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abstract

BACKGROUND AND OBJECTIVES: Parents of preterm children experience increased distress early in their children's lives. Whether the quality of life of parents of preterm children is comparable to that of parents of term children by the time their offspring reach adulthood is unknown. What precursors in their offspring's childhood predict parental quality of life?

METHODS: A prospective whole-population study in Germany followed very preterm (VP) (<32 weeks gestation) or very low birth weight (VLBW) (<1500 g) (N = 250) and term-born individuals (N = 230) and their parents (VP or VLBW: N = 219; term: N = 227) from birth to adulthood. Parental quality of life was evaluated with the World Health Organization Quality of Life assessment and the Satisfaction with Life questionnaire when their offspring were adults (mean age 27.3 years, 95% confidence interval [CI]: 27.2 to 27.3). Childhood standard assessments of VP or VLBW and term offspring included neurosensory disability, academic achievement, mental health, and parent-child and peer relationships.

RESULTS: Overall quality of life of parents of VP or VLBW adults was found to be comparable to parents of term individuals (P > .05). Parental quality of life was not predicted by their children being born VP or VLBW, experiencing disability, academic achievement, or the parent-child relationship in childhood but by their offspring's mental health (B = 0.15, 95% CI: 0.08 to 0.22) and peer relationships (B = 0.09, 95% CI: 0.02 to 0.16) in childhood.

CONCLUSIONS: As a testament to resilience, parents of VP or VLBW adults had quality of life comparable to parents of term adults. Support and interventions to improve mental health and peer relationships in all children are likely to improve parents' quality of life.

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Dr Wolke designed, conceptualized, and supervised the Bavarian Longitudinal Study and adapted the relevant instruments, participated in the analyses and interpretation of data, and drafted and revised the manuscript; Ms Baumann coordinated data preparation, analyzed and interpreted the data, and drafted and revised the manuscript; Dr Busch was responsible for data acquisition and critically revised the manuscript; Dr Bartmann designed and conceptualized the Bavarian Longitudinal Study and critically revised the manuscript; and all authors are accountable for all aspects of the work and approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Very preterm birth is associated with increased disability and schooling problems. Parents of preterm children are more stressed in the first year after preterm birth and report more burden still when their preterm children reach adolescence.

WHAT THIS STUDY ADDS: Parents of preterm adults do not consider their quality of life to be poorer than those of term adults. Poor child–peer relationships and mental health problems, but not prematurity or disability, predict poorer parental quality of life in the long-term.

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Being born very preterm (VP) or with very low birth weight (VLBW) is associated with a highly increased risk of mortality, neonatal complications, long-term morbidity,[1] and higher costs.[2] Medical achievements, such as more children surviving with chronic conditions, may have hidden consequences for health and the quality of life of parents.[3] Having a child born VP or VLBW increases parental stress and mental illness symptoms during the first 7 years of life.[4–8] The neonatal difficulties that the children encounter[7,9] and their physical, emotional, and social problems have been reported to mediate the link between preterm birth and parental stress.[10]

There is increasing evidence that motor,[11] cognitive,[12] and mental health problems[13] after VP or VLBW birth persist into adulthood. Adults born VP or VLBW are less likely to live independently, more often receive social benefits, more often have periods of unemployment, and are less likely to find a romantic partner[14,15] than term-born controls. Thus, their transition into adulthood is more challenging and their self-reported quality of life is lower than those of term adults.[16] These long-term consequences of VP or VLBW birth may also affect the quality of life of their parents even when the offspring are adults.

To date, only a few researchers have investigated parental psychological distress and burden as their VP or VLBW offspring transitioned into adolescence. Some found continued higher family burden and stress[17,18] and adverse effects on parents' emotional functioning.[19] Those parents who had adolescents with significant developmental difficulties reported being more burdened and stressed.[17] Researchers in only 1 study to date followed VLBW and control parents when their children reached adulthood. They found that differences in burden had ameliorated by adulthood, but it had curtailed the parents' job opportunities.[20] Although there is some indication that burden continues for parents of VP or VLBW at least into adolescence, there is complete paucity of findings on the parents' quality of life and life satisfaction when their VP or VLBW children reach adulthood. Which developmental difficulties in childhood may affect parental quality of life in the long-term is also unknown. However, this information is important to evaluate the full range of consequences of VP or VLBW birth, to direct resources appropriately, and to counsel parents about the long-term effects of VP or VLBW birth on their lives.[21]

Our aims with this prospective cohort study were to assess the quality of life of parents of adults who were born VP or VLBW compared with parents of term offspring and to investigate what factors in childhood predict the quality of life of parents of VP or VLBW and term offspring when they reach adulthood.

METHODS

Study Design and Participants

The Bavarian Longitudinal Study is a geographically defined, prospective whole-population study of VP and VLBW and term individuals in Germany born between January 1985 and March 1986.[12] The offspring and parents (major caretakers) of VP and VLBW (mothers: $N = 192$, fathers: $N = 27$) and term controls (mothers: $N = 212$, fathers: $N = 15$) were assessed 7 times since the birth of their offspring. For this study, parents were contacted and asked to fill in questionnaires on their quality of life and life satisfaction when the young adults were ~27 years of age (mean age 27.3, 95% confidence interval [CI]: 27.2 to 27.3). In total, data on parents' quality of life and life satisfaction were available for 446 parents (VP and VLBW: 219 parents of 250 offspring (because of multiple births); term controls: 227 parents of 230 offspring) (Fig 1). Ethical approval for this study was granted by the Ethical Board of the University Hospital Bonn, Germany (reference # 159/09). Parents gave fully informed, written consent for their participation and the participation of their children in childhood. Adolescents (13-year assessment) gave their own written consent to participation.

Measures

Parental Quality of Life

The German version of the World Health Organization Quality of Life instrument, Short Edition (WHOQoL-BREF)[22,23] was administered to assess parental quality of life. The WHOQoL-BREF has excellent validity,[22] is composed of 26 items, and assesses quality of life profiles across the following 4 domains: physical health (7 items), psychological health (6 items, eg, "How often do you have negative feelings such as blue mood, despair, anxiety, depression?"), social relationships (3 items, eg, "How satisfied are you with your personal relationships?"), and environment (8 items). In addition, a global assessment of an individual's perception of his or her quality of life and general health is computed (2 items, eg, "How would you rate your quality of life?"). The raw scores of the WHOQoL-BREF were transformed into scores ranging between 0 and 100, with a higher score denoting higher quality of life (VP and VLBW parents Cronbach's α [term control parents in brackets]: physical = 0.81 [0.85], psychological = 0.79 [0.74], social relationships = 0.64 [0.66], environment = 0.76 [0.74], and global = 0.70 [0.65]).

Parents then answered the 5-item Satisfaction with Life Scale,[24] which is also reported to have high validity and reliability.[25,26] The items were as follows: "In most ways my life is close to my ideal," "The conditions of

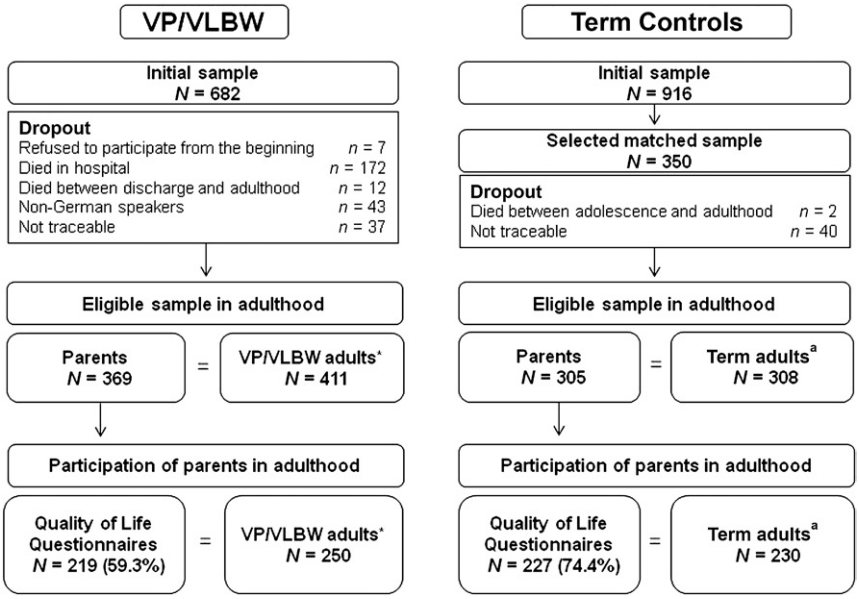

FIGURE 1
Flow diagram of the eligible sample of VP and VLBW and term control participants in adulthood and their parents. [a] Includes multiple births.

my life are excellent," "I am satisfied with my life," "So far I have gotten the important things I want in life," and "If I could live my life over, I would change almost nothing." Items are rated on a 7-point scale (1 = strongly agree to 7 = strongly disagree) and summarized into a global life satisfaction score (VP and VLBW parents: *Cronbach's* α = 0.91; term control parents: *Cronbach's* α = 0.90).

The global life satisfaction score, the 4 WHOQoL domain scores, and the global score of quality of life were highly correlated (r = 0.42–0.75). To avoid inflation of significant results by using multiple individual domain comparisons, the 5 WHOQoL and the Satisfaction with Life Scale were entered into a confirmatory factor analysis by using Mplus version 7.3,[27] yielding a single overall parental quality of life score (factor loadings shown in Supplemental Table 4). The standardized factor score, which represent overall parental quality of life, was retrieved.

Assessment of Child Functioning

Child functioning in 5 areas was assessed with multiple measures during childhood. Supplemental Tables 5 and 6 provide fully referenced and detailed descriptions of all measures.

Disability in childhood was defined as having cerebral palsy, blindness, noncorrected hearing problems, motor problems, or cognitive impairment at the ages of 6 or 8 years.

Mental health was measured with parental reports in the Child Behavior Checklist at 6 and 8 years and parental and child reports in the Strengths and Difficulties Questionnaire at 13 years (4 measures).

Academic achievement measures included the Kaufman Assessment Battery for Children achievement subtest at 6 and 8 years; tests of mathematics, reading, and spelling at 8 years; and child school success at 13 years (6 measures).

Parent-child relationship was assessed with nurses' observations of parenting neonatally and observations of maternal sensitivity at 6 and 8 years (3 measures).

Peer relationships were measured by using parental and child reports of the number of friends they have during interviews at 6 and 8 years and parental and child reports of the quality of peer relationships, which were assessed with the Pictorial Scale of Perceived Competence and Social Acceptance, at 6 and 8 years (8 measures).

To obtain domain scores of mental health, academic achievement, peer relationships, and parent-child relationships from the various childhood measures, we performed confirmatory factor analysis for each domain using Mplus version 7.3.[27] Measures were used as factor indicators, and standardized factor scores for each of the 4 child functioning domains were retrieved. All factor loadings >0.3 were included (see Supplemental Table 7).

Potential Confounders

The following variables were considered as potential confounders: parental sex; family socioeconomic status at birth classified as low, middle, and high[28]; maternal major depression diagnosed according to *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* at 6[29] or 8 years; maternal age; marital status at birth; and multiple births.

Statistical Analysis

All analyses were conducted by using SPSS version 22. Differences between parents of VP and VLBW and term control adults and between offspring groups were tested with a t test or χ^2 test. Multiple comparisons were Bonferroni adjusted.

To predict overall parental quality of life, VP or VLBW birth, child disability, and the domain scores for mental health, academic achievement, parent-child relationship, and peer relationships were entered in univariate regression analyses. For parents with multiple births, mean child functioning domain scores were used. Disability

TABLE 1 Family Demographics and Child Functioning in the VP and VLBW and Term Control Groups

	VP and VLBW	Term Controls	*P*
Parental demographics	*N* = 219	*N* = 227	
Parental sex, *n* (%)			.04
Mother	192 (87.7)	212 (93.4)	
Father	27 (12.3)	15 (6.6)	
Current parental age, mean (95% CI)	56.1 (55.4 to 56.8)	56.4 (55.8 to 57.0)	.51
Family socioeconomic status at birth, *n* (%)			.02
High	47 (21.6)	77 (33.9)	
Middle	105 (48.2)	92 (40.5)	
Low	66 (30.3)	58 (25.6)	
Maternal age at birth, mean (95% CI)	28.6 (27.9 to 29.2)	29.1 (28.5 to 29.7)	.27
Paternal age at birth, mean (95% CI)	31.7 (30.9 to 32.5)	32.4 (31.6 to 33.2)	.20
Marital status at birth (married or cohabiting), *n* (%)	200 (94.3)	222 (97.8)	.06
Current marital status (married or cohabiting), *n* (%)	151 (73.7)	184 (82.1)	.03
Maternal depression (DSM-IV diagnosis) at 6 or 8 y, *n* (%)	10 (5.3)	27 (11.9)	.02
Offspring's neonatal characteristics	*N* = 250	*N* = 230	
Sex, *n* (%)			.21
Female	116 (46.4)	120 (52.2)	
Male	134 (53.6)	110 (47.8)	
Gestation (wk), mean (95% CI)	30.4 (30.2 to 30.7)	39.6 (39.5 to 39.8)	<.001
Birth weight (g), mean (95% CI)	1304 (1265 to 1344)	3374 (3316 to 3433)	<.001
Multiple births, *n* (%)	73 (29.2)	9 (3.9)	<.001
Offspring's childhood functioning ≤13 y	*N* = 250	*N* = 230	
Any disability, *n* (%)	97 (38.8)	13 (5.7)	<.001
Mental health[a], mean (95% CI)	−0.08 (−0.16 to −0.01)	0.09 (0.01 to 0.16)	.002
Academic achievement[a], mean (95% CI)	−0.40 (−0.52 to −0.28)	0.42 (0.35 to 0.49)	<.001
Parent–child relationship[a], mean (95% CI)	−0.10 (−0.16 to −0.03)	0.10 (0.05 to 0.16)	<.001
Peer relationships[a], mean (95% CI)	−0.13 (−0.19 to −0.06)	0.13 (0.07 to 0.18)	<.001

DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.
[a] Standardized factor score.

was regarded as present if 1 of the multiples had a disability. Subsequently, to examine which child functioning domains were most strongly associated with the outcome, all child functioning domains and potential confounders were entered simultaneously in the regression model.

Regression analyses were repeated separately for the 6 original parental quality of life outcome scores.

RESULTS

Family Demographics and Child Functioning

Participating parents of VP and VLBW adults were more often fathers compared with parents of term adults (Table 1). More fathers of VP or VLBW adults were divorced or widowed than fathers of term controls. Parents of VP and VLBW individuals less often had a high socioeconomic status than parents of term individuals. No group differences were found for current paternal age, maternal age, or marital status at birth. Maternal clinical depression during their offspring's childhood was more frequent for parents of term controls.

By definition, VP and VLBW offspring were born with lower gestational ages and birth weight and were more often multiple births than term controls, but no group differences were found with regard to sex. In childhood, VP and VLBW offspring had more disabilities, more mental health problems, lower academic achievement, and worse parent-child and peer relationships than term-born comparisons (Table 1).

Participants Compared With Those Lost to Follow-up

Participating parents of VP and VLBW adults did not differ from parents of VP and VLBW who dropped out in terms of maternal and paternal age at birth and maternal depression when their children were aged 6 or 8 years (Supplemental Table 8). However, dropouts were more often socially disadvantaged (low family socioeconomic status: 48.0% vs 30.3%, $P = .002$) and less often married or cohabiting with a partner at the time of birth of their children (87.3% vs 94.3%, $P = .019$).

Participating parents of term control adults were not different regarding marital status at birth or maternal depression at 6 or 8 years compared with dropout term parents. Parents of term control adults who dropped out, however, were more often socially disadvantaged (low family socioeconomic status: 44.9% vs 25.6%, $P = .002$) and younger at the time of birth of their children (mean maternal age: 27.2 years [95% CI: 26.0 to 28.4] vs 29.1 years [95% CI: 28.5 to 29.7]; mean paternal age: 30.5 years [95% CI: 29.1 to 31.8] vs 32.4 years [95% CI: 31.6 to 33.2]).

VP and VLBW offspring did not differ in terms of sex, gestational age, and birth weight from dropouts (Supplemental Table 8). Dropout VP and VLBW adults were less often multiples compared with VP and VLBW who participated (18.6% vs 29.2%, $P = .016$).

No differences were found between term offspring and dropouts.

Parental Quality of Life and Their Offspring's Childhood Functioning

The overall Quality of Life factor score of parents of VP and VLBW and term offspring was not different (VP and VLBW: mean standardized factor score −0.02 [95% CI: −0.13 to 0.08], term controls: mean standardized factor score 0.02 [95% CI: −0.07 to 0.12], $P > .05$) (Fig 2). Table 2 shows the individual scale scores. There were no group differences for the 4 quality of life domain scores, global life satisfaction, global score of quality of life, and health perception (Bonferroni corrected $P > .008$). Because there were more fathers in the VP and VLBW group, we repeated analysis using a 2 × 2 analysis of variance with parent sex and prematurity as factors. The Quality of Life factor score did not differ according to parent sex, prematurity and the interaction effect of parent sex X prematurity was also not significant (overall model: degrees of freedom (3); F = 0.79; $P = .50$).

Of the 5 childhood domains of functioning, better mental health and better peer relationships in childhood were consistently predictive of higher overall parental Quality of Life factor scores in unadjusted and adjusted analyses (Table 3). Detailed analyses of the 5 WHOQoL and the Life Satisfaction scales are shown in Supplemental Table 9.

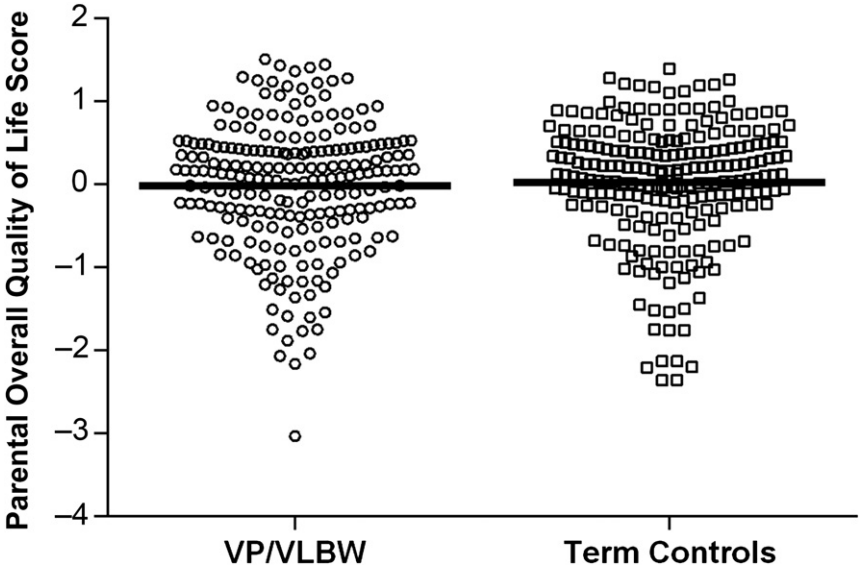

FIGURE 2
Parental overall quality of life factor score distribution and means (black line) in the VP and VLBW and term control group.

DISCUSSION

We found that the quality of life of parents of VP and VLBW offspring who had reached adulthood was not different from that of parents of term children. We also showed that, in offspring, better mental health and peer relationships in childhood (independently of whether they were born VP or VLBW or term) still predicted parents' quality of life more than a decade later.

VP and VLBW children more often experience disability,[30] mental health[31] and academic achievement problems,[32] and poorer peer relationships[33,34] in childhood than those born at term. This was confirmed in this prospective study of a geographically defined sample in Germany (Table 1). Despite the increased stress in the initial years[8,9] and the challenges faced by parents of VP and VLBW adults, who are still more likely to have neurodevelopmental[12,35] problems and difficulties with adaptation into independent living in adulthood,[14,16] their comparable quality of life to

TABLE 2 Parental Quality of Life Outcomes in the VP and VLBW and Term Control Groups: Subdomain Total Scores

	VP and VLBW ($N = 219$)	Term Controls ($N = 227$)	P
	Mean (95% CI)	Mean (95% CI)	
World Health Organization Quality of Life assessment			
Global score of quality of life and general health	69.6 (67.1 to 72.0)	73.7 (71.4 to 76.0)	.02
Physical health	80.1 (78.1 to 82.0)	80.0 (78.0 to 82.0)	.97
Psychological health	74.7 (72.9 to 76.4)	73.0 (71.4 to 74.6)	.17
Social relationships	72.8 (70.6 to 75.0)	73.9 (71.9 to 76.0)	.46
Environment	82.3 (80.7 to 83.8)	82.3 (80.9 to 83.7)	.99
Life satisfaction (global score)	26.2 (25.5 to 26.9)	26.9 (26.2 to 27.5)	.18

None are significant according to Bonferroni correction ($P > .008$).

TABLE 3 Unadjusted and Adjusted Associations Between Child Functioning and Parental Overall Quality of Life

	Unadjusted Impact			Adjusted Impact[a]		
	B	95% CI	*P*	B	95% CI	*P*
Parental overall quality of life						
VP and VLBW versus term	0.07	(−0.09 to 0.24)	.38	0.07	(−0.10 to 0.24)	.40
Any disability	0.01	(−0.21 to 0.23)	.96	−0.02	(−0.24 to 0.20)	.87
Mental health	0.15	(0.08 to 0.22)	<.001	0.15	(0.08 to 0.22)	<.001
Academic achievement	−0.02	(−0.07 to 0.04)	.61	−0.03	(−0.09 to 0.04)	.40
Parent–child relationship	0.02	(−0.05 to 0.08)	.59	0.02	(−0.05 to 0.08)	.65
Peer relationship	0.10	(0.03 to 0.16)	.004	0.09	(0.02 to 0.16)	.008

[a] Adjusted for all child functioning domains, socioeconomic status, multiple births, parental sex of informant, maternal depression (*Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* diagnosis) at 6 or 8 y, maternal age, and marital status at birth.

those of parents of term adults is a testament to their resilience. The findings are similar to the only other study of extremely low birth weight parents compared with term controls[20] in Canada, which detected no differences in maternal health and functioning. It suggests that in countries with universal access to health care, such as Germany and Canada, despite other cultural and educational differences, parents of VP and VLBW children on average show remarkable ability to cope with the challenges presented to them.

Furthermore, consistent with the study by Saigal et al,[20] we found that disability (despite the many sacrifices parents had to make to care for their disabled children) did not reduce the quality of life of parents when their offspring became adults. Similarly, academic performance in childhood and parent-child relationships did not predict parents' quality of life more than a decade later.

In contrast, poorer mental health and poor peer relationships in childhood predicted lower quality of life of parents. In other words, parents feel better about themselves and their relationships when their offspring had friends and were happy during childhood. This is likely to be due to the long-term adverse effects that both childhood mental health problems and social relationships can have on adult functioning. Both mental health problems, even when they are subclinical,[36,37] and being bullied, socially excluded, and without friends[38] have been shown to have long-lasting effects on adult adaptation, such as social relationships, partnering, wealth, and independent living. These affect the health-related quality of life of adults born VP or VLBW or at term[16] and are also reducing the quality of life of parents, as shown here.

This study has a range of strengths, the most important being the long-term follow-up of a large whole-population sample of VP and VLBW and term individuals recruited in the same obstetric hospitals and the use of reliable and valid tests to assess a range of childhood functions and parental quality of life over 27 years.

There are also limitations. First, although 66% of the eligible VP and VLBW and term parents participated at 27 years, the dropout was not random. This is found in many longitudinal studies,[39] but VP and VLBW or term offspring who participated or dropped out did not differ in neonatal characteristics. We controlled for factors that were found to differ between parents who dropped out and stayed or found to differ between participating VP and VLBW and control parents. Simulations have further shown that even when dropout is selective or correlated with the outcome of interest, regression functions may alter only marginally[40] but cannot be excluded.

CONCLUSIONS

Twenty-seven years after birth, parents of VP and VLBW adults have similar quality of life as parents of term adults. This is a testament to resilience, adaptability, and coping, and it reveals important new information for counseling of parents of VP and VLBW children dealing with disability and schooling problems in childhood. Parents' quality of life was mainly affected by their offspring's mental health and relationships with peers in childhood rather than by their children being born VP or VLBW, having disabilities, or poor school performance. Support and interventions to improve mental health and peer relationships in all children is likely to positively affect both the children as they grow up and the parents' quality of life and may reduce health-related costs.

Future researchers of very preterm children may want to include similar parental quality of life outcome measures to allow for comparisons across different samples to determine if the findings reported here are specific to variations of neonatal treatment, social conditions in countries, or health

systems, or are universal, as has been recently reported for other outcomes.[34,41–43]

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ABBREVIATIONS

CI: confidence interval
VLBW: very low birth weight
VP: very preterm
WHOQoL-BREF: World Health Organization Quality of Life instrument, Short Edition

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