Quality of life in preschool children born preterm

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The relationship of preterm birth to health-related quality of life (HRQoL) was examined for children aged 1 to 4 years. Three gestational age groups with a NICU history were selected, <32 weeks (n=65), 32 to 36 weeks (n=41), ≥37 weeks (n=54), and a reference group from the open population (n=50). The main instrument was the TNO-AZL Preschool Quality Of Life (TAPQOL) questionnaire, which was completed by the parents. In addition, other outcome measures obtained from parents or neonatologists were investigated. Children born <32 weeks had significantly lower HRQoL than the reference group in the scales for lungs, stomach, eating disorders, motor functioning, communication, and anxiety. Parental feelings towards the child were related to the child's HRQoL. We found differences between the neonatologists' and parents' perceptions of the children's situation, which can have clinical consequences (e.g. different opinions about what needed treatment). Neonatal intensive care after birth has HRQoL implications for all children, particularly in children born at <32 weeks of gestation.

In the 1960s neonatal intensive care was introduced, and although the survival rate of preterm children has improved, the prevalence of major disabilities in preterm children has remained steady (Veen et al. 1991, Tin et al. 1997). It is well documented that children born preterm are at risk for developmental disorders like cognitive and school performance problems; emotional and behavioural problems; neurological problems; and disorders in motor ability and physical health (e.g. Hille et al. 1994, Saigal et al. 1994, Middle et al. 1996, Thompson et al. 1997). Most studies up till now have concentrated on isolated physical or psychosocial effects of preterm birth. However, these studies provide a limited picture, focussing as they do, only on specific aspects of health. Health-related quality of life (HRQoL) is useful here, because it combines physical, psychological, and social well-being in one outcome measure. The assessment by a person of their own health functioning is called health status (HS; Theunissen 1999). However, a certain quantity of HS does not directly result in a certain quality of life. There are individual and culturally determined differences in adapting to HS problems. Therefore, we defined HRQoL as HS problems combined with the degree to which the person shows negative emotions to such problems (Theunissen 1999). To explore what this implies in preterm children, in this study special attention was given to a comparison between HRQoL results and HS results.

Preferably, HRQoL is self-administered, however, preschool children cannot be used as informants because HRQoL is usually assessed through paper and pencil questionnaires. Alternatively, a proxy respondent can be used. The closer the relationship between patient and proxy, the higher the agreement is between them (Theunissen et al. 1998). Therefore, the parent is the most preferable proxy informant about the child's HRQoL. As a result of using the parent as informant, an association could be expected between the feelings a parent has toward the child and the HRQoL they report.

Of course, HRQoL considerations have always been important for the individual neonatologist. As valuable as the estimations of neonatologists may be, their judgement could differ from the judgement of the parent. Possible agreement or disagreement between parent and neonatologist could have implications for medical decision-making regarding the child. Therefore, the judgement of the neonatologist, about the seriousness of the outcome and the perceived experience of the child, was compared with the HRQoL and HS as reported by the parent.

Measuring HRQoL in preschool children born preterm is relatively new. Based on what is known about developmental risks, we hypothesized that the lowest HRQoL could be found in children born very preterm (<32 weeks), medium HRQoL in children born preterm (32 to 36 weeks), and highest HRQoL in a reference group taken from the population. In addition, to test the relative effect of other perinatal factors apart from gestational age, a group of term (≥ 37 weeks) neonatal intensive care unit (NICU) survivors was included as a clinical control group. It was also hypothesized that term NICU survivors would have lower HRQoL than children in a reference group. Furthermore, the relation between HRQoL and several perinatal factors was investigated.

Method

PARTICIPANTS AND DATA-COLLECTION PROCEDURES

The study contained both a clinical sample and a reference

sample of children aged 1 to 4 years. The clinical sample consisted of the parents of 193 children, consecutively consulting the outpatient neonatology clinic of the Leiden University Medical Centre, The Netherlands, between July and December 1996. They were invited to complete the TNO-AZL Preschool Quality Of Life (TAPQOL; Fekkes 2000) questionnaire, a preschool child's HRQoL questionnaire using parents as proxy respondents. Parents were approached during their visit to the clinic or by mail. Response rate was 86%. Parents were asked for permission to study their children's medical case history. One-hundred-and-sixty-four parents granted permission. Four of these children were excluded as information on gestational age was lacking. Thus, 160 children were included in the clinical sample. Three clinical groups with a NICU history were constructed: 65 children born <32 completed weeks of gestation, 41 children born between 32 and 36 weeks and 54 children who were term NICU survivors (≥ 37 weeks) with neonatal problems other than a preterm birth (such as asphyxia).

A random sample of 50 preschool children, drawn from six 'well-baby clinics' distributed all over The Netherlands, was used as a reference group alongside the three clinical groups. Criteria about informed consent and anonymity were met according to the TNO medical ethics committee. Demographic data such as the preschool child's sex, age, number of siblings, maternal and paternal educational level, occupation of the mother, religious denomination, and parents' age were not different between the four groups.

MEASURES

TAPQOL

The TAPQOL instrument is constructed as a sequel to the TACQOL, a questionnaire to measure HRQoL of children 6 to 12 years of age (Verrips et al. 1997). The TAPQOL has 10 scales that are relevant for children of 1 to 1 year 6 months of age: stomach, skin, lungs, sleeping, appetite, eating disorders, liveliness, positive mood, problem behaviour, and anxiety. For children of 1.5 to 5 years old (75% of our sample), the TAPQOL includes three more scales: motor functioning, social functioning, and communication. Parents were instructed to compare the quality of their child's life with that of peers of the same age.

Every item starts with a specifically formulated HS problem (e.g. lungs scale item: 'Has your child been short of breath?'; anxiety scale item: 'Was your child anxious?'). Response categories are 'never', 'sometimes', or 'often'. If the answer is 'sometimes' or 'often', the item leads to a second part about emotional response: 'At that time, my child felt…': 'fine', 'not so good', 'quite bad', or 'bad'. Items were scored between 0 and 4. Scale scores were obtained by adding item scores within scales, and transforming crude scale scores to a linear 0 to 100 scale, with higher scores indicating better HRQoL. Emotional responses were not assessed using the items on liveliness, positive mood, problem behaviour, anxiety, and social functioning scales, because these questions already include an emotional dimension. In this situation, item scores were on a 0 to 2 scale (0=often, 1=sometimes, 2=never) and scale scores ranged from 0 to 100. Item scores of the other scales were also encoded excluding the emotional evaluation to obtain HS scores (0=often, 1=sometimes, 2=never) and scale scores ranged from 0 to 100, with higher scores representing better HS.

In our sample the Cronbach alpha coefficient range of HRQoL was 0.61 to 0.88. Stomach, eating disorders, and social functioning had alpha's below 0.70. The range of HS scales was 0.59 to 0.89. Stomach, skin functioning, eating disorder, and social functioning had alphas below 0.70. The construction and psychometric performance of the instrument has been described in more detail elsewhere (Theunissen 1999). The instrument has good construct, criterion, and concurrent validity.

Medical case history checklist of preschool children with a NICU history

The checklist list assesses NICU diagnoses such as birth factors, pulmonary disorders, and circulation disorders and treatments that were considered clinically relevant. The checklist was specially developed for this study by a neonatologist and a developmental psychologist.

Judgement of the neonatologist: global HRQoL of the child

This instrument, developed for this study, contained three questions: present medical complications as a result of NICU period (answers: 'yes' or 'no'), seriousness of outcome ('not applicable' to 'very serious' using a 0- to 7-point Likert scale), and perceived suffering of the child ('not applicable' to 'very serious' using a 0- to 7-point Likert scale).

Caretaker's feelings towards their infant with NICU history

The 'Caretaker's feelings towards their infant' (CAFEIN) instrument contains three scales: (1) attachment and upbringing (six items, e.g. 'Did you find it difficult to grow attached to the child?', Cronbach alpha=0.64); (2) positive emotions in relation with the child (six items, e.g. 'Did having your child make you feel happy?', Cronbach alpha=0.72); and (3) negative emotions in relation to the child (eight items, e.g. 'Were you worried about the child?', Cronbach alpha=0.80). The list was developed for this study by a developmental psychologist. The questions follow the format of the TACQOL, with scale scores ranging from 0 to 100. Construct validity of the questionnaire was good: item ordinality was confirmed by homogeneity analysis and the structure of the questionnaire was confirmed by factor analyses (Theunissen 1999).

About the preschool child and parents

In addition, questions were asked which assessed the demographics of children and their parents. This included general information such as parental age and education.

DATA ANALYSIS

The HRQoL results of the three clinical groups and the reference group were summarized with mean scores and standard errors (SE). Differences between groups with respect to HRQoL were tested by MANOVA. This was done with and without confounding variables (birthweight for gestational age standard deviation score [SD], preschool child's sex and age, maternal and paternal educational level) to single out the effect of gestational age and socioeconomic status (SES).

The relation of several perinatal factors with HRQoL was investigated in two steps. In step one, the relation between the HRQoL scales and the perinatal factors was analysed with canonical correlation analysis. The purpose of this procedure is to determine how similar sets of variables are to one another. Canonical correlation analysis is an extension of MANOVA, with more than one dependent variable. Global tests for the null hypothesis (no correlation) were performed

at the nominal level of 0.05 using the first canonical correlation. Age of the child during HRQoL assessment was added as a covariate, because developmental differences in preschool children can be large. Since the parents were instructed to compare the quality of their child's life with that of peers of the same age, age was not corrected for weeks of gestation (Miller et al. 1984, den-Ouden et al. 1991). The motor functioning, social functioning, and communication scales were excluded from these canonical correlation analyses, because they were not relevant for children younger than 1.5 years of age (25% of our sample). In step two, multiple regression analyses (MANOVA) of each HRQoL scale were performed separately on clusters of perinatal factors, with age of the preschool child as covariate.

Furthermore, canonical correlation analyses were used to associate the judgement of the neonatologist and the feelings of the parents (CAFEIN) with HRQoL scales. All of the aforementioned computations with HRQoL were done for HS as well. Significance was set at $p \leq 0.05$. Statistical analyses were performed using SPSS (version 6.1).

Results

Table I presents the definitions of the perinatal variables and SES and their distribution among the three clinical groups. As can be seen, most perinatal problems occurred in the very preterm group (Pearson χ^2 $p<0.05$).

PREMATURITY VERSUS HRQOL

Figure 1 presents the means of the HRQoL scales of the four groups. In Table II, the differences between groups with and without confounding variables are shown.

Overall, preschool children born at <32 weeks of gestation

Table I: Distribution of clinical variables amongst three clinical groups (according to information in case histories)

	Very preterm <32 wk n (%)	*Preterm 32–36 wk n (%)*	*Term NICU survivors ≥ 37 wk n (%)*
Birth factors			
Birthweight (g)			
≤ 1330	51 (80)	3 (7)	0 (0)
1330–2500	13 (20)	28 (68)	14 (26)
>2500	0 (0)	10 (24)	40 (74)[f]
Standard deviation for birthweight at given gestational age, <–2 SD	8 (13)	7 (17)	14 (26)
Infant's sex, Male	37 (57)	25 (61)	33 (61)
Multiple pregnancy	22 (34)	7 (17)	3 (6)[f]
Complications during pregnancy	46 (77)	34 (85)	27 (51)[f]
Apgar score at 5 minutes, <7	14 (22)	6 (15)	11 (22)
Pulmonary disorders and treatments			
Idiopathic respiratory distress syndrome (IRDS)	38 (59)	8 (20)	3 (6)[f]
Oxygen administration	37 (60)	12 (29)	14 (26)[f]
Continuous Positive Airway Pressure (CPAP)	53 (84)	10 (24)	4 (8)[f]
Intermittent Positive Pressure Ventilation (IPPV)	53 (83)	10 (24)	20 (38)[f]
Pneumothorax	10 (15)	3 (7)	3 (6)
Bronchopulmonary dysplasia (BPD)[a]	12 (19)	1 (2)	0 (0)[f]
Circulation disorders			
Persistent ductus arteriosus (PDA)[b]	17 (26)	3 (7)	2 (4)[f]
Hypotension[c]	11 (17)	0 (0)	2 (4)[f]
Other disorders			
Hyperbilirubinemia	35 (54)	11 (27)	13 (24)[f]
Intraventricular haemorrhage (IVH)[d]	12 (18)	3 (7)	0 (0)[f]
Nr of diagnoses mentioned in event history[e]			
≤ 3 diagnoses	14 (22)	22 (55)	40 (76)
3–5 diagnoses	22 (34)	13 (33)	10 (19)
>5 diagnoses	28 (44)	5 (13)	3 (6)[f]
Socioeconomic status			
Maternal educational level			
Low	17 (29)	13 (34)	18 (35)
Medium	25 (42)	14 (37)	25 (48)
High	17 (29)	11 (29)	9 (17)
Paternal educational level			
Low	20 (36)	14 (37)	23 (46)
Medium	13 (23)	11 (29)	16 (32)
High	23 (41)	13 (34)	11 (22)
No occupation of mother	37 (57)	20 (50)	28 (53)

[a] Bancalari et al. 1979; [b] Diagnosed by ultrasound; [c] Mean arterial pressure (30 mmHG); [d] Papile et al. 1978; [e] Number of diagnoses out of a list of 26 possible diagnoses including 'other'; [f] χ^2 (Pearson) $p<0.05$.

had significantly lower scores than the reference group in the scales for lungs, stomach, eating disorders, motor functioning, communication, and anxiety. When corrected for confounding variables the difference on the stomach scale disappeared. In the other group combinations almost no significant HRQoL differences were found. A significant difference was found between the very preterm and preterm group for motor functioning (adjusted only), communication, and anxiety. Therefore, the hypothesized relation between HRQoL and gestational age was partly supported. Hypothesis 2, that the term NICU survivors would have lower HRQoL than the reference group, was supported for motor functioning and communication.

RELATION BETWEEN PERINATAL FACTORS AND HRQOL

The first canonical correlation and multiple correlations between the HRQoL scales on the one side and perinatal factors on the other side are presented in Table III. As can be seen, a significant canonical correlation of all HRQoL scales together was found with birth factors, pulmonary disorders and treatments, circulation disorders, and other disorders, but not with SES. Nevertheless, SES variables correlated with appetite, eating disorders, and problem behaviour scales.

RELATION BETWEEN OUTCOME MEASURES

HRQoL versus HS

The most salient difference between HRQoL and HS scores concerned motor functioning. The adjusted mean HRQoL of the very preterm child was 10.5 points lower then the mean HRQoL of the reference group, whereas the HS of the very preterm child was 18.7 points lower than the HS of the reference group. For the difference between the very preterm and the preterm groups the same kind of effects were found (–6.1 HRQoL and –9.7 HS respectively). Therefore, as far as the motor functioning of the very preterm child is concerned, HS was estimated to be much lower than HRQoL. In contrast, for lungs, stomach, and sleeping the reverse is true: The HS of the very preterm was estimated to be higher than the HRQoL.

Correlations between perinatal factors and HRQoL motor functioning were lower and correlations were found significant less often than between perinatal factors and HS motor functioning. For instance, the correlation of HRQoL with birth factors was estimated at 0.27 ($p=0.532$), the correlation of HS with birth factors was estimated at 0.61 ($p=0.001$). Therefore, HRQoL motor functioning related less to the perinatal factors than HS motor functioning. In contrast, however, HRQoL appetite and communication related more to the perinatal factors than HS appetite and communication.

HRQoL versus judgement of the neonatologist

The neonatologist judged the medical outcome of NICU history, the seriousness of outcome, and the quality of the health experience of the preschool child. According to the first canonical correlation, the judgement of the neonatologist correlated with the HS estimated by the parents (MANOVA canonical correlation $F=0.53$, $p=0.037$), but not with the HRQoL (0.42, $p=0.182$). Therefore, neonatologists did not include the emotional evaluation of HS problems in their judgement, whereas the parents did.

HRQoL versus feelings of the parents

According to the first canonical correlation, assessment of

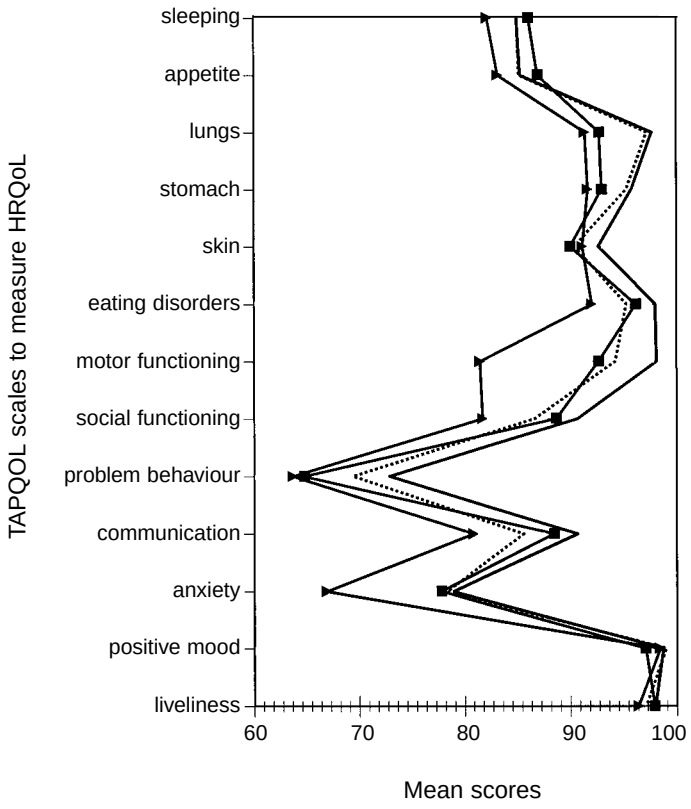

Figure 1: *HRQoL group means of: ▲, very premature (<32 weeks); ■, premature (32–36 weeks); -----, term NICU survivors (≥ 37 weeks); and ——, reference groups.*

the feelings of a parents towards children using the CAFEIN, correlated with both HRQoL (0.65, $p=0.0001$) and HS (MANOVA canonical correlation $F=0.62$, $p=0.0001$). Therefore the expected correlation between feelings of the parent and the reported HRQoL was found.

Discussion

The order of the gestational age groups, although not always significant, is often as we expected. This means lowest HRQoL in the very preterm (<32 weeks), medium HRQoL in the preterm (32 to 36 weeks), and highest HRQoL in the reference group. We found significant differences on scales with a physical character (lungs, stomach, eating disorders, motor functioning) but also on psychosocial scales (communication and anxiety). Furthermore, the HRQoL of the term NICU survivors is worse than the HRQoL of the reference group. Apparently, the need for neonatal intensive care after birth has implications for HRQoL in early childhood, but to an even greater degree in children born very preterm.

In other studies, relations between various perinatal factors and preschool child development were found (e.g. Stanton et al. 1991, Thompson et al. 1997). In our study, an association was found between perinatal factors and HRQoL. SES was less strongly associated with HRQoL than birth factors, pulmonary disorders and treatments, circulation disorders, and other disorders. Development in preschool children of families of lower SES appeared to be worse here than in other studies (e.g. Halsey et al. 1993, Thompson et al. 1997), but the parents'

Table II: Differences in mean HRQoL scores[a] between very preterm, preterm and reference group and between term NICU survivors and reference group

	Very preterm– reference		*Very preterm– preterm*		*Preterm–reference*		*Term NICU–reference*	
	raw data	*adjusted[b]*	*raw data*	*adjusted*	*raw data*	*adjusted*	*raw data*	*adjusted*
Sleeping	–5.1 (3.7)	–4.2 (4.5)	–6.3 (4.0)	–6.8 (4.5)	1.5 (4.2)	2.6 (4.9)	0.0 (3.9)	5.5 (4.8)
Appetite	–2.9 (2.9)	–1.5 (3.4)	–3.3 (3.1)	–3.4 (3.5)	0.4 (3.3)	1.9 (3.8)	–0.4 (2.5)	1.1 (3.0)
Lungs	–10.2 (3.5)[c]	–11.2 (4.2)[c]	–2.9 (3.7)	–5.1 (4.2)	–7.3 (3.9)	–6.1 (4.6)	–0.7 (2.8)	–1.5 (3.5)
Stomach	–7.1 (3.5)[c]	–6.3 (4.3)	–2.4 (3.8)	–3.3 (4.3)	–4.7 (4.0)	–3.0 (4.7)	–0.6 (3.2)	0.1 (4.1)
Skin	–1.5 (2.6)	–2.9 (3.2)	–2.0 (2.8)	2.7 (3.2)	–3.5 (2.9)	–5.6 (3.4)	–3.3 (3.0)	–4.1 (3.8)
Eating disorders	–6.8 (2.3)[c]	–5.8 (2.6)[c]	–3.3 (2.4)	2.3 (2.6)	–3.5 (2.6)	–3.5 (2.8)	–1.9 (1.2)	–1.8 (1.5)
Motor functioning	–8.5 (2.1)[c]	–10.5 (2.7)[c]	–4.5 (2.4)	–6.1 (2.8)[c]	–4.0 (2.5)	–4.4 (3.2)	–3.7 (1.6)[c]	–4.0 (2.3)
Social functioning	–3.0 (3.9)	–5.6 (4.5)	–8.0 (4.3)	–6.4 (4.6)	5.0 (4.5)	0.8(5.1)	2.5 (3.7)	0.1 (5.0)
Problem behaviour	–5.7 (3.7)	–6.1 (4.3)	–1.1 (4.0)	0.0 (4.3)	–4.7 (4.2)	–6.1 (4.7)	3.5 (2.8)	2.1 (3.2)
Communication	–10.2 (2.9)[c]	–11.1 (3.1)[c]	–7.6 (3.3)[c]	–8.9 (3.3)[c]	–2.5 (3.5)	–2.3 (3.6)	–7.5 (3.6)[c]	–12.5 (4.8)[c]
Anxiety	–11.4 (3.9)[c]	–14.4 (4.6)[c]	–10.9 (4.2)[c]	–10.1 (4.6)[c]	–0.6 (4.4)	–4.3 (5.0)	0.6 (3.7)	–1.7 (4.5)
Positive mood	–0.5 (1.5)	–0.1 (1.9)	–1.4 (1.6)	1.7 (1.9)	–1.9 (1.7)	–1.7 (2.0)	–0.3 (1.2)	–0.2 (1.5)
Liveliness	–1.6 (1.9)	–2.1 (2.1)	–1.5 (2.0)	–1.1 (2.1)	–0.1 (2.2)	–1.0 (2.3)	–0.9 (1.8)	–1.7 (2.1)

[a] Differences in mean (SE) based on uni-variate t value and 0.95 confidence intervals; [b] Adjusted for birthweight SD, infant's sex and age, maternal and paternal educational level; [c] $p<0.05$.

Table III: Multiple correlations between perinatal factors and HRQoL

	All perinatal factors	*Birth factors*	*Pulmonary disorders and treatments*	*Circulation disorders*	*Other disorders*	*SES*
All HRQoL scales[a]	0.65[b]	0.55[b]	0.53[b]	0.46[b]	0.47[b]	0.41
Sleeping	0.45	0.21	0.27	0.05	0.14	0.09
Appetite	0.42	0.27	0.32[b]	0.28[b]	0.30[b]	0.25[b]
Lungs	0.50	0.21	0.35[b]	0.13	0.11	0.08
Stomach	0.45	0.24	0.29	0.10	0.17	0.11
Skin	0.45	0.27	0.23	0.24[b]	0.15	0.15
Eating disorders	0.53[b]	0.31	0.30[b]	0.12	0.18	0.23[b]
Motor functioning	0.58	0.27	0.38[b]	0.15	0.40[b]	0.12
Social functioning	0.47	0.34	0.30	0.32[b]	0.35[b]	0.09
Problem behaviour	0.51	0.34[b]	0.24	0.27[b]	0.29[b]	0.25[b]
Communication	0.55	0.44[b]	0.36[b]	0.29[b]	0.38[b]	0.24
Anxiety	0.46	0.34[b]	0.36[b]	0.27[b]	0.27[b]	0.20
Positive moods	0.34	0.17	0.18	0.17	0.24	0.13
Liveliness	0.48	0.33[b]	0.28	0.18	0.11	0.08

[a] Excluding scales only relevant for children >1 y 6 mo of age (motor functioning, social functioning, and communication), [b] Significant MANOVA Canonical correlation F: $p\leq 0.05$.

perception of their preschool child's HRQoL was found to be less influenced by their SES.

We defined HRQoL as HS weighted by the emotional response to problems in HS. HRQoL motor functioning of very preterm children was higher than would have been estimated without emotional evaluation (that is HS). In contrast, HRQoL lungs, stomach, and sleeping were lower in very preterm children (<32) than would have been estimated by HS alone. In this study, the judgement of the neonatologist correlated with the HS but not with the HRQoL. As a result of the above, one could imagine a clinical situation where the neonatologist is surprised that a parent does not want the child to have full treatment for the child's motor functioning problems. The parent simply does not consider the motor problems to be as serious as the neonatologist does. On the other hand the parent may see lung, stomach, and sleeping problems as being more of an emotional burden than the neonatologist. The parent, therefore, may not understand why these problems in their preschool child receive less attention from the neonatologist.

As expected we found that the feelings of parents towards their children related to parental perceptions of HRQoL. Thereby, the data may reveal as much about the parents as about the children. Sometimes, parents of children born preterm are considered to be worse reporters of their child's functioning than parents of children born at term, due to a 'prematurity stereotype'. Parents supposedly treat and perceive their children differently than parents with a term child, because of the preterm birth. However, from previous research we know that this stereotype is not supported (Donahue and Pearl 1995, Becker et al. 1997, Schermann Eizirik et al. 1997). Still, the HRQoL of the preschool child could be both the result or the cause of the parent's feelings towards the preschool child. However, parents are the main decision-makers in respect of the rearing and medical treatment of their children. In this way, their perception of the preschool child's HRQoL is clinically relevant.

A limitation of the study is the use of a relatively small hospital-based sample of NICU children. Children who had no complaints after neonatal intensive care, children who were being treated in rehabilitation centres because of severe disabilities, and children who were followed-up in other hospitals were not included in the sample. This may have caused both underestimation and overestimation of HRQoL respectively, probably counterbalancing each other.

In conclusion, the study revealed that at 1 to 4 years after birth, the HRQoL of children born after <32 weeks of gestation was lower than the HRQoL of children born with >32 weeks of gestation. Parents' SES was less strongly associated with HRQoL than were birth factors, pulmonary, circulation, and other disorders. A proportional relation is found between parent's feelings toward the child and the HRQoL of the child. Furthermore, we found differences between the neonatologist's and the parent's perception of the child's situation, which can have clinical consequences. Needing neonatal intensive care after birth has HRQoL implications for all children, and, to an increasing degree, for children born very preterm. To determine the stability of HRQoL in preschool children born preterm, longitudinal research will be needed, preferably with a larger, regional sample.

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References

Becker PT, Engelhardt KF, Steinmann MF, Kane J. (1997) Infant age, context, and family system influences on the interactive behavior of mothers of infants with mental delay. *Research in Nursing and Health* **20:** 39–50.

den-Ouden AL, Rijken M, Brand R, Verloove-Vanhorick SP, Ruys JH. (1991) Is it correct to correct? Developmental milestones in 555 "normal" preterm infants compared with term infants. *Journal of Pediatrics* **118:** 399–404.

Donahue ML, Pearl R. (1995) Conversational interactions of mothers and their preschool children who had been born preterm. *Journal of Speech and Hearing Research* **38:** 1117–25.

Fekkes M, Theunissen NCM, Brugman E, Veen S, Verrips EGH, Koopman HM, Vogels T, Wit JM, Verloove VS. (2000) Development and psychometric evaluation for the TAPQOL: a health-related quality of life instrument for 1-5-year-old children. *Quality of Life Research* **9:** 961–72.

Halsey CL, Collin MF, Anderson CL. (1993) Extremely low birth weight children and their peers: a comparison of preschool performance. *Pediatrics* **91:** 807–11.

Hille ETM, den-Ouden L, Bauer L, Van-den-Oudenrijn C, Brand R, Verloove-Vanhorick SP. (1994) School performance at nine years of age in very premature and very low birth weight infants: perinatal risk factors and predictors at five years of age. *Journal of Pediatrics* **125:** 426–34.

Middle C, Johnson A, Alderdice F, Petty T. (1996) Birthweight and health and development at the age of 7 years. *Child Care, Health and Development* **22:** 55–71.

Miller G, Dubowitz LM, Palmer P. (1984) Follow-up of pre-term infants: is correction of the developmental quotient for prematurity helpful? *Early Human Development* **9:** 137–44.

Saigal S, Rosenbaum P, Stoskopf B, Hoult L, Furlong W, Feeny D, Burrows E, Torrance G. (1994) Comprehensive assessment of the health status of extremely low birth weight children at eight years of age: comparison with a reference group. *Journal of Pediatrics* **125:** 411–17.

Schermann Eizirik L, Hagekull B, Bohlin G, Persson K, Sedin G. (1997) Interaction between mothers and infants born at risk during the first six months of corrected age. *Acta Paediatrica* **86:** 864–72.

Stanton WR, McGee R, Silva PA. (1991) Indices of perinatal complications, family background, child rearing, and health as predictors of early cognitive and motor development. *Pediatrics* **88:** 954–9.

Theunissen NCM. (1999) Health Related Quality of Life in Children. (PhD Thesis). Leiden: Leiden University Medical Center.

— Vogels AGC, Koopman HM, Verrips GH, Zwinderman AH, Verloove-Vanhorick SP, Wit JM. (1998) The proxy problem: child report versus parent report in health-related quality of life research. *Quality of Life Research* **7:** 387–97.

Thompson RJ, Gustafson KE, Oehler JM, Catlett AT. (1997) Developmental outcome of very low birth weight infants at four years of age as a function of biological risk and psychosocial risk. *Journal of Developmental and Behavioral Pediatrics* **18:** 91–6.

Tin W, Wariyar U, Hey E. (1997) Changing prognosis for babies of less than 28 weeks' gestation in the north of England between 1983 and 1994. Northern Neonatal Network. *British Medical Journal* **314:** 107–11.

Veen S, Ens-Dokkum MH, Schreuder AM, Verloove-Vanhorick SP, Brand R, Ruys JH. (1991) Impairments, disabilities, and handicaps of very preterm and very-low-birthweight infants at five years of age. *Lancet* **338:** 33–6.

Verrips GH, Vogels AGC, Verloove-Vanhorick SP, Fekkes M, Koopman HM, Kamphuis RP, Theunissen NCM, Wit JM. (1997) Health-related quality of life measure for children – the TACQOL. *Journal of Applied Therapeutics* **1:** 357–60.