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Cognitive assessment of very low birth weight infants using the Dutch version of the PARCA-R parent questionnaire

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ABSTRACT

Objective: Very low birth weight (VLBW) infants are at an increased risk of long-term cognitive impairment. Early identification and timely interventions are important. We aimed to validate the Dutch version of the revised Parent Report of Children's Abilities (PARCA-R) questionnaire.
Methods: The subjects were survivors from the Belgian participating centers to the NIRTURE trial. As part of a study-related follow-up, PARCA-R was sent out at the age of 2 years. As part of a normal hospital follow-up, these infants were assessed by the Bayley Scales of Infant Development – second edition (BSID-II) at the age of 9, 18 and 36 months. MRI was performed at term in the group of VLBW infants of ZOL Genk as standard care.
Results: PARCA-R was sent out to 193 surviving infants. BSID-II was performed in 36% (n = 70) at 9 months, in 30% (n = 58) at 18 months and in 12% (n = 23) at 36 months. MRI was available for 32 infants. We received 86 responses to the PARCA-R. Parent report composite (PRC) scores were significantly correlated with the Mental Development Index (MDI) ($p < 0.0001$ (9 months); $p = 0.003$ (18 months); $p = 0.01$ (36 months)). PRC scores were significantly lower in those with an abnormal MRI (92 vs.124; $p = 0.04$).
Conclusion: We support the use of the PARCA-R as a time and cost efficient alternative for identifying cognitive delay.
Practice implications: We suggest that the combination of BSID-II, MRI at term and PARCA-R would be the ideal testing method for identifying VLBW infants at risk for cognitive developmental delay by two years of age.

1. Introduction

Advances in perinatal care have improved survival rates of very low birth weight (VLBW) (birth weight (BW) <1500 g) infants. However, a substantial number of these children have long-term cognitive impairment [1]. As a consequence, between 40 and 60% of these VLBW infants require some form of special assistance in school. Early identification of disability and timely targeting of interventions are extremely important [2].

The Bayley Scales of Infant Development (BSID) is the 'gold standard' for assessing neurodevelopmental outcome in VLBW infants [3–6]. However, these assessments are expensive and time-consuming. The revised Parent Report of Children's Abilities (PARCA-R) parent questionnaire has shown to have good concurrent validity and diagnostic utility, making it a cost and time efficient alternative for the cognitive assessment of VLBW infants [7–11].

In this retrospective study, we aimed to validate the Dutch version of the PARCA-R questionnaire by correlating the results to the Mental Developmental Index (MDI) of the BSID-II as well as to the MRI results of these infants. Moreover, we tried to establish a cut-off point for determining mild (MDI < 85) and severe (MDI < 70) developmental delay.

2. Methods

The subjects were all VLBW infants admitted to the neonatal intensive care units (NICUs) of the University Hospital Leuven, Belgium and of ZOL Genk, Belgium who were part of the NIRTURE trial (ISRCTN78428828). The study protocol was approved by the Institutional Review Boards of each study center (EudraCT number, 2004-002170-34). Written informed consent of at least one of the parents was an inclusion criterion [12,13].

As part of the study-related follow-up of these patients, a PARCA-R questionnaire was sent out to the parents at the chronological age of 2 years. The Dutch version is identical to the English version adapted from Saudino et al. [14] and validated by Johnson et al. [7,8]. The questionnaire is constructed by sub-scales and scored identical to the scoring instructions used by Johnson et al. [7,8]: non-verbal cognition scale ("your child's play"; range 0–34), vocabulary sub-scale ("what your child can say"; range: 0–100), sentence complexity scale ("how your child uses words" part A + part B = C; range 0–24), linguistic skills scale (sum vocabulary and sentence complexity sub-scale score; range 0–124) and parent report composite score (PRC) (sum non-verbal

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cognition scale and linguistic skills scale score; range 0–158). As part of the normal hospital follow-up of VLBW infants, these infants were neurologically assessed by BSID-II (psychomotor developmental index (PDI) and MDI) at the age of 9 (PDI1/MDI1), 18 (PDI2/MDI2) and 36 (PDI3/MDI3) months. MRI was performed at term in the group of VLBW infants of ZOL Genk as standard care.

For statistical analysis, Mann–Whitney U test and Spearman rank correlation coefficients were used. The cut-off for statistical significance was set at $p < 0.05$, two-tailed. The predictive accuracy of variables was assessed by comparing the area under the receiver operating characteristic (ROC) curve that plots sensitivity vs (1-specificity) [15].

3. Results

211 VLBW infants were included in the NIRTURE trial (February 2005–August 2007) in the NICUs of the University Hospital Leuven, Belgium and of ZOL Genk, Belgium. Of these 211 infants, 193 survived. Median BW was 1105 g (900–1330) and median postmenstrual age (PMA) was 29 weeks (27–31).

We received 86 responses to the parent PARCA-R questionnaire (response rate 44%). BSID II was performed in 36% (70/193) at the age of 9 months, in 30% (58/193) at the age of 18 months and in 12% (23/193) at the age of 36 months. Although dropout rates are high, they coincide with the ones found in literature [16]. The MRI results were available for 32 VLBW infants.

Scoring of the PARCA-R is performed as described in the Methods section. BSID-II is given on an individual basis (45–60 min) by experienced examiners. It evaluates along the mental scale (sensory/perceptual acuities, discriminations, acquisition of object constancy, memory learning and problem solving, vocalization and beginning of verbal communication, basis of abstract thinking, habituation, mental mapping; complex language and mathematical concept formation) and the motor scale (degree of body control, large muscle coordination, finer manipulatory skills of the hands and fingers, dynamic movement, postural imitation and stereognosis). Original mental and motor scale record forms were used [3].

No correlation was found with BW, PMA or PDI (PDI1/PDI2/PDI3). Both the sub-scales and the overall parent report composite (PRC) scores were significantly correlated with the MDI1, MDI2 and MDI3 (Table 1).

Fig. 1 shows the ROC curve of the PRC to predict a MDI1 score <85 and <70 indicating mild and severe developmental delays. The area under the curve (AUC) was 0.935 (0.849–0.980); $p < 0.0001$ for MDI1 <85 and 0.926 (0.838–0.975); $p < 0.0001$ for MDI1 <70. The optimal PRC cut-off maximizing both the test sensitivity and specificity was 68 to predict a MDI1 <85 and 35 to predict a MDI1 <70. A ROC-determined cut-off of ≤68 for identifying MDI1 <85 had a sensitivity of 100% and a specificity of 82.46%. Predictive values were 56.52% for a positive and 100% for a negative test. A ROC-determined cut-off of ≤35 for identifying MDI1 <70 had a sensitivity of 100% and a specificity of 85.2%. Predictive values were 16.6% for a positive and 100% for a negative test (Table 2).

The MRI of the brain was considered abnormal as soon as the protocol described anything else than normal. In total, 24 MRI scans were protocolled by the attending radiologist as negative, only 8 were abnormal. The MRI scans were not reviewed more in detail and lesions were not linked to any cognitive sequelae. PRC scores were significantly lower in those VLBW infants who had an abnormal MRI (median (interquartile range) 92 (98–138) vs. 124 (37.5–110)). Mann–Whitney U, test two-tailed $p = 0.04$.

4. Discussion

Long-term follow-up of developmental outcome in VLBW infants is crucial as these infants are at an increased risk of adverse neurodevelopmental outcome [1,2]. Serial assessments of cognitive and language skills by standardized tools (BSID-II and BSID-III) are recommended as part of the standardized follow-up [3–6]. However, these tests are time-consuming, expensive, require experienced trained personnel and are often stressful and tiring for the child. Parental questionnaires represent an inexpensive alternative. The PARCA-R was validated against BSID-II and BSID-III for the use in preterm infants at 2 years of age [7–11].

In this retrospective study, the validity of the Dutch version of the PARCA-R questionnaire was assessed as an alternative for the standardized follow-up of neurodevelopmental outcome in VLBW

Table 1
Correlations between PARCA-R scores (sub-scales and overall PRC) and MDI1, 2 and 3 and correlations between overall PRC scores and PDI1, 2 and 3.

MDI1 (n = 70) age 9 months	Spearman's coefficient (95% CI's)	P-value	PDI1 (n = 70) age 9 months	Spearman's coefficient (95% CI's)	P-value
PRC	0.480 (0.276–0.642)	<0.0001	PRC	−0.0888 (−0.329–0.163)	NS
PRC linguistic	0.465 (0.258–0.631)	0.0001			
PRC non-verbal	0.521 (0.326–0.674)	<0.0001			
PRC sentence	0.493 (0.292–0.652)	<0.0001			
PRC sentence A	0.420 (0.206–0.597)	0.0003			
PRC sentence B	0.412 (0.195–0.589)	0.0004			
PRC vocabulary	0.444 (0.233–0.615)	0.0001			
MDI2 (n = 58) age 18 months	Spearman's coefficient (95% CI's)	P-value	PDI2 (n = 58) age 18 months	Spearman's coefficient (95% CI's)	P-value
PRC	0.376 (0.130–0.578)	0.003	PRC	0.116 (−0.157–0.372)	NS
PRC linguistic	0.354 (0.106–0.561)	0.006			
PRC non-verbal	0.428 (0.190–0.618)	0.0008			
PRC sentence	0.393 (0.150–0.592)	0.002			
PRC sentence A	0.258 (−0.00031–0.484)	NS			
PRC sentence B	0.380 (0.135–0.581)	0.003			
PRC vocabulary	0.307 (0.052–0.524)	0.01			
MDI3 (n = 23) age 36 months	Spearman's coefficient (95% CI's)	P-value	PDI3 (n = 23) age 36 months	Spearman's coefficient (95% CI's)	P-value
PRC	0.521 (0.138–0.768)	0.01	PRC	−0.0536 (−0.447–0.58)	NS
PRC linguistic	0.505 (0.117–0.759)	0.01			
PRC non-verbal	0.495 (0.103–0.753)	0.01			
PRC sentence	0.559 (0.191–0.789)	0.005			
PRC sentence A	0.329 (−0.0964–0.653)	NS			
PRC sentence B	0.546 (0.172–0.782)	0.007			
PRC vocabulary	0.422 (0.0122–0.711)	0.04			