; mean gestational age 27.9wks, SD 2.9wks; mean birthweight 798g, SD 129g) at TEA, and
related them to general movements at the age of 3 months after term and neurological outcome at the age of 2 years 6 months. Results: At TEA, 10 of the 13 infants had abnormal general movements. All infants showed abnormal leg lifting with extended legs; nine showed stiff movements, three showed cramped movements, and two showed cramped synchronized general movements. At 3 months, three infants still had abnormal general movements. Concurrent movements were abnormal in nine infants owing to monotony and jerkiness. Abnormal posture was seen in seven infants. None developed cerebral palsy; one infant showed cognitive and motor delay. Neurological outcome was not related to general movement quality and optimality score at TEA. Interpretation: Abnormal general movements at TEA are common in extremely low-birthweight infants. General movements often appear stiff and cramped with extended legs. At the age of 3 months after term, general movements are mostly normal, but concurrent movements are not. Nevertheless, these abnormalities do not imply an impaired neurological outcome such as cerebral palsy.


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Growth hormone deficiency in children and adolescents with cerebral palsy: relation to gross motor function and degree of spasticity.

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Children with Cerebral Palsy (CP) often have poor linear growth during childhood with short final height. Thus, we aimed to assess serum growth hormone (GH), insulin like growth factor-1 (IGF-1) and insulin like growth factor binding protein-3 (IGFBP-3) levels among CP patients and their relation to each of gross motor function and degree of spasticity. Fifty CP children and adolescents were studied in comparison to 50 healthy age-, sex- and pubertal stage-matched children and adolescents. All subjects were subjected to clinical evaluation, Intelligence Quotient (IQ) assessment and measurement of serum GH, IGF-1 and IGFBP-3. All auxological and hormonal parameters were significantly lower among cases. Fifty two% of cases were GH-deficient and 62% had reduced IGF-1 and IGFBP-3 levels. Gross Motor Function Measure- 88 (GMFM-88) score correlated negatively with each of basal (r = -0.71, p = 0.02) and peak stimulated GH (r = -0.88, p = <0.001); IGF-1 (r = -0.64, p = 0.04) and IGFBP-3 (r = -0.69, p = 0.031). There were significant negative correlations between the degree of spasticity assessed by Modified Ashworth Scale and each of basal (r = -0.61, p = 0.032) and peak stimulated GH (r = -0.78, p = 0.01); IGF-1 (r = -0.65, p = 0.041) and IGFBP-3 (r = -0.62, p = 0.035). Growth Hormone Deficiency (GHD) is prevalent in children with CP and could be one of the causes of their short stature.

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Alteration of protein expression profile following voluntary exercise in the perilesional cortex of rats with focal cerebral infarction.

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Identification of functional molecules in the brain related to improvement of the degree of paralysis or increase of activities will contribute to establishing a new treatment strategy for stroke rehabilitation. Hence, protein expression changes in the cerebral cortex of rat groups with/without voluntary exercise using a running wheel after cerebral infarction were examined in this study. Motor performance measured by the accelerated rotarod test and alteration of protein expression using antibody microarray analysis comprised 725 different antibodies in the cerebral cortex adjacent to infarction area were examined. In behavioral evaluation, the mean latency until falling from the rotating rod in the group with voluntary exercise for five days was significantly longer than that in the group without voluntary exercise. In protein expression profile, fifteen proteins showed significant quantitative changes after voluntary exercise.
exercise for five days compared to rats without exercise. Up-regulated proteins were involved in protein phosphorylation, stress response, cell structure and motility, DNA replication and neurogenesis (11 proteins). In contrast, down-regulated proteins were related to apoptosis, cell adhesion and proteolysis (4 proteins). Additional protein expression analysis showed that both growth-associated protein 43 (GAP43) and phosphorylated serine41 GAP43 (pSer41-GAP43) were significantly increased. These protein expression changes may be related to the underlying mechanisms of exercise-induced paralysis recovery, that is, neurite formation, and remodeling of synaptic connections may be through the interaction of NGF, calmodulin, PKC and GAP43. In the present study at least some of the participation of modulators associated with the improvement of paralysis might be detected.

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Prevention and Cure


Neuroprotective approaches: before and after delivery.

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Infants born preterm are especially vulnerable to cerebral palsy, the risk of which is inversely proportional to gestational age at birth. The contribution of prematurity to the overall burden of cerebral palsy is substantial. This article reviews and discusses potential antenatal and postnatal neuroprotective approaches targeted at the numerous risk factors associated with cerebral palsy among preterm infants, including magnesium sulfate.

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The effect of the neonatal resuscitation courses on the long-term neurodevelopmental outcomes of newborn infants with perinatal asphyxia*

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Background: In previous studies, it has been demonstrated that Neonatal Resuscitation Program (NRP) courses improve the early outcomes of infants with perinatal asphyxia, however there has been no evidence to demonstrate the effect of NRP on long-term outcomes of perinatal asphyxia. The goal of this study was to determine the effect of the NRP courses on the long-term neurodevelopmental outcome of perinatal asphyxia. Methods: This prospective study included infants referred to our Neonatal Unit during the years of 2003-2005. Those patients who were referred before NRP courses (pretraining period) were designated as Group 1, those who were referred after the first NRP course (transition period) as Group 2, and those who were referred after the second NRP course (posttraining period) as Group 3. Neurodevelopmental outcomes were assessed and compared at 4-6 years of age. Results: The study comprised 40 patients; 23 in Group 1, 9 in Group 2 and 8 in Group 3. The number of patients who had been diagnosed as cerebral palsy was 13 in Group 1, 2 in Group 2, and 1 in Group 3 which decreased significantly. The number of patients with seizures and EEG abnormality was 12 and 14 in Group 1, 3 and 2 in...
Group 2, 1 and 1 in Group 3 respectively which also decreased significantly. Conclusions: NRP courses have positive effects on early as well as long-term neurodevelopmental outcomes of infants with perinatal asphyxia. Further studies are required for determining the effects of NRP courses on minor deficits, such as cognitive and behavioral disturbances.


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