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MEDICAL INFORMATION IN A NEONATAL UNIT: HOW IS IT PERCEIVED BY PARENTS AND HEALTH CARE PROVIDERS?

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Background: Patient satisfaction is used as one of the measurements for quality of health care services and it has been related with how quality of communication between physicians and patients is perceived.The aim of this study is to to describe differences between parents and health care providers in perception of the medical information given by doctors to parents.

Methods: Single center, cross-sectional study. A 176 items questionnaire was administered to a sample of parents whose baby was admitted to a neonatal unit (at the time of the study or in the past) and to all doctors and nurses working at the same NICU. Medical information characteristics such as quantity, quality, understanding, concealment, priorities, etc. at different moments of the hospitalization were investigated by a self-administered questionnaire (health care providers, parents at follow-up clinic and those with a baby in the NICU) or by phone (other parents). Questionnaires were designed to allow item by item comparison between different categories of responders. The answers were on a 0 to 10 scale. Kruskal-Wallis test with Dunn post-test or Mann-Whitney test were used in the analysis.

Results: Overall parents response rate was 69% (n=97) whereas health care providers was 80% (n=98). Characteristics of the medical information provided by doctors to parents rated on a 0 to 10 scale: median (interquartile range).

Medical information	Parents (n=97)			Health care providers (n=98)		P value
Characteristics	F-up clinic(n=18)	Phone (n=56)	NICU(n=23)	Doctors(n=25)	Nurses(n=73)	
Quantity	8 (8–10)	8 (7–10)	8 (6–10)	8 (7–8)	6 (5–8)	[it]0.001
Quality	8 (8–10)	8 (7–9)	8 (6–10)	7 (6–8)	6 (5–7)	[it]0.001
Understandable	9.5 (8–10)	9(7.5–10)	8 (6–10)	7 (7–9)	5 (3–7)	[it]0.001
Concealment	1(0–2.5)	0 (0–3)	1 (0–7)	3 (2–6)	6 (3–7)	[it]0.001

P value: statistical differences between parents and health care providers

Conclusion: Medical information provided to parents whose baby has been admitted to a NICU seems satisfactory in scope and quality. Parents assessment is consistently more favourable than health care providers. Among parents, those with a baby still admitted to the NICU show a slightly less favourable perception. Nurses assessment of medical information is clearly more unfavourable than parents or doctors for most of the items.

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COMBINATION THERAPY WITH ERYTHROPOIETIN AND N-ACETYLCYSTEINE PROVIDES PRONOUNCED IMPROVEMENT OF LONG LASTING SENSORIMOTOR AND NEUROPATHOLOGICAL DISTURBANCES FOLLOWING PERINATAL ASPHYXIA IN RATS

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Background: Perinatal asphyxia (PA) accounts for the majority of developmental and cognitive deficits. Various therapeutic interventions after hypoxia-ischemia (HI) have been shown to reduce brain injury in the short-term perspective, although long-term functional and structural improvements are still uncertain. **Objective:** The aim of this study was to evaluate the neuroprotective efficiency of erythropoietin (EPO), N-acetylcysteine (NAC) and their combination after neonatal HI with respect to long term (neuropathology and sensorimotor function) outcome.

Methods: 7 days old rats were separated into 5 groups: A (control), neither ligated nor exposed to hypoxia, B (HI) ligated and exposed to hypoxia, C, D and E ligated, exposed to hypoxia and treated respectively with NAC (100mg/kg), EPO (2000 U/kg) and their combination. At the age of 42 days, the behavior of the rats was evaluated through 5 sensorimotor tests. Muscle power, motor coordination, reflexes and limb placing (LP) were tested to different sensory stimulations. The sensorimotor tests lasted six days. The study was completed with the evaluation of brain tissue damages at the age of 48 days.

Results: In all the separate tests the HI rats performed significantly worse than the control and treated rats (table). In particular the differences between the groups in the grip traction, postural reflex and limb placing task were more pronounced compared to other tests (table). Neonatal HI resulted in extensive neuronal damage that was significantly limited after treatment.

	Control (8)	HI (15)	HI-NAC (10)	HI-EPO(10)	HI-NAC/EPO (10)
Grip traction (sec)	91.2a	42.5b	79.7 a	74.8 a	77 a
Foot fault(fault/sec)	0.05a	0.17a	0.11a	0.14a	0.11a
Rota rod (sec)	235.3 a	122 b	185.7 ab	192.6 ab	192.2 ab
Postural reflex (%)	87.5 a	18.1 b	64.2 a	64.2 a	90.4 a
LP sensory	83.3 a	24.2 b	64.2 a	54.7 c	73.8 a
LP visual	79.1 a	15.1 b	61.9 a	57.6 a	66.6 a
LP lateral pressure	95.8 a	21.1 b	64.2 c	59.5 c	80.9 a
LP pushed to edge	100 a	21.1 b	66.6 c	66.6 c	73.8 c
LP back pressure	83.3 a	24.4 b	66.6 a	59.5 a	80.9 a

groups with different letter (a, b, c) differ significantly

Conclusion: HI brain damage during the neonatal period resulted in long-term disorders in motor coordination, muscle power and the reaction of the limbs to sensory stimuli. EPO and NAC attenuated the effects of HI on the neonatal brain by reducing the progression of neuronal injury and improving sensorimotor function. However their combination resulted in more pronounced functional improvement. Behavioral alterations represent a useful endpoint for studying the consequences of a perinatal HI insult and the efficacy of potential neuroprotective treatments.

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DIAGNOSIS OF ANDERSON-FABRY DISEASE IN CHILDHOOD. WHAT SHOULD WE FOCUS ON?

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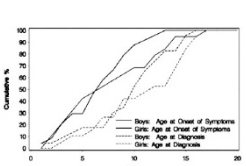
Background: Anderson-Fabry disease (FD) is an X-linked lysosomal storage disorder which also affects female carriers and has an early onset of symptoms in childhood in both genders. Signs and symptoms are frequently misunderstood and often diagnosis is made approximately 10–20 years after their onset. This has been clearly demonstrated by Fabry outcome survey (FOS) a European database on the natural history of FD and the effects of enzyme replacement therapy with agalsidase alfa (Replagal).

Methods: Demographic data on 82 children (40 boys and 42 girls) below 18 years of age, with a median age at FOS entry of 12.9 (0.7–17.9) were analysed

Results: Most frequently reported symptoms (60–80%) were neurological and gastrointestinal including altered temperature sensitivity, pain, acroparaesthesiae, dyshydrosis, abdominal pain and altered bowel habits. Over 40% had auditory (tinnitus, vertigo), and dermatological (angiokeratoma) symptoms. Median age at onset of symptoms was 6 years whilst median age at diagnosis was 10 years (figure).



Conclusion: Data in FOS show that also the selected group of paediatric patients has a consistent delay of diagnosis. As ERT is licensed for use in FD and could potentially delay or prevent the onset of life-threatening complications of FD seen in adults, early diagnosis is important. Emphasis is therefore to have a heightened awareness of the clinical presentation of childhood FD, especially when they present with an unusual constellation of symptoms including pain, dyshydrosis, abdominal pain and tinnitus.

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CARDIOVASCULAR SUPPORT IN LOW BIRTH WEIGHT INFANTS AND CEREBRAL HEMODYNAMICS: A RANDOMIZED BLINDED CLINICAL TRIAL

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Background: The decisition to treat systemic hypotension in LBWI is based on the belief of keeping adecuate organ perfusion. However, the impact of vasopressor treatment on cerebral tissue perfusion has not been systematically evaluated on the basis of a controlled clinical trial. Aims: To explore the effects on brain hemodynamics of two inotropes used to treat hypotension in LBWI.

Methods: Newborns <1501g BW or <31 wk GA, with mean blood pressure (MAP) h, were randomly assigned to DP (2.5, 5, 7.5, 10 μg/K/min) (n=27) or EP (0.125, 0.250, 0.375, 0.5 μg/K/min) (n=32), increased in stepwise fashion every 20 min until the desired MAP (MAP-OP) was attained and maintained. Outcome measures: Quantitative changes in cerebral concentrations of oxyhemoglobin (HbO) and deoxyhemoglobin (HbR), cerebral intravascular oxygenation (ΔHbD) that is Δ(HbO-HbR), and cerebral blood volume (ΔCBV), were assesed by near infrared spectroscopy. Simultaneous MAP, heart rate (HR), trascutaneous PCO2/PO2 and peripheral oxygen saturation were continuously recorded and stored for latter analysis at: baseline (BL), at 20 min after each increase in dose (T1, T2, T3 and T4) until MAP-OP was reached, and then every 20 min up to 1 h of stable MAP-OP (60-OP).

Results: BW and GA were 974±282 g and 27.9±2.3 wk, respectively. The studies were performed at a mean age of 5.3±3.7 hours of life. MAP-OP was achieved at: T1 DP 22.2%, EP 18.8%; T2 DP 33.3%, EP 28.1%; T3 DP 25.9%, EP 18.8%; T4 DP 14.8%, EP 28.1%. No differences were found in the rate of treatment failure (DP 3.7%, EP 6.3%). There was a significant linear increase in MAP, HR and ΔCBV from BL throughout the study period ($p<0.001$) without differences between the groups except for HR (higher in EP at MAP-OP and 60-OP, $p<0.01$). The increase in ΔCBV was coupled with a significant increase in ΔHbD. Changes in MAP were significantly correlated with ΔHbD at MAP-OP and at 60-OP. PCO2 and PO2 values remained unvaried. The effect of drug-dose escalation showed no differences in the variables' behaviour except for a higher HR in EP from 20 min after dose 2 (T2) and onwards ($p<0.05$ at T2). Drug-induced changes in cerebral hemodynamics varied according to GA.

Conclusion: In hypotensive LBWI cardiovascular support with low-moderate dose DP or low-dose EP improve cerebral perfusion, as indicated by the increase in both ΔCBV and ΔHbD. Low-dose EP is as effective as low-moderate dose DP to increase MAP in LBWI.

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RANDOMIZED, CONTROLLED TRIAL ON EARLY LOW-DOSE HYDROCORTISONE TREATMENT FOR PREVENTION OF BRONCHOPULMONARY DYSPLASIA (BPD)

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Background: Lung inflammation and early adrenal insufficiency are major risk factors of BPD in very low birth weight infants. Early low-dose hydrocortisone treatment may effectively prevent BPD with fewer side effects than early dexamethasone (Pediatrics. 1999;104:1258). **Objectives:** To study whether a low-dose hydrocortisone (HC) prevents BPD without acute side effects, and to evaluate serum cortisol levels before and after the supplementation.

Methods: The study was multicenter, randomized placebo-controlled blinded trial. Infants weighing 501-1250 g with gestation age <30 weeks and with respiratory failure were eligible before 36 hours of age. HC or placebo was given for 10 days as follows: HC 2.0 mg/kg/d for 2 days, 1.5 mg/kg/d for 2 days and 0.75 mg/kg/d for 6 days. ACTH test was done at the onset of study and one day after the intervention (Synacthen dose 0.1 ug/kg: serum cortisol levels evaluated before and at 30 min). Primary outcome was survival without BPD at the age of 36 gestational weeks.

Results: The study was discontinued after 51 infants were enrolled as a consequence of increased risk of gastrointestinal (GI) perforations in the HC group (17% vs. 0%, $p=0.04$). Survival without BPD tended to be higher (55% vs. 45%, OR 1.76, 95% CI 0.52–5.91) and patent ductus arteriosus significantly decreased in the HC group (40% vs. 73%, OR 0.25, 95% CI 0.08–0.80). There were no differences between the study groups in the growth pattern until 36 weeks of gestation. The subgroup of infants with normal ACTH response (delta cortisol > 100 nmol/l) at the onset of the study had high risk of GI-perforations during HC (3/8 vs. 0/9, $p=0.04$). In this subgroup there was no difference in the incidence of BPD between the HC and placebo groups (2/8 vs. 2/9 OR 1.17, 95% CI 0.12–10.99). Among infants with impaired adrenal function (delta cortisol < 100 nmol/l) at birth, HC appeared to decrease the odds of BPD (2/10 vs. 6/9, OR 0.13, 95% CI 0.02–0.99). There were no GI-perforations in this subgroup.

Conclusion: Early low-dose hydrocortisone increases the risk of gastrointestinal perforations among VLBW infants who respond normally to ACTH at birth. The subgroup of infants with impaired early adrenal function benefited from HC treatment without GI-perforations. Further studies are required to define the indications of hydrocortisone for prevention of BPD.

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A 16-YEAR STUDY OF LOW BIRTH WEIGHT INFANTS IN CHINA

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Purpose: To compare the growth and neurodevelopment from birth to age 16 yrs of premature (PRE), small-for-gestational-age (SGA), and normal-birth-weight (NBW) infants born and raised in China.

Methods: Prospective cohort study of 203 low-birth-weight (LBW, <2500 g) and 71 NBW (>2500 g) infants who were born at 2 Shanghai hospitals in 1983 and matched for birth date, gender, and parental occupation. Infants<1,200 g were excluded from the study due to their low likelihood of survival. SGA (n=101) was defined as LBW<10th percentile for gestational age37 wks and PRE as gestational age<37 wks. Primary outcome variables were Wt, Ht, body mass index (BMI), head circumference (HC), Wechsler intelligence quotient (IQ), and scholastic achievement test scores (SATs) at age 16 yrs. Secondary outcomes were the tempo of Ht, Wt, and HC growth; and childhood neurodevelopment assessed by the Gesell developmental quotient (DQ). Subjects were seen monthly to age 1 yr, every 6 mos to 3 yrs, yearly to 6 yrs, and once at 16 yrs. Generalized estimating equations (GEE) with adjustment for gender were used to compare the groups for outcomes and tempo of growth over time. Standardized Z scores for mean outcomes in the SGA and PRE groups were plotted against age to display size, development, and catch-up relative to the NBW group.

Results: Of the 274 enrolled subjects, 234 (85%) returned at 6 mos, 135 (49%) at 6 yrs, and 104 (38%) at 16 yrs. There were NS differences between SGA, PRE, and NBW enrollees in baseline characteristics or rates of follow-up. Wt at each visit through 6 yrs ($P<0.02$) and ht and HC through 16 yrs ($P<0.001$) were lower in SGA and PRE than NBW subjects. There were NS differences in BMI at 16 yrs or in wt or ht change over time, but HC change was greater among PRE than either SGA or NBW subjects ($P<0.001$). DQ through 3 yrs, IQ at 5 and 16 yrs, and SATs at 16 yrs were lower among LBW than NBW subjects ($P<0.0001$), with NS differences between SGA and PRE subjects. Catch-up peaked at ages 6–9 mos for wt, 12–24 mos for ht, and 18–24 mos for HC.

Conclusions: Adolescents in China who were LBW lag behind NBW peers in ht, cognitive ability, and school achievement. As the first study in China of long-term outcome, our findings suggest that these adolescents represent a population in need of support. The isolation of China and homogeneity in social and family structure during the research period provide a unique setting for the study of LBW effect but also highlight the importance of additional studies with larger in other regions of the country.