Qual Life Res (2016) 25:2123–2139
DOI 10.1007/s11136-016-1259-9

REVIEW

Quality of life of individuals born preterm: a systematic review of assessment approaches

Martina Estevam Brom Vieira[1,2] · **Maria Beatriz Martins Linhares**[2]

Accepted: 22 February 2016 / Published online: 19 March 2016

Abstract
Purpose To review the existing literature regarding factors associated with quality of life (QoL) of individuals who were born preterm. The review focuses on assessment approaches and information sources.
Methods A systematic review of empirical studies published in PubMed, PsycARTICLES, PsycINFO, LILACS, and SciELO databases between 2007 and 2015. Search terms were chosen that relate preterm birth to QoL.
Results Twenty-two articles were included. Of these, ten investigated QoL in children, six investigated adolescents, and six investigated adults. All studies used generic instruments to assess QoL. There was a high rate of parental report to assess QoL in studies of children. Adolescent and adult studies most often assessed QoL through self-report. Parents of children who were born preterm reported worse QoL for their children compared with parents of children born full term. Teenagers and adults who were born preterm self-reported more positive outcomes in their QoL. The main risk factors associated with worse QoL in children who were born preterm were congenital malformations, mechanical ventilation during the neonatal phase, cognitive impairments, behavioral problems, physical disabilities, low family income, and black race.
Conclusions Agreement between parents and children about QoL in preterm individuals was lower in younger age groups compared with older age groups. The differences in QoL throughout the different age groups may have arisen because of developmental changes or differences in the source of information used (i.e., parent report or self-report). We recommend that QoL assessments in children born preterm should consider both parent report and self-report.

Keywords Quality of life · Preterm birth · Risk factor · Assessment

Introduction

Prematurity is characterized by physical and neurological immaturity of infants at birth, which can have negative impacts on several biological systems [1–3]. Consequently, individuals born preterm may experience recurring health problems, in addition to developmental delays or disorders at various points of development [4–6].

In recent decades, scientific research on infants who are born preterm no longer focuses only on specific diseases or isolated areas of development, such as motor skills, cognition, language, or personal/social behavior. Instead, it has assessed the impact of premature birth on multidimensional holistic outcomes, such as functional abilities and quality of life (QoL). In particular, QoL has become a very important outcome that should be considered in matters of

Electronic supplementary material The online version of this article (doi:10.1007/s11136-016-1259-9) contains supplementary material, which is available to authorized users.

✉ Maria Beatriz Martins Linhares
linhares@fmrp.usp.br

Martina Estevam Brom Vieira
martinabrom@gmail.com

[1] Department of Physiotherapy and Physical Education, State University of Goias, Goiânia, Brazil

[2] Department of Neurosciences and Behavior, Ribeirão Preto Medical School, University of São Paulo, Avenida Tenente Catão Roxo, 2650, Prédio da Saúde Mental, Campus Universitário Monte Alegre, Ribeirão Preto, SP CEP 14051-140, Brazil

public health and epidemiology, as it complements traditional information on mortality and morbidity [7, 8].

Despite the increasing number of studies assessing QoL in preterm individuals, these have applied a wide variety of methodological approaches, leaving several questions unanswered. Analyzing data from multiple studies across this area of research may provide answers to some of these questions. We previously conducted a systematic review [6] that aimed to provide a general survey of the development and QoL of children born preterm at preschool and school age. Our analysis indicated that children born prematurely are at an increased risk of delay in several areas of development. However, insufficient findings were observed with respect to QoL outcomes. This was because there was a limited range of ages included in the review. Samples were only available for children aged between 3 and 12 years. Furthermore, we did not perform a critical analysis of the methods used to assess QoL.

Recent systematic reviews that have exclusively investigated QoL in preterm infants [9, 10] have only included infants with very low birth weight [9] and did not analyze factors associated with QoL in this population. They also did not provide a critical analysis of assessment instruments or their applicability. Furthermore, the most recent reviews only searched databases up to 2007, thus justifying an update of findings in this area.

The purpose of the present study was to review the most recent literature regarding factors associated with QoL in preterm individuals. We aimed to critically analyze the concept of QoL assessment, focusing on the dimensions of this construct, instruments, and procedures for data collection and analysis. Our review was guided by the following questions: (1) What are the characteristics and psychometric properties of the instruments used to assess QoL in preterm individuals? (2) What methods of data collection and management are used for such instruments? (3) Where reported, is there any agreement between measures of self-reported QoL and parental measures of QoL? (4) What factors are associated with QoL in preterm individuals?

Methods

We adhered to Preferred Reporting Items for Systematic Reviews and Meta-Analyses [11] when searching for and selecting articles in the following databases: PubMed, PsycARTICLES, PsycINFO, SciELO, and LILACS. Our search terms were determined by searching Mesh (PubMed), *Decs* (SciELO and LILACS), and Index (PsycINFO and PsycARTICLES) terms and descriptors listed in previous relevant studies. In selecting our search terms, we attempted to achieve high sensitivity, at the cost of low specificity. The search term combinations were: (*Infant, Premature OR Premature Birth OR Prematurity OR Preterm*) *AND* (*Quality of Life OR Health related quality of life OR Health-related quality of life OR Personal Satisfaction OR Well being OR Well-being OR Life satisfaction*). The detailed search method for each database is presented in the supplementary material (Online Resource 1).

We included empirical studies with observational designs assessing QoL in individuals who were born preterm (gestational age [GA] <37 weeks), regardless of birth weight, from the perspective of the individuals themselves or their main caregiver (parents or legal guardians). We included all articles published between January 2007 and January 2015, in English, Portuguese, or Spanish.

Review articles, meta-analyses, commentaries, editorials, letters, and clinical trials were excluded. We also excluded studies that evaluated parents' or caregivers' QoL, studies reporting children's QoL from the perspective of individuals other than parents or legal guardians, and studies evaluating QoL only according to clinical indicators or that were restricted to environmental factors.

Two authors selected the studies. Figure 1 illustrates that 375 articles were initially identified in our database search. After both authors systematically applied the inclusion and exclusion criteria, 22 articles remained.

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement was used to analyze the quality of reporting in the selected studies [12]. The STROBE statement recommends topics that should be included in an accurate and complete report of an observational study. It provides a checklist of 22 items related to the title, abstract, introduction, methods, results, and discussion. Appropriate reporting of studies is important to assess their strengths and weaknesses, and the generalizability of findings.

Additionally, we analyzed the psychometric properties of the QoL instruments used in the studies. For this specific analysis, we conducted additional literature searches to identify articles about the psychometric parameters of the instruments.

We organized the samples of preterm participants according to GA, using categories proposed by the World Health Organization (WHO) to classify prematurity as follows: extremely preterm (<28 weeks), very preterm (28–<32 weeks), and moderately preterm (32–<37 weeks) [13].

Results

Study characteristics

The majority of studies (17 studies; 77 %) used a prospective longitudinal design [14–30]. These samples

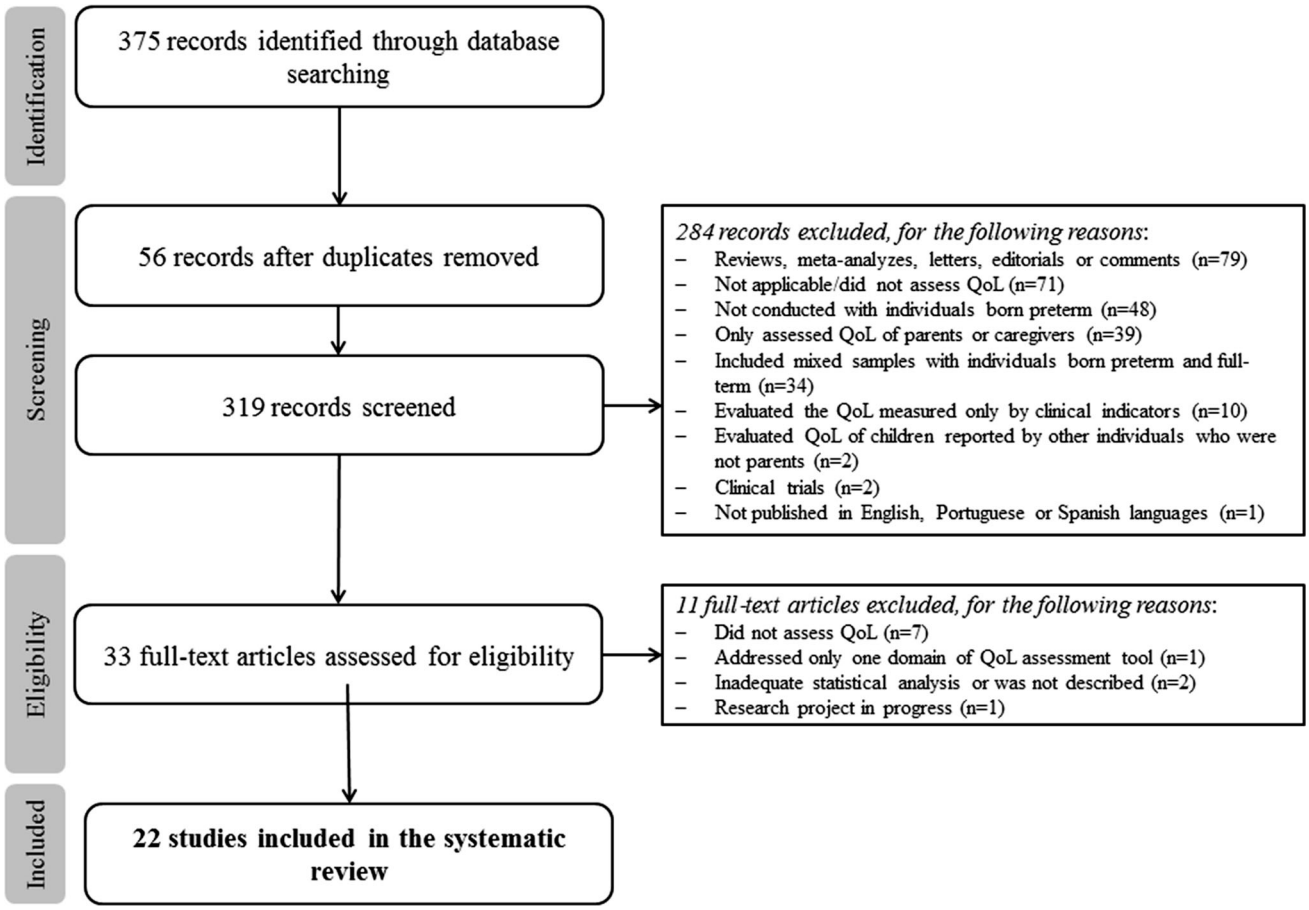

Fig. 1 Flowchart of article selection

were recruited in the neonatal period. Only two studies conducted repeated QoL measures at 14, 19, and 28 years of age in the same cohort of individuals who were born preterm [21, 26]. Four studies implemented retrospective longitudinal designs [31–34]. One study conducted a cross-sectional design [35].

Longitudinal designs can identify possible predictors of QoL outcomes. However, there is an increased chance of attrition during follow-up (dropouts) in such studies. Sample sizes ranged from 43 to 630 preterm participants. In half of the studies, non-response bias should be considered, as there were non-response rates (dropouts) of more than 25 % of the target population. Nevertheless, the vast majority of these compared sociodemographic and perinatal clinical characteristics between respondents and non-respondents, and considered any differences when discussing their findings. Only one study did not report having taken such methodological care [35].

There were other strengths in the literature, including good representativeness, with both population-based and multicenter samples used in 11 studies (50 %). Fourteen studies (64 %) were analytical and included a control group consisting of full-term healthy individuals. All of the studies attempted to control for confounding variables through matching and/or during the analyses. The most commonly controlled variables were gender, age, parental level of education, and socioeconomic status. The only exception was the study by Schiariti et al. [31], which identified differences between the group of preterm children and the control group in terms of gender and family income. However, they did not control for these differences in their analyses, nor did they highlight the risk of bias this introduces in their discussion.

We observed great variety in the methodological approaches used to assess QoL in preterm individuals. This culminated in significant diversity in the ages of samples and the way in which the instruments were applied. Figure 2 illustrates that almost half of the studies assessed QoL in children under 12 years of age, and most of these chose parents as the only source of information about the children's well-being.

As the age of participants increased, the source of information regarding QoL changed. All studies conducted with adolescents or adults relied on self-report for QoL

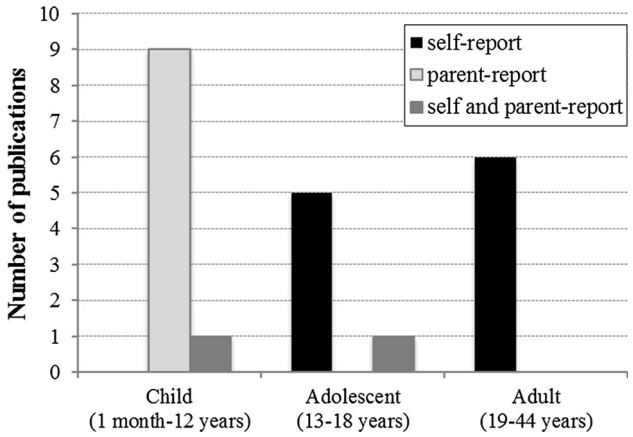

Fig. 2 Distribution of studies according to the source of information on quality of life assessments and age group ($n = 22$)

assessment. Only two articles dealt with QoL in preterm individuals from both the parents' perspective and that of the individuals themselves [17, 20].

Table 1 presents the instruments and measures used in the studies. Sixteen different instruments were used to assess QoL. They were mostly generic measures (i.e., designed to assess QoL in the general population). The only exception was the London Handicap Scale (LHS) [26], which is a condition-specific instrument designed to assess QoL in individuals with chronic diseases. Considering that the immaturity of preterm neonates may affect them in a multisystemic way, generic instruments are the most appropriate tools to assess QoL in this population [36].

All of the self-report instruments followed the three basic characteristics specified by the WHO: subjectivity, multidimensionality, and influence of positive and negative dimensions [37]. However, subjectivity can be affected by instruments that assess QoL in children based only on the parents' perspective (parental report) because only the parents' perception and concerns about their children are considered.

Sixteen articles (73 %) assessed QoL using self-administered questionnaires. Eleven of the instruments (68 %) have reported excellent or good psychometric properties. Three instruments (Fragen zur Lebenszufriedenheit-Module, Visual Analog Scale, and LHS) have been subjected to preliminary psychometric assessment. Just one instrument (Child Health Questionnaire—Parent Report 28) should be considered cautiously as it has been shown to be insufficiently reliable when each domain is analyzed separately. Only two instruments have no published psychometric evaluations [14, 30]. Notably, in two studies the authors adapted instruments, which affected the accuracy and precision of their results [33, 35].

Regarding the quality of reporting in the studies, most (77 %) included more than 70 % of the STROBE items, which demonstrates satisfactory description quality. We consider six observational studies (27 %) to have moderate description quality as only between 50 and 70 % of STROBE items were included [21, 24, 28, 31, 32, 35]. Only two observational studies included less than half of the STROBE items, consequently failing to provide important methodological information or discussion of the findings [23, 34]. The STROBE items that were most frequently missing included information about missing data, the way in which missing data were considered in the analysis, and information on the number of participants with missing data for each variable of interest.

Quality of life in children born preterm

Table 2 presents a summary of the ten studies that assessed QoL in preterm infants aged 1 month to 12 years. Seven studies compared QoL assessed using parental report between preterm children and full-term children (control group), with samples aged between 2 and 11 years [14, 16–18, 31–33]. Worse QoL in the children was reported by parents of preterm children compared with parents of the control group. This difference remained even after adjusting for gender, age, and socioeconomic status [14, 18, 33]. In these studies, parents of preterm children at preschool or school age reported more problems in various QoL domains, primarily related to physical health, behavior, or functionality. They also reported a higher impact of those problems on their own lives [31].

Studies that reported reduced well-being among preterm individuals were conducted with children who exhibited high neonatal clinical risk, such as GA < 32 weeks [14, 16–18, 31, 33], birth weight <1500 g [17, 33], or admission to the Neonatal Intensive Care Unit (NICU) [17, 31]. The presence of cognitive or functional disabilities [14, 16–18] and behavioral problems [16] at school age (6–11 years of age) in preterm children was also noted. The study by Ketharanathan et al. [32] was distinctive in being the only one to report no statistically significant difference between the parents' reports of QoL of their children (aged 2–5 years) who were born preterm compared with age-matched controls who were born full term. This may be explained by the fact that the preterm children in Ketharanathan et al. [32] had a higher GA, had not required admission to the NICU, and did not show any major behavioral problems.

Schiariti et al. [31] compared parents' reports of QoL in groups of preterm individuals who were stratified by GA. They found that QoL at 3 years of age in individuals with a GA of 28–32 weeks was similar to the group with a GA < 28 weeks. However, both groups of preterm

Table 1 Instruments and measures used to assess QoL

Instrument/measure	Age	Report	Domains	Validity and reliability[a]
Health Utilities Index mark III (HUI3) [18–22, 24, 26]	>5 years	Parent Self	Cognition; vision; hearing; speech; ambulation; dexterity; emotion; pain	Internal consistency: 0.81 Test–retest reliability: 0.48–0.94 (κ estimates) Validity assessed: face, content, construct, convergent, discriminative, predictive Population norm data are available from numerous large general population surveys Provides a comprehensive, reliable, responsive, and valid measure of HRQoL [41, 42]
Short Form-36 health survey (SF-36) [24, 27–29, 34]	>14 years	Self	Physical functioning; role limitation due to physical problems; bodily pain; general health perception; vitality; social functioning; role limitation due to emotional problems; mental health	Internal consistency: >0.70 Test–retest reliability: >0.70 Validity assessed: construct, clinical, content, concurrent, criterion, predictive, sensitivity to change Good psychometric properties [43–45]
TNO-AZL Preschool Quality of Life Questionnaire (TAPQoL) [32]	1–5 years	Parent	Stomach; skin; lungs; sleeping; appetite; eating problems; liveliness; positive mood; problem behavior; anxiety; motor functioning; social functioning and communication	Internal consistency: 0.66–0.88 Validity assessed: construct, convergent, criterion Good psychometric performance [46]
Infant and Toddler Quality of Life Questionnaire (ITQOL) [31]	2 months–5 years	Parent	Physical abilities; growth/development; bodily pain/discomfort; temperaments and moods; general behavior; getting along with others; general health perception; parental impact: time; parental impact: emotions; family activities; family cohesion; change in health	Internal consistency: 0.72–0.94 Test–retest reliability: ≥0.50 Validity assessed: Concurrent, Discriminative Adequate psychometric properties [47, 48]
Child Health Questionnaire—parent report 28 (CHQ-PF28) [15]	4–19 years	Parent	Physical functioning; role/social-physical; general health; bodily pain; family activities; parental impact-time; parental impact-emotional; role/social/emotional/behavioral; self-esteem; mental health; behavior; family cohesion; change in health	Internal consistency: 0.34–0.89 (summary measures: >0.70) Test–retest reliability: 0.14–0.78 Validity assessed: construct, convergent, discriminative, sensitivity to change Acceptable psychometric properties when considering the summary measures but not as reliable in the use of each separate domain [49]
17-Dimensional health-related measure (17D) [33]	8–11 years	Self	Mobility; vision; hearing; breathing; sleeping; eating; speech; elimination; school/hobbies; learning/memory; discomfort/symptoms; depression; distress; vitality; appearance; friends; concentration	Test–retest: 0.95–0.96 Validity assessed: Clinical, Construct Valid and reliable instrument [50]

Table 1 continued

Instrument/measure	Age	Report	Domains	Validity and reliability[a]
Fragen zur Lebenszufriedenheit—Module [questions on life satisfaction modules] (FLZ-M) [23]	Adolescent Adult	Self	Global QoL; HRQoL	Internal consistency: 0.82 (Global QoL), 0.89 (HRQoL) Test–retest reliability: 0.87 (Global QoL), 0.85 (HRQoL) Validity assessed: construct, convergent, discriminant, sensitivity to change Preliminary psychometric properties Other psychometric assessments still need to be performed [51]
Revised Children Quality-of-Life Questionnaire (KINDL^{R}) [16]	8–16 years	Parent	Physical well-being; emotional well-being; self-esteem; well-being with regard to family; well-being with regard to friends/friendship; well-being with regard to school/all-day function	Internal consistency: 0.54–0.82 Test–retest reliability: 0.80 Validity assessed: clinical, construct, convergent, discriminant, sensitivity to change German version with excellent psychometric properties [16, 52]
QUALIN [35]	3 months–3 years	Parent	NA	Internal consistency: 0.75–0.78 Inter-rater reliability: >0.50 validity assessed: construct, predictive satisfactory psychometric properties [53]
Health Utilities Index mark II (HUI2) [19]	>5 years	Parent Self	Sensation; mobility; emotion; cognition; self-care; pain; fertility	Internal consistency: 0.82 Inter-rater reliability: 0.36–0.96 Validity assessed: face, content, construct, convergent, discriminative, predictive Provides a comprehensive, reliable, responsive, and valid measure of HRQoL [41, 42, 54]
Child health and Illness Profile-Child Edition (CHIP-CE) [17]	6–11 years	Parent Self	Satisfaction; comfort; resilience; risk avoidance; achievement	Internal consistency: 0.70–0.82 (self-reported form), 0.79–0.88 (parent-reported form) Test–retest reliability: 0.63–0.66 (Self-reported form), 0.71–0.85 (Parent-reported form) Validity assessed: construct, convergent, and criterion Both parent and child report versions have good to excellent psychometric properties [55, 56]
Visual Analog Scale (VAS) [25]	Adolescent	Self	NA	Validity assessed: empirical, convergent Satisfactory but preliminary psychometric properties [57]
Vécu et Santé Perçue de l'Adolescent et de l'Enfant (VSP-A) parent version [14]	8–17 years	Parent	Relationships with family; body image; vitality; relationships with friends; leisure activities; psychological well-being; physical well-being; school performance; relationships with teachers	Not published

Table 1 continued

Instrument/measure	Age	Report	Domains	Validity and reliability[a]
Questions about general well-being in daily life (by authors) [30]	Adult	Self	NA	Not assessed
London Handicap Scale (LHS) [26]	Adult	Self	Mobility; physical independence (self-care); occupation (daily activities); social integration; orientation; economic self-sufficiency	Internal consistency: 0.85 Test–retest reliability: 0.91 Validity assessed: construct, concurrent, face Acceptable but preliminary psychometric properties [58–60]
WHO Quality of Life instrument, short edition (WHOQoL-BREF) [26]	Adult	Self	Physical health; psychological; social relationships; environment	Internal consistency: 0.68–0.82 Validity assessed: construct, discriminant Good to excellent reliability and performs well in preliminary tests of validity [61]

NA not applicable, *QoL* quality of life, *HRQoL* health-related quality of life

[a] Adapted from [40, 62, 63], information in the 24 articles included in this review and additional research (referred in the table above)

individuals were at a disadvantage compared with the QoL reported by the parents of full-term children. Multivariate analyses suggested that better QoL outcomes were associated with the highest GA among groups of preterm individuals with a GA < 32 weeks [33] or 32–35 weeks [35]. Thus, the effect of the level of prematurity on QoL in preterm children requires further investigation.

Clinical risk factors associated with worse parent-reported QoL at preschool age in preterm children included non-lethal congenital malformations [33] and the use of continuous positive airway pressure ventilation support during the neonatal period [32]. Better parent-reported QoL at 5 years of age in children born preterm was associated with multiple pregnancies [33]. Furthermore, receiving immunoprophylaxis against respiratory syncytial virus infection (as per medical recommendation) before the age of 3 months was a protective factor for parent-reported QoL during the first year of life [35]. Results were inconclusive regarding the association between QoL and birth weight status or gender [14, 16, 17, 32, 33].

Better parent-reported QoL at 1 [35] or 6–10 years of age [14] was associated with several psychosocial factors including having siblings, parental mental health, and a reduced burden of care on parents. However, risk factors associated with the worst parental and self-reported QoL at school age (6–11 years of age) in preterm children included belonging to more disadvantaged social groups [14, 17, 18] and black race [17]. Findings were inconsistent regarding the parents' schooling and employment status [16, 18, 33].

School-age children's cognitive level was measured using the intelligence quotient (IQ) assessed with the Kaufman Assessment Battery for Children. Study authors considered different cutoff points of IQ < 85 [17], IQ < 81 [19], and IQ < 70 [16] to delimit low cognitive level. Nevertheless, low cognitive level was consistently associated with poorer parent-reported QoL [16, 19] and self-reported QoL [17]. Likewise, Berbis et al. [14] identified reduced parent-reported QoL in children at 6–10 years of age with global developmental disability, cerebral palsy, epilepsy, and hearing or visual impairments. Additionally, negative QoL outcomes were also reported by parents in school-age children with behavioral problems [16] or psychiatric disorders [19].

The only study that used both self- and parental reports of QoL evaluated children at 8 years of age and reported low levels of agreement between the two ratings in all QoL domains [17]. Parents reported worse QoL in various domains, whereas children reported the same QoL as their full-term peers. Using the Child Health and Illness Profile-Child Edition, preterm children reported less comfort and resilience than their parents but better performance at school and better peer relationships. These findings held

Table 2 Characteristics of the studies and summary of main results related to QoL of children born preterm (1 month–12 years of age; $n = 10$)

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL results[a]
		Study group	Control group					
Mendez Rubio et al. [35]—Association between lower respiratory tract infection hospitalizations and HRQoL in PT	Transversal nested in cohort	71 MPT hospitalized GA 32–35 weeks	145 MPT not hospitalized GA 32–35 weeks	<6 months	QUALIN modified scale for infants	Parent report; structured Interview	Hospitalized vs. not hospitalized *Bivariate and multivariate analyses*	Ns *Associated variables*: better HRQoL with higher GA, have siblings who are 0–3 years old, being recommended palivizumab and receiving it, lower caregiver overload, higher caregiver mental HRQoL, no absence from work
Ketharanathan et al. [32]—HRQoL and emotional and behavioral problems in mild to moderate premature individuals at (pre-) school age	Longitudinal retrospective	218 MPT GA 32–35 weeks	FT of the general Dutch pediatric population	2–5 years	TAPQoL	Parent report; self-administered	MPT vs. FT *Univariate and multivariate analyses*	MPT = FT: Ns in most domains (*skin*, *lungs*, *appetite, positive mood, anxiety, social functioning*, *motor functioning*) MPT > FT in three domains (*behavior*, *communication*, *sleep*) MPT < FT in two domains (*stomach*, *liveliness*) *Associated variables*: worse HRQoL with use of CPAP at newborn (predictor of lung problems)
Schiariti et al. [31]—Caregiver-reported health outcomes of preschool children born at 28–32 weeks	Longitudinal retrospective	201 VPT GA 28–32 weeks *NICU sample*	50 EPT GA < 28 weeks 293 healthy FT	3.5 years	ITQOL	Parent report; self-administered	VPT vs. EPT and VPT vs. FT *t* test	VPT = EPT: Ns (except *general health perception*, EPT < VPT) VPT < FT (VPT with worse QoL, except *Pain/discomfort*, VPT = FT)
Rautava et al. [33]—HRQoL in 5-year-old VLBW infants	Longitudinal retrospective	588 VLBW GA < 32 weeks BW ≤ 1500 g	176 FT	5 years	17D modified to allow the evaluation of children at 5 years	Parent report; self-administered	VPT vs. FT *Tobit regression* *Generalized linear model*	VPT < FT even after controlling for clinical and sociodemographic confounders *Associated variables:* better HRQoL with multiple pregnancy, higher GA, and higher BW; worse HRQoL with non-lethal congenital malformation
Berbis et al. [14]—QoL of early school-age French children born preterm: a cohort study	Cohort Longitudinal prospective	82 VPT GA 24–32 weeks	303 French reference population	6–10 years	VSP-A	Parent report; self-administered	VPT vs. reference *Analysis of covariance* *Multiple linear regression*	VPT < Reference in global score and *body image*, *vitality*, *psychological well-being*, and *school performance* domains even after adjustment for child's age, gender, and SES *Associated variables*: worse HRQoL with major neurocognitive disorders at 4–8 years; better HRQoL with higher maternal parity and higher SES

Table 2 continued

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL results[a]
		Study group	Control group					
Gray et al. [15]—Behavior and QoL at school age of children who had BPD	Cohort Longitudinal prospective	66 VPT/BPD GA 26–33 weeks *NICU sample*	60 VPT control GA 26–33 weeks *NICU sample*	8 years	CHQ-PF28	Parent report; self-administered	VPT/BPD vs. VPT control *t* test *Kruskal–Wallis*	Ns (except *family cohesion*, BPD < VPT)
Stahlmann et al. [16]—Outcome of EPT infants at early school age	Cohort Longitudinal prospective	75 EPT GA < 27 weeks	Normal sample from reference data (German children)	8 years	KINDL^R	Parent report; self-administered	EPT vs. normal sample *t* test *Linear regression*	EPT < normal sample in total score and *physical well-being*, *emotional well-being*, *well-being/friends* *Associated variables*: worse HRQoL with behavioral problems and child IQ < 70
Hack et al. [17]—Health status of ELBW children at 8 years of age	Cohort Longitudinal prospective	202 EPT/ELBW GA 26 ± 2 weeks BW < 1000 g *NICU sample*	176 FT/NBW	8 years	CHIP-CE	Self-report; interview; parent report	EPT vs. FT *t* test *Chi-square test* *Fisher exact test* *Multiple linear regression*	Poor agreement between parent and child ratings Self-report: EPT = FT in all five domains Parent report: EPT < FT in four domains (*satisfaction*, *comfort*, *achievement*, *risk avoidance*) *Associated variables*: worse self-reported HRQoL with black race, male, lower SES, and child IQ < 85; worse parent-reported HRQoL with black race, male, and lower SES
Petrou et al. [18]—Costs and health utilization associated with EPT birth	Cohort Longitudinal prospective	190 EPT GA 20–25 weeks	141 FT classmates	11 years	HUI3	Parent report; self-administered	EPT vs. FT *Fisher's exact test* *t* test *Tobit regression*	EPT < FT in all eight attributes and at MAU score even after controlling for clinical and sociodemographic confounders (EPT with worse QoL) *Associated variables*: worse HRQoL with lower SES

Table 2 continued

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL results[a]
		Study group	Control group					
Petrou et al. [19]—Economic costs and preference-based HRQoL outcomes associated with childhood psychiatric disorders	Cohort Longitudinal prospective	39 EPT with psychiatric disorder GA 20–25 weeks	151 EPT control GA 20–25 weeks	11 years	HUI2 and HUI3	Parent report; self-administered	EPT with disorder vs. EPT control *Fisher exact test* *t* test *Tobit regression*	EPT with disorder < EPT control (in HUI3 and HUI2 MAU scores and *emotion*, *pain*, *dexterity*, and *cognition*) even after controlling for clinical and sociodemographic confounders *Associated variables*: worse HRQoL with psychiatric disorder and cognitive impairment (IQ < 81) in childhood

GA gestational age, *PT* preterm (GA < 37 weeks), *FT* full term (GA ≥ 37 weeks), *g* grams, *EPT* extremely preterm (GA < 28 weeks), *VPT* very preterm (GA = 28–32 weeks), *MPT* moderately preterm (GA = 32–35 weeks), *BW* birth weight, *LBW* low birth weight, *ELBW* extremely low birth weight, *VLBW* very low birth weight, *NBW* normal birth weight (>2499 g), *vs.* versus, *RCT* randomized controlled trial, *NIDCAP* Newborn Individualized Developmental Care and Assessment Program, *NICU* neonatal intensive care unit, *SES* socioeconomic status, *QoL* quality of life, *HRQoL* health-related quality of life, *MAU* multiattribute utility, *BPD* bronchopulmonary dysplasia, *IQ* intelligence quotient, *DC* developmental care, *NA* not applicable, *SD* standard deviation, *Ns* no statistically significant difference

[a] In all measures of QoL, higher scores represent better QoL

true even when excluding premature individuals who had sensorineural disability [17].

Quality of life in adolescents born preterm

Table 3 shows the six articles on QoL in premature individuals in the adolescent age group (13–18 years of age). Five studies (83 %) in this age group compared self-reported QoL between individuals born preterm and a full-term control group [20, 22–25]. The vast majority of these studies reported that preterm adolescents reported satisfactory QoL, of a similar level to healthy full-term adolescents, both in high-risk samples [22, 24, 25] and those with low neonatal clinical risk [23].

However, Wolke et al. [20] reported that individuals born very preterm who did not have any sensorineural disabilities had worse QoL than full-term adolescents, regardless of the source of information (parents or adolescents themselves). Despite the overall agreement between parents and adolescents [20], consistency between ratings depended on the QoL domain being assessed using the Health Utilities Index Mark 3. Agreement was higher in domains related to physical health (vision, dexterity, ambulation, and hearing), but lower in domains related to psychological functioning (expressive language, emotion, cognition, and pain). Generally, adolescents reported more problems in language, cognition, and pain than their parents did. According to the authors, this negative view of adolescents about their own cognitive and emotional aspects may be related to this particular developmental phase, which includes more social and educational requirements [20].

Mid-late adolescence (14–19 years of age) did not affect self-reported QoL of preterm individuals [21]. Worse self-reported QoL in adolescents born preterm with a low birth weight was associated with physical disabilities at 5 years of age [21], as well as low IQ, language delays, emotional problems, cerebral palsy, and hearing or visual impairments at 8 years of age [20]. Similarly, worse QoL was related to factors in adolescence that may negatively affect perceptions of QoL during that same period, such as internalizing behavior disorders and neuromotor disabilities [21].

Quality of life in adults born preterm

Table 4 shows a summary of the six studies that assessed QoL in preterm individuals assessed as adults (19–44 years of age). All five studies comparing self-reported QoL in preterm adults with full-term adults reported favorable results with similar QoL [27–30, 34]. Furthermore, preterm adults reported better QoL in three domains of the SF-36, even after adjusting for gender and clinical variables [29].

Table 3 Characteristics of the studies and summary of main results related to QoL in adolescents born preterm (13–18 years of age; $n = 6$)

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL results[a]
		Study group	Control group					
Wolke et al. [20]—Self and parent perspectives on HRQoL of adolescents born VPT	Cohort Longitudinal prospective	206 VPT I BW < 1500 g GA < 32 weeks *No disability or mild disability*	12 VPT II *Moderate to severe disability* 282 FT	13 years	HUI3	Self-report; self-administered and parent report; self-administered *For VPT II: only parent report*	VPT I vs. FT and VPT I vs. VPT II *Regression and comparison analysis*	VPT I < FT in MAU score and *vision*, *dexterity*, and *ambulation* for both self- and parent report even after adjustment for child's gender and SES Agreement was moderate to good on *vision*, *dexterity*, *ambulation*, and *hearing* and low to moderate on *speech*, *cognition*, *emotion*, and *pain* VPT II < VPT I in MAU score and six attributes except *vision* and *pain* *Associated variables*: worse HRQoL with problems in function at 8.5 years
Verrips et al. [21]—Long-term follow-up of HRQoL of life in young adults born VPT or with a VLBW	Cohort Longitudinal prospective	630 VPT/VLBW GA < 32 weeks BW < 1500 g	NA	14 and 19 years	HUI3	Self-report; self-administered	14 years vs. 19 years *t* test *Pearson correlation* *Multiple linear regression*	HRQoL: 14 years = 19 years Changes: HRQL in 45 % was stable, 25 % was better, and 30 % was worse *Associated variables*: worse HRQoL with physical handicaps at 5 years and internalizing behavior, neuromotor problems, and non-adaptive coping strategies at 19 years
Gray et al. [22]—Self-reported health status and HRQoL of EPT teenagers	Cohort Longitudinal prospective	140 EPT GA < 29 weeks	108 FT	15–16 years	HUI3	Self-report; self-administered	EPT vs. FT *Fisher exact test* *t* test	EPT = FT in MAU score and seven attributes (except *cognition*, VPT < FT)
Reuner et al. [23]—Long-term development of low-risk LBW PT born infants	Cohort Longitudinal prospective	65 PT/LBW GA < 37 weeks BW ≤ 2500 g *No significant postnatal risk*	41 FT	17 years	FLZ-M	Self-report; self-administered	PT vs. FT *t* test *Mann–Whitney* *ANOVA*	PT = FT in global QoL and HRQoL domains (normal range)

Table 3 continued

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL results[a]
		Study group	Control group					
Roberts et al. [24]—QoL at age 18 years after EPT birth in the post-surfactant era	Cohort Longitudinal prospective	194 EPT/ELBW GA < 28 weeks BW < 1000 g	148 FT/NBW	18 years	HUI3 SF-36	Self-report	EPT vs. FT *t* test *Chi-square test* *Wilcoxon* *Linear regression*	EPT = FT even after excluding the individuals with major disability HUI3 results: EPT = FT in MAU score and seven attributes (except *dexterity*, EPT < FT) SF36 results: EPT = FT (except *physical functioning*, EPT < FT)
Hallin and Stjernqvist [25]—Adolescents born EPT: behavioral outcomes and QoL	Cohort Longitudinal prospective	52 EPT GA < 29 weeks IQ: > 55	54 FT	18 years	VAS	Self-report; semi-structured interview	EPT vs. FT *t* test *Linear or logistic regression*	EPT = FT even after adjusting for IQ and parental educational level

GA gestational age, *PT* preterm (GA < 37 weeks), *FT* full term (GA ≥ 37 weeks), *g* grams, *EPT* extremely preterm (GA < 28 weeks), *VPT* very preterm (GA = 28–32 weeks), *BW* birth weight, *CV* conventional ventilation, *LBW* low birth weight, *ELBW* extremely low birth weight, *VLBW* very low birth weight, *NBW* normal birth weight (>2499 g), *vs.* versus, *RCT* randomized controlled trial, *SES* socioeconomic status, *QoL* quality of life, *HRQoL* health-related quality of life, *MAU* multiattribute utility, *IQ* intelligence quotient, *NA* not applicable, *Ns* no statistically significant difference

[a] In all measures of QoL, higher scores represent better QoL

Table 4 Characteristics of the studies and summary of main results related to QoL of adults born preterm (19–44 years of age; $n = 6$)

Study	Study design	Sample		Age	Outcome measure	Data collection	Data analysis	QoL Results[a]
		Study group	Control group					
van Lunenburg et al. [26]—Changes in QoL into adulthood after VPT birth and/or VLBW in the Netherlands	Cohort Longitudinal prospective	314 VPT GA < 32 weeks BW < 1500 g	*NA*	19 and 28 years	HUI3, LHS, and WHOQoL-BREF (only at 28 years)	Self-report; self-administered	19 years vs. 28 years *t* test *Pearson correlations*	HRQoL: 19 years = 28 years in HUI3 and LHS scores Overall HRQoL were close to optimal in all assessments
Lund et al. [27]—Mental health, QoL, and social relations in young adults born with LBW	Cohort Longitudinal prospective	43 VPT GA 29 ± 2.5 weeks BW ≤ 1500 g *NICU sample*	74 FT/ NBW	20 years	SF-36	Self-report; self-administered	VPT vs. FT *ANOVA + Scheffe's* post hoc *test* *Kruskal–Wallis + Mann–Whitney U-test*	VPT = FT in all domains (except *mental health*, VPT < FT)
Beaudoin et al. [34]—Healthcare utilization and HRQoL of adult survivors of PT birth complicated by BPD	Longitudinal retrospective	149 PT/BPD 233 PT/RDS GA < 37 weeks	234 PT control 149 healthy FT	20 years	SF-36	Self-report; self-administered	PT/BPD vs. PT/RDS vs. PT X FT *One-way ANOVA or t* test *Linear regression*	PT = FT regardless of history of respiratory disease
Baumgardt et al. [28]—HRQoL of former VPT infants in adulthood	Cohort Longitudinal prospective	52 VPT GA 26–35 weeks BW < 1250 g	75 FT	23 years	SF-36	Self-report	VPT vs. FT *t* test *Chi-square test* *Mann–Whitney U-test*	VPT = FT in both summary scores (physical and mental health) *Associated variables*: worse HRQoL with male gender
Dalziel et al. [29]—Psychological functioning and HRQoL in adulthood after PT birth	Cohort Longitudinal prospective	126 MPT GA 32–35 weeks *No major disability*	66 FT	31 years	SF-36	Self-report	MPT vs. FT *t* test *Mann–Whitney U-test* *Chi-square test* *Linear and logistic regression*	MPT > FT in three domains (*bodily pain, general health perceptions*, *social functioning*) and MPT = FT in the other five domains even after adjustment for gender and clinical variables
Ulrich et al. [30]—On the well-being of adult expremies in Denmark	Cohort Longitudinal prospective	69 MPT GA 32–37 weeks	304 FT	32 years	Questions about general well-being	Self-report; self-administered	MPT vs. FT *Univariate analysis* *Multiple regression*	MPT = FT

GA gestational age, *PT* preterm (GA < 37 weeks), *FT* full term (GA ≥ 37 weeks), *g* grams, *VPT* very preterm (GA = 28–32 weeks), *MPT* moderately preterm (GA = 32–35 weeks), *BW* birth weight, *LBW* low birth weight, *ELBW* extremely low birth weight, *VLBW* very low birth weight, *NBW* normal birth weight (>2499 g), *vs.* versus, *NICU* neonatal intensive care unit, *QoL* quality of life, *HRQoL* health-related quality of life, *BPD* bronchopulmonary dysplasia, *RDS* respiratory distress syndrome, *NA* not applicable

[a] In all measures of QoL, higher scores represent better QoL

Despite these positive outcomes, preterm individuals compared with full-term adults were still more likely to have chronic diseases [28], internalizing behavior disorders, fewer interactions with friends, and lower self-esteem related to sports and social acceptance [27].

The only domain of the SF-36 in which worse QoL was reported among adults who were born preterm was "Mental Health" [27]. However, three other studies using the same instrument did not find this difference [28, 29, 34]. Notably, the adults in the study by Lund et al. [27] generally had more health problems.

Disparate results were reported for possible factors, such as gender, that might be associated with QoL in preterm individuals as adults. Baumgardt et al. [28] reported worse self-reported QoL in men than in women, whereas Ulrich et al. [30] reported no significant interaction between gender and general well-being. Many other clinical and sociodemographic factors investigated were not related to QoL outcomes in adulthood [30, 34].

Discussion

In this review, we investigated associations between prematurity and QoL. Similarly to a previous systematic review by Zwicker and Harris [9], we found apparent improvements in QoL in preterm individuals as they get older, and this finding was unrelated to birth weight. Unlike the previous review, here we used more studies with samples of preterm individuals for whom a reference range of birth weight was not established. As well as reaffirming previous findings, we furthered knowledge by investigating possible explanations for this difference in QoL between age groups. We identified and analyzed risk and protective factors associated with QoL and considered the sources of information used by the studies.

Preterm children generally had lower QoL than children who were born full term. However, adolescents and adults who were born preterm had comparable QoL scores to full-term individuals. These results should be considered cautiously because of the great variety of instruments and methods used in the studies. Moreover, QoL is a subjective construct that can change according to a person's stage of life as wishes, necessities, and demands change over time [8]. Additionally, individuals with a history of various risk factors may develop resilience to overcome such adversity. Many protective factors can coexist and consequently offset adversity faced in childhood, creating a positive adaptive outcome [38].

It is possible that differences in QoL between age groups may not only be due to developmental changes, but also the particular source of information. Parents and guardians were the main informants for children's QoL in younger age groups, whereas studies with adolescents and adults were based on self-report. Parents of children with health problems tend to underestimate the QoL of their offspring [39]. Therefore, one should consider the influence of feelings, desires, and personal perceptions in analyses of parent-reported measures of a child's QoL. For such parents and guardians, the birth of their children can be a particularly stressful time, which may influence their perception. Nonetheless, parental reports are still relevant because they have a major influence on children's education and identification of possible health problems [40].

Agreement between parental and children reports of QoL in preterm individuals was lower in the younger age group compared with adolescents. Parents reported worse QoL in domains related to physical health, whereas preterm individuals reported worse QoL in mental and emotional health domains. This suggests that parents of individuals born premature emphasize aspects related to physical health when determining the QoL of their children. However, these assertions are based on the analysis of only two studies that evaluated agreement between parents and children. Therefore, this issue requires further exploration and confirmation in other samples of preterm individuals. Similar conclusions were drawn in a previous systematic review that sought to verify the relationship between parent- and self-reported QoL in children with chronic health problems [40]. Parents and children seem to agree on subjects related to physical health, which involve more observable aspects of a child's life (illness, limitation of daily activities, etc.). However, there was high disagreement in QoL related to social and emotional functioning, which are more subjective domains, including personal feelings and perceptions.

These findings, along with our own, suggest that for samples of individuals born preterm, QoL assessments in children should consider both parent- and self-reported measures [40]. Discrepancies between the sources of information should be considered when discussing results, with a focus on disagreements between parents and children in specific QoL domains.

Several other factors besides premature birth were associated with QoL and may explain the differences between age groups. QoL was associated with clinical factors during the perinatal and neonatal phases and sociodemographic factors only in individuals who were born preterm and evaluated in childhood. However, some studies with adolescents or adults also included these as possible predictors of QoL and found no such association. This suggests that neonatal clinical risk conditions are associated with QoL specifically in early development. Moreover, these conditions could lead to parents having a worse perception of the QoL of their vulnerable children.

Problems that are often seen in individuals who are born very preterm (e.g., cognitive deficits, behavioral problems,

and sensorineural or physical disabilities) were consistently associated with poorer QoL outcomes in children and adolescents who were born under high-risk conditions. However, most of these cognitive and behavioral disadvantages do not appear to be related to QoL in older age groups. It must therefore be considered how these individuals can report satisfactory QoL in adulthood despite the difficulties they faced.

This review also aimed to critically analyze the methodological quality of the included observational studies. The majority of studies showed good methodological quality, using standardized, accurate, and precise instruments, which reduces the risk of bias in our findings. Moreover, few studies were identified as having specific methodological problems. However, in one cross-sectional study, confounding variables were not controlled for in the analysis [35], and in two studies, instruments were used that had psychometric properties that had not yet been published [14, 30].

Previous studies of QoL of preterm individuals have focused on high-risk samples; therefore, future research should assess samples of preterm individuals with low clinical risk or who are defined as moderate or late preterm. Studies should also consider self-reported QoL of children and further investigate the influence of GA, birth weight, gender, parental schooling, and employment status on QoL of preterm individuals from different age groups. Factors influencing QoL of preterm individuals in adulthood should be better explored. These analyses should be combined with longitudinal assessments of QoL using repeated measures, which would permit observations of changes over time. We suggest that more complex statistical analyses should be conducted to identify predictive models that can evaluate mediating and moderating effects on QoL outcomes. A previous systematic review by Mottram and Holt [10] on the influence of GA on QoL recommended that future studies could also use qualitative designs. Considering the findings of the present systematic review, this recommendation has not yet been adopted by researchers. Finally, the present review highlights the relevance of including QoL assessments in studies of preventive and therapeutic interventions with individuals born preterm. We recommend that clinical trials control for factors associated with QoL outcomes indicated in observational studies, such as sociodemographic factors, cognitive level, behavior problems, and neurosensory impairments.

Conclusion

Discrepancies were found between parent- and self-reported QoL of individuals born preterm dependent on age group and source of information. In childhood, parents of preterm children reported worse QoL compared with parents of full-term children, whereas adolescents or adults who were born preterm self-reported more positive QoL outcomes. Several risk factors associated with preterm birth could explain such differences. Neonatal risk conditions and developmental problems during childhood may be related to parents' negative QoL. Nevertheless, the factors that might be associated with QoL in individuals born preterm require further investigation, especially in adulthood.

Acknowledgments The authors are grateful to the National Council for Scientific and Technological Development (CNPq) for financial support awarded to the authors (Grant Number 142168/2014-9 for Vieira MEB and Grant for productive researcher for Linhares MBM).

Funding This study was funded by National Council for Scientific and Technological Development (CNPq). The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

Ethical standard The present study is a review of literature and does not contain any studies with human participants or animals performed by any of the authors.

References

1. Bourchier, D., & Weston, P. J. (2014). Metabolic acidosis in the first 14 days of life in infants of gestation less than 26 weeks. *European Journal of Pediatrics, 174*, 49–54.
2. Brew, N., Walker, D., & Wong, F. Y. (2014). Cerebral vascular regulation and brain injury in preterm infants. *American Journal of Physiology—Regulatory, Integrative and Comparative Physiology, 306*(11), R773–R786.
3. Fernandez, R., D'Apremont, I., Dominguez, A., & Tapia, J. L. (2014). Survival and morbidity of very low birth weight infant in a South American Neonatal Network. *Archivos Argentinos de Pediatría, 112*(5), 405–412.
4. Feldman, R. (2009). The development of regulatory functions from birth to 5 years: insights from premature infants. *Child Development, 80*(2), 544–561.
5. Woods, P. L., Rieger, I., Wocadlo, C., & Gordon, A. (2014). Predicting the outcome of specific language impairment at five years of age through early developmental assessment in preterm infants. *Early Human Development, 90*(10), 613–619.
6. Vieira, M. E., & Linhares, M. B. (2011). Developmental outcomes and quality of life in children born preterm at preschool- and school-age. *Jornal de Pediatria (Rio de Janeiro), 87*(4), 281–291.
7. Michel, G., Bisegger, C., Fuhr, D. C., & Abel, T. (2009). Age and gender differences in health-related quality of life of children and adolescents in Europe: A multilevel analysis. *Quality of Life Research, 18*(9), 1147–1157.
8. Saigal, S., & Tyson, J. (2008). Measurement of quality of life of survivors of neonatal intensive care: Critique and implications. *Seminars in Perinatology, 32*(1), 59–66.
9. Zwicker, J. G., & Harris, S. R. (2008). Quality of life of formerly preterm and very low birth weight infants from preschool age to adulthood: A systematic review. *Pediatrics, 121*(2), e366–e376.

10. Mottram, R., & Holt, J. (2010). Is gestational age a factor in determining the health-related quality of life of children and young people born preterm? A critical review of the literature. *Journal of Neonatal Nursing, 16*(2), 80–90.
11. Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLOS Medicine, 6*(7), e1000097. doi:10.1371/journal.pmed1000097.
12. von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gotzsche, P. C., & Vandenbroucke, J. P. (2014). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for reporting observational studies. *International Journal of Surgery, 12*, 1495–1499.
13. Althabe, F., Howson, C. P., Kinney, M., & Lawn, J. (2012). *Born too soon: The global action report on preterm birth*. Geneva: World Health Organization.
14. Berbis, J., Einaudi, M. A., Simeoni, M. C., Brevaut-Malaty, V., Auquier, P., d'Ercole, C., et al. (2012). Quality of life of early school-age French children born preterm: a cohort study. *European Journal of Obstetrics, Gynecology, and Reproductive Biology, 162*(1), 38–44.
15. Gray, P. H., O'Callaghan, M. J., & Poulsen, L. (2008). Behaviour and quality of life at school age of children who had bronchopulmonary dysplasia. *Early Human Development, 84*(1), 1–8.
16. Stahlmann, N., Rapp, M., Herting, E., & Thyen, U. (2009). Outcome of extremely premature infants at early school age: Health-related quality of life and neurosensory, cognitive, and behavioral outcomes in a population-based sample in northern Germany. *Neuropediatrics, 40*(3), 112–119.
17. Hack, M., Forrest, C. B., Schluchter, M., Taylor, H. G., Drotar, D., Holmbeck, G., et al. (2011). Health status of extremely low-birth-weight children at 8 years of age: Child and parent perspective. *Archives of Pediatrics and Adolescent Medicine, 165*(10), 922–927.
18. Petrou, S., Abangma, G., Johnson, S., Wolke, D., & Marlow, N. (2009). Costs and health utilities associated with extremely preterm birth: Evidence from the EPICure study. *Value in Health, 12*(8), 1124–1134.
19. Petrou, S., Johnson, S., Wolke, D., Hollis, C., Kochhar, P., & Marlow, N. (2010). Economic costs and preference-based health-related quality of life outcomes associated with childhood psychiatric disorders. *The British Journal of Psychiatry, 197*(5), 395–404.
20. Wolke, D., Chernova, J., Eryigit-Madzwamuse, S., Samara, M., Zwierzynska, K., & Petrou, S. (2013). Self and parent perspectives on health-related quality of life of adolescents born very preterm. *The Journal of Pediatrics, 163*(4), 1020–1026.e2.
21. Verrips, G., Brouwer, L., Vogels, T., Taal, E., Drossaert, C., Feeny, D., et al. (2012). Long term follow-up of health-related quality of life in young adults born very preterm or with a very low birth weight. *Health and Quality of Life Outcomes, 10*, 49.
22. Gray, R., Petrou, S., Hockley, C., & Gardner, F. (2007). Self-reported health status and health-related quality of life of teenagers who were born before 29 weeks' gestational age. *Pediatrics, 120*(1), e86–e93.
23. Reuner, G., Hassenpflug, A., Pietz, J., & Philippi, H. (2009). Long-term development of low-risk low birth weight preterm born infants: Neurodevelopmental aspects from childhood to late adolescence. *Early Human Development, 85*(7), 409–413.
24. Roberts, G., Burnett, A. C., Lee, K. J., Cheong, J., Wood, S. J., Anderson, P. J., et al. (2013). Quality of life at age 18 years after extremely preterm birth in the post-surfactant era. *The Journal of Pediatrics, 163*(4), 1008–1013.e1.
25. Hallin, A. L., & Stjernqvist, K. (2011). Adolescents born extremely preterm: Behavioral outcomes and quality of life. *Scandinavian Journal of Psychology, 52*(3), 251–256.
26. van Lunenburg, A., van der Pal, S. M., van Dommelen, P., van der Pal-de Bruin, K. M., Bennebroek Gravenhorst, J., & Verrips, G. H. (2013). Changes in quality of life into adulthood after very preterm birth and/or very low birth weight in the Netherlands. *Health and Quality of Life Outcomes, 11*, 51.
27. Lund, L. K., Vik, T., Lydersen, S., Lohaugen, G. C., Skranes, J., Brubakk, A. M., et al. (2012). Mental health, quality of life and social relations in young adults born with low birth weight. *Health and Quality of Life Outcomes, 10*, 146.
28. Baumgardt, M., Bucher, H. U., Mieth, R. A., & Fauchere, J. C. (2012). Health-related quality of life of former very preterm infants in adulthood. *Acta Paediatrica, 101*(2), e59–e63.
29. Dalziel, S. R., Lim, V. K., Lambert, A., McCarthy, D., Parag, V., Rodgers, A., et al. (2007). Psychological functioning and health-related quality of life in adulthood after preterm birth. *Developmental Medicine and Child Neurology, 49*(8), 597–602.
30. Ulrich, M., Mortensen, E. L., Jensen, C., & Kamper, J. (2013). On the well-being of adult expremies in Denmark. *Acta Paediatrica, 102*(6), 602–606.
31. Schiariti, V., Hoube, J. S., Lisonkova, S., Klassen, A. F., & Lee, S. K. (2007). Caregiver-reported health outcomes of preschool children born at 28 to 32 weeks' gestation. *Journal of Developmental and Behavioral Pediatrics, 28*(1), 9–15.
32. Ketharanathan, N., Lee, W., & de Mol, A. C. (2011). Health-related quality of life, emotional and behavioral problems in mild to moderate prematures at (pre-)school age. *Early Human Development, 87*(10), 705–709.
33. Rautava, L., Hakkinen, U., Korvenranta, E., Andersson, S., Gissler, M., Hallman, M., et al. (2009). Health-related quality of life in 5-year-old very low birth weight infants. *The Journal of Pediatrics, 155*(3), 338–343.e1–3.
34. Beaudoin, S., Tremblay, G. M., Croitoru, D., Benedetti, A., & Landry, J. S. (2013). Healthcare utilization and health-related quality of life of adult survivors of preterm birth complicated by bronchopulmonary dysplasia. *Acta Paediatrica, 102*(6), 607–612.
35. Mendez Rubio, I., Lazaro de Mercado, P., Carbonell Estrany, X., & Figueras Aloy, J. (2010). Quality of life of preterm infants and admissions due to respiratory infections. *Anales de Pediatría (Barcelona), 73*(3), 121–131.
36. Saigal, S. (2013). Quality of life of former premature infants during adolescence and beyond. *Early Human Development, 89*(4), 209–213.
37. World Health Organization. (1995). The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine, 41*(10), 1403–1409.
38. Rutter, M., & Sroufe, L. A. (2000). Developmental psychopathology: Concepts and challenges. *Development and Psychopathology, 12*(3), 265–296.
39. Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: A review of the literature. *Quality of Life Research, 17*(6), 895–913.
40. Eiser, C., & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood, 84*(3), 205–211.
41. Horsman, J., Furlong, W., Feeny, D., & Torrance, G. (2003). The Health Utilities Index (HUI®): Concepts, measurement properties and applications. *Health and Quality of Life Outcomes, 1*(1), 54.
42. Costet, N., Le Gales, C., Buron, C., Kinkor, F., Mesbah, M., Chwalow, J., et al. (1998). French cross-cultural adaptation of the Health Utilities Indexes Mark 2 (HUI2) and 3 (HUI3) classification systems: Clinical and Economic Working Groups. *Quality of Life Research, 7*(3), 245–256.
43. McHorney, C. A., Ware, J. E, Jr, & Raczek, A. E. (1993). The MOS 36-item short-form health survey (SF-36): II. Psychometric

and clinical tests of validity in measuring physical and mental health constructs. *Medical Care, 31*(3), 247–263.
44. Hemingway, H., Stafford, M., Stansfeld, S., Shipley, M., & Marmot, M. (1997). Is the SF-36 a valid measure of change in population health? Results from the Whitehall II Study. *British Medical Journal, 315*(7118), 1273–1279.
45. Failde, I., & Ramos, I. (2000). Validity and reliability of the SF-36 Health Survey Questionnaire in patients with coronary artery disease. *Journal of Clinical Epidemiology, 53*(4), 359–365.
46. Fekkes, M., Theunissen, N. C., Brugman, E., Veen, S., Verrips, E. G., Koopman, H. M., et al. (2000). Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1-5-year-old children. *Quality of Life Research, 9*(8), 961–972.
47. Raat, H., Landgraf, J. M., Oostenbrink, R., Moll, H. A., & Essink-Bot, M. L. (2007). Reliability and validity of the Infant and Toddler Quality of Life Questionnaire (ITQOL) in a general population and respiratory disease sample. *Quality of Life Research, 16*, 445–460.
48. Klassen, A. F., Lee, S. K., Raina, P., Chan, H., Matthew, D., & Brabyn, D. (2002). Reliability and validity of the Infant Toddler Quality of Life questionnaire. *Quality of Life Research, 11*, 684.
49. Raat, H., Botterweck, A. M., Landgraf, J. M., Hoogeveen, W. C., & Essink-Bot, M. L. (2005). Reliability and validity of the short form of the Child Health Questionnaire for Parents (CHQ-PF28) in large random school based and general population samples. *Journal of Epidemiology and Community Health, 59*, 75–82.
50. Apajasalo, M., Rautonen, J., Holmberg, C., Sinkkonen, J., Aalberg, V., Pihko, H., et al. (1996). Quality of life in pre-adolescence: A 17-dimensional health-related measure (17D). *Quality of Life Research, 5*(6), 532–538.
51. Henrich, G., & Herschbach, P. (2000). Questions on Life Satisfaction (FLZ^M): A short questionnaire for assessing subjective quality of life. *European Journal of Psychological Assessment, 16*(3), 150–159.
52. Bullinger, M., Brutt, A. L., Erhart, M., & Ravens-Sieberer, U. (2008). Psychometric properties of the KINDL-R questionnaire: Results of the BELLA study. *European Child and Adolescent Psychiatry, 17*(Suppl 1), 125–132.
53. Manificat, S., Dazord, A., Langue, J., Danjou, G., Bauche, P., Bovet, F., et al. (2000). Evaluation de la qualité de vie du nourrisson et du très jeune enfant: Validation d'un questionnaire. *Étude multicentrique européenne. Archives de Pédiatrie, 7*(6), 605–614.
54. Feeny, D., Furlong, W., & Barr, R. D. (1998). Multiattribute approach to the assessment of health-related quality of life: Health utilities index. *Medical and Pediatric Oncology, Suppl, 1*, 54–59.
55. Riley, A. W., Forrest, C. B., Rebok, G. W., Starfield, B., Green, B. F., Robertson, J. A., et al. (2004). The child report form of the CHIP-child edition: Reliability and validity. *Medical Care, 42*(3), 221–231.
56. Riley, A. W., Forrest, C. B., Starfield, B., Rebok, G. W., Robertson, J. A., & Green, B. F. (2004). The parent report form of the CHIP-child edition: Reliability and validity. *Medical Care, 42*(3), 210–220.
57. Badia, X., Herdman, M., & Dipstat, M. R. (2001). Feasibility and validity of the VAS and TTO for eliciting general population values for temporary health status: A comparative study. *Health Services and Outcomes Research Methodology, 2*(1), 51–65.
58. Park, E. Y., & Choi, Y. I. (2014). Rasch analysis of the London Handicap Scale in stroke patients: A cross-sectional study. *Journal of Neuroengineering and Rehabilitation, 11*, 114.
59. Jenkinson, C., Mant, J., Carter, J., Wade, D., & Winner, S. (2000). The London Handicap Scale: A re-evaluation of its validity using standard scoring and simple summation. *Journal of Neurology, Neurosurgery and Psychiatry, 68*(3), 365–367.
60. Harwood, R. H., Gompertz, P., & Ebrahim, S. (1994). Handicap one year after a stroke: Validity of a new scale. *Journal of Neurology, Neurosurgery and Psychiatry, 57*(7), 825–829.
61. Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial: A report from the WHOQOL group. *Quality of Life Research, 13*(2), 299–310.
62. Solans, M., Pane, S., Estrada, M. D., Serra-Sutton, V., Berra, S., Herdman, M., et al. (2008). Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments. *Value in Health, 11*(4), 742–764.
63. Rajmil, L., Herdman, M., Fernandez de Sanmamed, M. J., Detmar, S., Bruil, J., Ravens-Sieberer, U., et al. (2004). Generic health-related quality of life instruments in children and adolescents: A qualitative analysis of content. *Journal of Adolescent Health, 34*(1), 37–45.