

Health of extremely preterm infants: parental perspectives and family important outcomes

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Supplemental material

Table s1: Criteria for discharge from the neonatal follow-up clinic

Normal Bayley assessment at the 18-month-visit
AND
Normal neurological examination at the 36-month-visit
AND
Normal language and motor skills at the 36-month-visit (based on physician's assessment)
AND
No parental concerns regarding behavior and development at the 36-month visit
Transferred to another neonatal follow-up program (family moved away)
Parents refuse follow-up after several attempts to book an appointment

Table s2. Frequency of each theme according to child or parent characteristics

	Development n (%)	Respiratory illness and fragility n (%)	Growth and feeding n (%)	Nothing n (%)
NDI level				
- No, N=157	82 (52%)	36 (23%)	16 (10%)	41 (26%)
- Mild-moderate, N=68	37 (54%)	23 (34%)	9 (13%)	7 (10%)
- Severe, N=53	35 (66%)	9 (17%)	13 (24%)	4 (8%)
Parent				
- Mother, N=199	107 (54%)	50 (25%)	30 (15%)	35 (18%)
- Father, N=86	49 (57%)	20 (23%)	10 (12%)	19 (22%)
Age				
- 18 months CA, N=89	33 (37%)	29 (33%)	21 (24%)	19 (21%)
- 36 months CA, N=77	44 (57%)	21 (27%)	15 (20%)	9 (12%)
- 5 years, N=78	51 (65%)	16 (21%)	4 (3%) [#]	14 (18%)
- 7 years, N=41	28 (68%)	4 (10%)		12 (29%)
Education level				
- < high school, N=44	17 (39%)	6 (14%)	4 (9%)	18 (41%)
- ≥ high school, N=231	134 (58%)	62 (27%)	33 (14%)	34 (15%)
Gestational age group				
- 22-24 weeks, N=55	32 (58%)	14 (26%)	10 (18%)	7 (13%)
- 25-26 weeks, N=95	54 (57%)	22 (23%)	13 (14%)	18 (19%)
- 27-28 weeks, N=135	70 (52%)	34 (25%)	17 (13%)	29 (22%)

5 and 7 years-old children combined due to low numbers

Table s3. Child and parent characteristics associated with improvement themes

	Development OR (95% CI)	Respiratory illness and fragility OR (95% CI)	Growth and feeding OR (95% CI)	Nothing OR (95% CI)
NDI level				
- No	1	1	1	1
- Mild-moderate	1.09 (0.62-1.93)	1.72 (0.92-3.21)	1.34 (0.56-3.21)	0.33 (0.14-0.77)
- Severe	1.78 (0.93-3.40)	0.69 (0.31-1.54)	2.86 (1.27-6.45)	0.23 (0.08-0.68)
Parent				
- Mother	1	1	1	1
- Father	1.14 (0.68-1.90)	0.90 (0.50-1.64)	0.74 (0.34-1.59)	1.33 (0.71-2.49)
Age				
- 18 months CA	0.27 (0.12-0.60)	4.47 (1.46-13.74)	8.88 (2.93-26.95)	0.66 (0.28-1.52)
- 36 months CA	0.62 (0.28-1.38)	3.47 (1.10-10.92)	6.96 (2.21-21.87)	0.32 (0.12-0.84)
- 5 years	0.88 (0.39-1.96)	2.39 (0.74-7.68)	1 [#]	0.53 (0.22-1.28)
- 7 years	1	1		1
Education level				
- < high school	0.46 (0.24-0.88)	0.43 (0.17-1.07)	0.60 (0.20-1.79)	4.01 (1.99-8.10)
- ≥ high school	1	1	1	1
Gestational age group				
- 22-24 weeks	1.29 (0.69-2.43)	1.01 (0.49-2.09)	1.54 (0.66-3.62)	0.53 (0.22-1.30)
- 25-26 weeks	1.22 (0.72-2.07)	0.90 (0.48-1.66)	1.10 (0.51-2.39)	0.85 (0.44-1.65)
- 27-28 weeks	1	1	1	1