



Quality of life among parents of preterm infants: a scoping review

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Abstract

Purpose To synthesize the body of knowledge on the factors influencing the QoL of mothers and fathers of preterm infants.

Methods A scoping review was performed. Publications indexed in PubMed®, Web of Science™, CINAHL® and PsycINFO® were searched, targeting studies presenting original empirical data that examined parental perception on QoL after a preterm delivery. Eligibility and data extraction were conducted by two independent researchers. The main quantitative findings were synthesized and qualitative data were explored by content analysis.

Results The studies, 11 quantitative and 1 mixed methods, were derived mainly from the USA ($n=6$). Heterogeneity across the studies was observed regarding the operationalization of QoL and the use of units of analysis (mothers, parents, families and caregivers). In a context where 40 out of 45 covariates were analysed by only one or two studies, results suggested that parental QoL after a preterm delivery is influenced by factors related with mother's characteristics, family issues and health care environment rather than infants' variables. Factors regarding fathers' characteristics and structural levels were not addressed.

Conclusions Standardizing the operationalization of the QoL when analysing mothers and fathers of preterm infants calls for a structured questionnaire adapted to their specific needs. Further research should include both mothers and fathers, invest in mixed methods approaches and be performed in different countries and settings for allowing integration and comparison of findings.

Keywords Quality of life · Premature birth · Parents · Family-integrated care · Scoping review

Introduction

Preterm birth, occurring before completing 37 gestational weeks [1], constitutes the leading cause of neonatal mortality and morbidity worldwide [2]. The increased preterm birth rates and the higher survival chances of these infants, consistently reported over the last three decades [3], have

justified the increasing number of studies concerning health and quality of life (QoL) of children and adults born preterm [4–6]. These studies aim to develop optimal evidence-based effective perinatal intensive care [7] and to standardize approaches to the organization of care and medical interventions [8]. Recent studies point to the need to also acknowledge parents' experiences and views focused on developing family-integrated neonatal services [9, 10]. Nevertheless, the factors influencing parental QoL during and after preterm infants' hospitalization in Neonatal Intensive Care Unit (NICU) have not been systematized.

A preterm birth affects the family environment not only during the infant's hospitalization in NICU, but for many years [11]. Mothers and fathers of preterm infants revealed an increased risk of developing parental stress [12–14], depressive symptoms and anxiety shortly after delivery [15, 16], as well as poorer family functioning and higher family burden several years after birth, when compared with families of full-term infants [17]. Existing literature reviews provide information about parental mental health

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and stress, and identify the effects of a preterm delivery on the family structure, with a specific focus on parents of very or extremely low birth weight infants [18], with or without neuropsychomotor disturbance [19]. These reviews were not performed with a systematic methodology neither focused on the factors influencing QoL of mothers and fathers of preterm infants, defined as the individuals' perception of their own physical, psychological, social and environmental well-being, taking into account their culture and value systems, goals and expectations [20]. Such systematic knowledge could represent a relevant tool for designing and developing sustainable and effective family-centred and integrated health care when parenting a preterm infant. Moreover, the evidence provided would contribute to enrich medical practices thus improving health governance in the context of prematurity.

This scoping review aims to synthesize the body of knowledge on the factors influencing the QoL of mothers and fathers of preterm infants.

Methods

We followed the guidance for descriptive systematic scoping reviews by Levac et al. [21], based on the methodological framework developed by Arksey and O'Malley [22].

Stage 1: Identifying the research question

The central question guiding this scoping review is the following one: What are the main factors influencing the QoL of mothers and fathers of preterm infants?

Stage 2: Identifying relevant studies

A search of the publications on four electronic databases (PubMed®, Web of Science™, CINAHL® and PsycINFO®) was undertaken in July 2017, with no restriction set for language or time of publication, using the following search expression: (“QoL” OR “quality of life” OR “life quality” OR “life qualities”) AND (“mother” OR “father” OR “mothers” OR “fathers” OR “parent” OR “parents” OR “family” OR “families” OR “maternal” OR “paternal” OR “parental”) AND (“birth, premature” OR “births, premature” OR “premature births” OR “preterm birth” OR “birth, preterm” OR “births, preterm” OR “preterm births” OR “infants, premature” OR “premature infant” OR “preterm infants” OR “infant, preterm” OR “infants, preterm” OR “preterm infant” OR “premature infants” OR “neonatal prematurity” OR “prematurity, neonatal”). The search was followed by

backward reference tracking, examining the references of the selected publications based on full-text assessment.

Stage 3: Study selection

The inclusion criteria allowed only empirical, peer-reviewed, original full-length studies that explored the QoL of mothers and/or fathers of preterm infants as their main outcome. The exclusion criteria disallowed studies focusing on the QoL of infants, adolescents or adults born prematurely, studies with data about parents' QoL only during pregnancy and studies in which the infants' gestational age was above 37 weeks.

The first and the last authors (M.A. and E.A.) independently screened all the papers retrieved initially, based on the title and abstract and afterwards, based on the full-text. This was crosschecked in both phases. The study selection was guided by the research question and inclusion and exclusion criteria. An almost perfect strength of agreement was achieved in both phases (total percentage of agreement = 96.5%; Cohen's kappa = 0.91, 95% CI 0.87–0.96). Disagreement was solved by joint discussion until consensus could be reached or, when consensus was not achieved, by the assessment of the second author (S.S.), based on the same criteria defined for study selection.

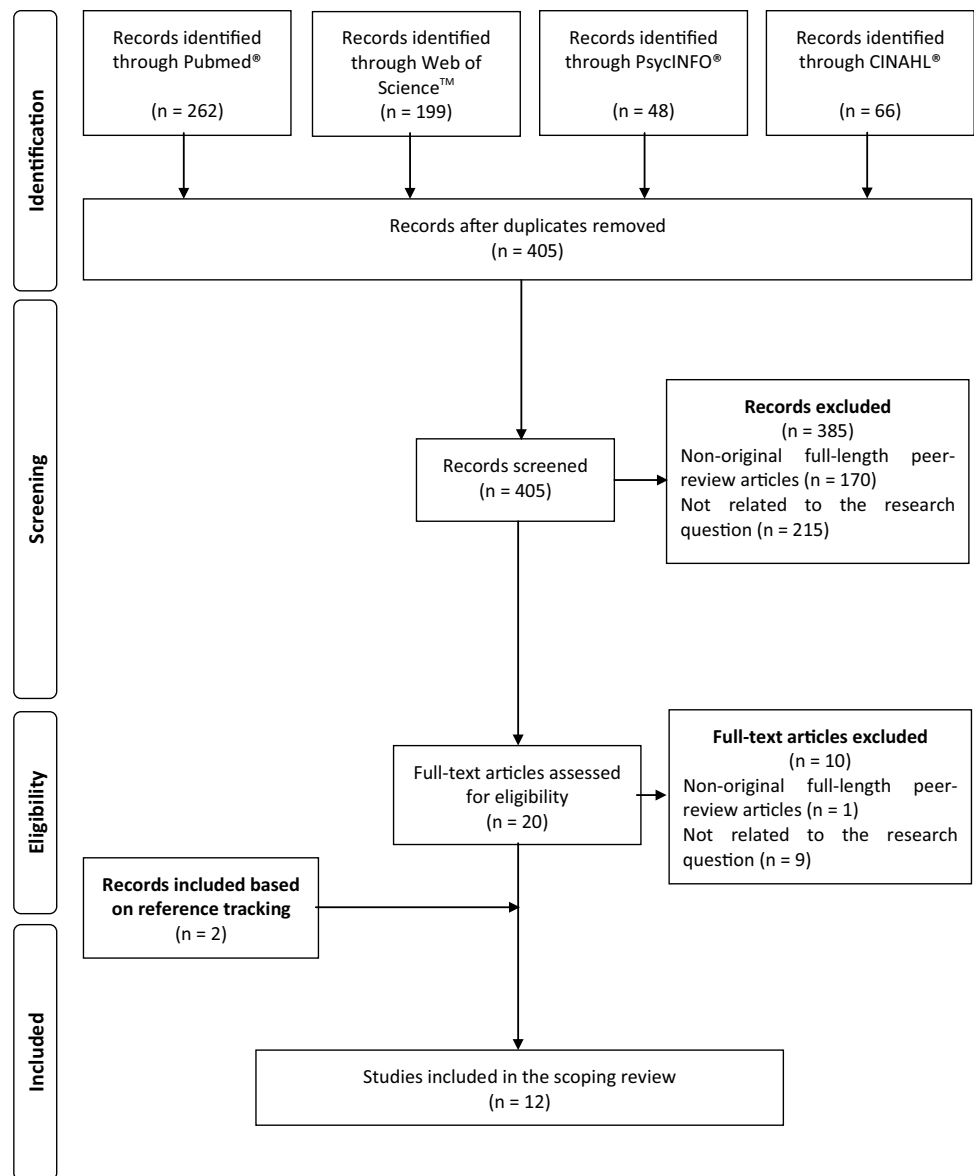
The screening process is summarized in Fig. 1. The titles of 575 records were retrieved. After the removal of the duplicates, 405 records were examined. Based on title and abstract assessments, 385 records were excluded, mainly because they were neither original full-length peer-review studies nor explored parental QoL as the main outcome. Of the 20 fully read papers, 10 met the inclusion criteria. After the backward reference tracking, two papers were included and the final scoping review was composed by 12 papers.

Stage 4: Charting the data

A standardized data extraction sheet was developed and completed by two independent researchers (M.A. and E.A.). Descriptive data for the characterization of studies included research design; information about the authors and publication year; country where the study was developed; study aim; participants and sample; and instruments used to assess parental QoL.

We retrieved quantitative data on variables whose association with parental QoL was statistically significant and the directions of the associations were registered. All the remaining variables whose association with QoL of parents of preterm infants was tested and reported were also extracted.

Fig. 1 Flowchart showing the search results and screening process for the scoping review on QoL of parents of preterm infants



The qualitative data presented in only one study [23] were analysed according to the protocol for content analysis developed by Stemler [24]. In each of the main themes identified by the authors of the above-mentioned study, we selected the categories with the highest and the lowest difference between the two interviewed groups (families of infants with cerebral palsy or hydrocephalus and families of neurologically normal infants). Additionally, the most frequently reported categories related with positive and negative impacts of a preterm birth on family QoL were retrieved.

Stage 5: Collating, summarizing and reporting the results

The main characteristics of the 12 studies included can be found in Table 1. Studies were grouped by research design and ordered by the year of publication.

The factors influencing the QoL of mothers and fathers of preterm infants were identified and then grouped into issues related with mother, infant, family and health care (Table 2). The main findings are presented in Table 3.

Table 1 Empirical studies examining QoL of parents of preterm infants ($n = 12$)

Publication	Country	Aim	Participants and sample	Assessment of QoL
Cross-sectional studies				
Rivers et al. [23]	USA	Explore the QoL of VLBW infants and their families, by comparing families of infants with neurologic <i>sequelae</i> with families of infants who were neurologic intact, 3 to 7 years after the infants' admission to NICU	22 families of neurologically abnormal PT infants admitted to the NICU 15 families of neurologically normal PT infants	Open-ended questions
Donohue et al. [25]	USA	Compare the QoL of caregivers of VLBW infants and of full-term infants, 12 to 18 months after delivery	83 primary caregivers (80 mothers) of VLBW PT infants who had been cared for in an urban inner-city NICU 84 primary caregivers (83 mothers) of full-term infants cared in the well-baby nursery, paired for maternal race, age and parity	Quality of Life Inventory ^a
Lee and Kimble [32]	USA	Explore relationships between impaired sleep and well-being, in mothers of low birth weight infants hospitalized in the NICU, at 2nd week postpartum	20 first-time mothers of LBW PT infants	The 36-item Medical Outcomes Short Form-36 version 2 (SF36v2) ^b
Lee et al. [33]	USA	Describe maternal daytime activity levels and their association with HRQOL, at 2nd week postpartum	51 healthy first-time mothers of LBW PT infants	The 36-item Medical Outcomes Short Form-36 version 2 (SF36v2) ^b
Lee and Hsu [34]	USA	Assess the role of sleep on the association between maternal stress and health-related well-being (depression, fatigue and HRQOL) among mothers with PT infants in the NICU, at 2nd week postpartum	55 first-time mothers of LBW PT infants	The 36-item Medical Outcomes Short Form-36 version 2 (SF36v2) ^b
McGowan et al. [29]	Ireland	Explore the health outcomes and family functioning of late PT infants according to the provision of neonatal intensive care, 3 years after delivery	Mothers of 101 late PT infants (34+0 to 36+6 weeks of gestation) who received any episode of neonatal intensive care Mothers of 122 late PT infants who did not receive any intensive care or who received special care only for up to a maximum of 3 days	The PedsQL Family Impact Module ^c
Case-control studies				
McLean et al. [31]	Australia	Assess the impact of caring for a PT infant receiving HOT on mothers QoL after discharge	10 mothers of PT infants diagnosed with chronic lung disease receiving HOT 10 mothers of PT infants who previously received HOT 20 mothers of PT infants who did not require HOT	The 36-item Medical Outcomes Short Form (SF36) ^d
Sharma and Sohi [26]	NR	Compare self-perceptions of QoL of mothers of PT and term babies during the first 6 months of infant's age	50 mothers of PT babies 50 mothers of term babies	The WHOQOL-BREF questionnaire ^e

Table 1 (continued)

Publication	Country	Aim	Participants and sample	Assessment of QoL
Longitudinal studies				
Hill and Aldag [27]	USA	Examine PT, near-term and term mothers' self-reported QoL at 1st and 3rd weeks postpartum	37 mothers of PT infants (24 to 33 weeks of gestation) 59 mothers of near-term infants (34 to 37 weeks of gestation) 88 mothers of term infants (38 to 41 weeks of gestation)	Maternal Postpartum Quality of Life Instrument (MAPP-QoL) ^f
Mautner et al. [28]	NR	Explore the influence of PT delivery as risk factor for HRQoL between the 24th and 37th weeks of gestation and the 3rd to 4th months postpartum (using three time points) ^g	32 women with a PT delivery 18 women with gestational hypertensive disorders 11 women with gestational diabetes 29 women with uncomplicated pregnancies	The WHOQOL-BREF questionnaire ^e
Nordheim et al. [30]	Norway	Examine parental QoL after participation of their VLBW infants in a nutrition RCT during NICU hospitalization and at 3.5 years of infants' age	31 parents ($\approx 45\%$ fathers) of VLBW PT infants participating in a nutrition RCT 31 ($\approx 50\%$ fathers) parents of non-participating VLBW PT infants	Quality of Life Scale-Norwegian version (QoLS-N) ^h
Moura et al. [35]	Brazil	Identify factors associated with the QoL of mothers of VLBW PT infants during the first 3 years after delivery (using five time points)	75 mothers of PT infants (≤ 34 weeks of gestation) with VLBW	The WHOQOL-BREF questionnaire ^e

HOT home oxygen therapy, *HRQoL* health-related quality of life, *LBW* low birth weight, *NICU* neonatal intensive care unit, *NR* not reported, *PT* preterm (< 37 weeks of gestation, except if otherwise specified), *QoL* quality of life, *RCT* clinical randomized intervention trial, *USA* United States of America, *VLBW* very low birth weight (< 1500 g)

^aDomains: health; self-esteem; goals and values; creativity; learning; money; work; play; helping; love; relationship with friends, family and children; satisfaction with home, neighbourhood and community; overall QoL (range -6 -6)

^bDomains: physical health; emotional health (range 0-100)

^cDomains: Global HRQoL (range 0-100)

^dDomains: vitality; general mental health; role limitations due to emotional problems; social relationships; environment (range 0-100)

^eDomains: global QoL; physical health; psychological health; socioeconomic; relational/spouse-partner; relational/family friends; health and functioning (range 0-30)

^fDomains: overall QoL; psychological/baby; socioeconomic; relational/spouse-partner; relational/family friends; health and functioning (range 0-30)

^gFor the purposes of this scoping review, we only used data from the last moment of data collection

^hDomains: overall QoL (range 16-112)

Table 2 Synthesis of the factors whose association with QoL of parents of preterm infants was tested

Factors (number of studies)	Negative influence	Positive influence	No association
Mother (<i>n</i> = 8)			
Mental health	✓✓✓✓ ^{25, 33–35}		✓ ³⁵
Disturbed sleep	✓✓✓ ^{32–34}		
Fatigue	✓✓ ^{33,34}		
Stress	✓ ³⁴		
Pregnancy complications	✓ ²⁸		✓ ³⁵
Time postpartum		✓ ²⁷	
Light exposure		✓ ³²	
Religion		✓ ³⁵	
Circadian activity rhythms			✓✓ ^{32,33}
Parity			✓✓ ^{26,35}
Number of miscarriages			✓ ³⁵
Night-time total sleep time			✓ ³²
Self-reported physical health			✓ ²⁵
Age			✓ ³⁵
Skin colour			✓ ³⁵
Educational level			✓ ³⁵
Occupation			✓ ³⁵
Working status			✓ ²⁶
Infant (<i>n</i> = 7)			
Health problems	✓✓✓ ^{23a,31,35}		✓✓ ^{23b,25}
Gestational age	✓✓ ^{27,35}		✓✓ ^{26,31}
Birth weight		✓ ²⁵	✓✓✓ ^{26,31,35}
Gender		✓ ³⁵	✓ ²⁶
Length of stay in NICU			✓✓ ^{29,35}
Chronological age			✓✓ ^{31,35}
Intrauterine growth restriction			✓ ³⁵
APGAR score at 5 min			✓ ³⁵
Motor and language quotient			✓ ²⁵
Family (<i>n</i> = 5)			
Lack/existence of support system	✓ ²³	✓ ²³	
Memories of neonatal period (Guilt/Optimism)	✓ ²³	✓ ²³	
Relationships to child (spoiled/high appreciation)	✓ ²³	✓ ²³	
Presence/absence of impact on parents' lives	✓ ²³	✓ ²³	
Changed/not changed plans for future children	✓ ²³	✓ ²³	
Family income	✓ ³⁵		
Stable marital union		✓ ³⁵	
Family set up			✓ ²⁶
Number of adults in home			✓ ²⁵
Place of residence			✓ ³¹
Health care (<i>n</i> = 4)			
Absence/presence of medical information	✓ ²³	✓ ²³	
Presence/absence of financial problems	✓ ²³	✓ ²³	
Misbehaviour of medical personnel	✓ ²³		
Hospitalization in NICU	✓ ³⁵		
Participation in a nutrition RCT		✓ ^{30c}	✓ ^{30d}
Mode of delivery			✓✓ ^{28,35}
Number of prenatal care visits			✓ ³⁵
Use of antenatal corticosteroids			✓ ³⁵

Table 2 (continued)

NICU neonatal intensive care unit, *RCT* clinical randomized intervention trial

✓Represents the number of studies reporting the respective association

^aRegarding the dimensions: stress related to the unwillingness of the paediatrician to agree that child had a problem or needed referral for therapy, and difficulties related to the physical work to care for child

^bRegarding the dimensions: absence of problems with the neonatal hospital bill and the importance given to the support provided by extended family

^cDuring infant's hospitalization in NICU

^dAt 3.5 years after delivery

Results

Study characteristics

Research design

Six studies were cross-sectional, two were case–control and four were longitudinal studies. Eight of the studies had at least one comparison group, such as caregivers and mothers of full-term infants [25–27], women with other pregnancy complication than a preterm delivery [28], mothers of near-term (34–37 weeks of gestation) infants [27], parents of very low birth weight (VLBW) infants not participating in a Clinical Randomized Intervention Trial [30], mothers of preterm infants who did not require and previously received home oxygen therapy [31], mothers of infants who did not receive any intensive care or who received special care only for up to a maximum of 3 days [29] and families of neurologically normal infants [23]. The remaining four studies [32–35] assessed the QoL of mothers of preterm infants.

Almost all studies used a quantitative methodology ($n = 11$), assessing QoL through seven different standard instruments. The only mixed methods study relied on interviews using a structured questionnaire and open-ended questions [23]. The timing of data collection ranged from the first to third weeks postpartum during NICU hospitalization [27], until 3 months [28] to 7 years after delivery [23].

Country of study origin and year of publication

Half of the studies were conducted in the USA, and the remaining derived from 4 countries: Ireland ($n = 1$), Australia ($n = 1$), Norway ($n = 1$) and Brazil ($n = 1$). Two studies did not report the country of study origin, being authored by researchers from India [26] and Austria [28]. The studies were published between 1987 [23] and 2017 [35].

Participants and sample

In the total of the 12 papers, samples were composed mostly of mothers ($n = 9$), followed by samples of parents ($n = 1$), families ($n = 1$) and primary caregivers ($n = 1$). In the latter,

97.6% were mothers [25]. The gender of the participants is not specified in the study analysing families [23]. Samples varied from 20 first-time mothers [32] to 223 mothers of late preterm infants [29], and there were 167 caregivers [25], 37 families [23] and 62 parents of VLBW infants [30].

Assessment of QoL

Half of the studies used the WHOQOL-BREF Questionnaire [26, 28, 35] or the 36-item Medical Outcomes Short Form-36 version 2 [32–34]. The remaining quantitative studies assessed parental QoL through the following instruments: The 36-item Medical Outcomes Short Form (SF36) [31]; Quality of Life Inventory [25]; The PedsQL Family Impact Module [29]; Maternal Postpartum Quality of Life Instrument (MAPP-QOL) [27] and Quality of Life Scale-Norwegian version (QoLS-N) [30]. Five instruments assessed the global/overall QoL [25–30, 35], and three studies measured the domains physical health and emotional health using the same instrument [32–34]. The other 29 QoL domains were evaluated by only one study each [25, 27, 31]. Study by Rivers, Caron and Hack [23] evaluated QoL through the following questions: How has your life been changed by the birth of your premature child?; What has the financial impact of your child's birth been on your family?; How has your child's birth affected your plans for future children?

Factors influencing the QoL of parents of preterm infants

Factors related with mothers and infants' characteristics were more frequently addressed, followed by those centred on the family and health care. Across all the studies assessed, 45 variables potentially associated with QoL were identified, and in most studies few were considered simultaneously. Only 5 variables were assessed by more than two studies. Inconsistent results were reported concerning four of the five remaining variables: maternal mental health and infant's health problems, gestational age and birth weight. Additionally, the way these variables were measured differed between studies, resulting in inconclusive data.

Table 3 Main findings of studies on the factors influencing the QoL of parents of preterm infants ($n = 12$)

Factors	Main findings
Mother	
Mental health	Higher EPDS scores: Lower mental maternal HRQOL ($P < 0.01$) [33, 34] Higher median BDI scores: Lower maternal QoL on physical, psychological, social and environmental domains ($P < 0.05$) [35] Higher Psychiatric Symptoms Index ^a scores: Poor overall maternal QoL ($P < 0.001$) [25]
Sleep	More severely disturbed sleep: Lower mental and physical maternal HRQOL ($P < 0.05$) [32–34] Higher daytime sleepiness: Lower physical and mental maternal HRQOL ($P < 0.01$) [32, 33]
Fatigue	Higher levels of fatigue: Lower physical and mental maternal HRQOL ($P < 0.01$) [33, 34]
Stress	Higher levels of stress: Lower mental maternal HRQOL ($P < 0.01$) [34]
Pregnancy complications	PT delivery (vs. Gestational hypertensive disorders or Gestational diabetes or. Uncomplicated pregnancy): Lower maternal QoL on physical domain ($P < 0.05$) [28]
Time postpartum	Week 3 (vs. Week 1): Higher maternal QoL on health and functioning domain ($P < 0.001$) [27]
Light exposure	≥ 12 h: Higher physical maternal HRQOL ($P < 0.01$) [32]
Religion	Evangelical: Higher maternal QoL on social domain ($P = 0.019$) [35]
Infant	
Health problems	Receiving HOT: Lower maternal QoL on vitality and mental health dimensions ($P < 0.05$) [31] Posthemorrhagic hydrocephalus: Lower maternal QoL on psychological ($P = 0.010$) and social domains ($P = 0.001$) [35] Bronchopulmonary dysplasia: Lower maternal QoL on physical domain ($P = 0.005$) [35] Higher score for neonatal acute physiology with perinatal extension: Lower maternal QoL on social domain ($P = 0.027$) [35] Cerebral palsy or hydrocephalus (vs. Neurologically normal): More stress related to the unwillingness of the paediatrician to agree that child had a problem or needed referral for therapy, and more difficulties related to the physical work to care for child [23]
Gestational age	24–33 weeks (vs. 34–37 weeks or 38–41 weeks): Lower maternal QoL on psychological/baby domain ($P < 0.001$) [27] Lower number of gestational weeks: Lower maternal QoL on physical domain ($P = 0.010$) [35]
Birth weight	VLBW (vs. Full-term): Higher overall caregiver's QoL ($P < 0.05$) [25]
Gender	Female: Higher maternal QoL on environmental domain ($P = 0.011$) [35]
Family	
Support system	The contact with other parents of preterm children had a positive impact on family QoL, while the lack of support provided by extended family had a negative impact on family QoL [23]
Memories of neonatal period	Religion or optimistic philosophy of life during neonatal period had a positive impact on family QoL, while the guilt considered as a problem in adjustment influenced negatively the family QoL [23]
Values and relationships to child	High appreciation of their child had a positive impact on family QoL, while considering child more “spoiled” or more protected by parents had a negative impact on family QoL [23]
Perceived impact on parents' lives	No much life changes influenced positively family QoL, while the difficulties related to the physical work to care for child had a negative impact on family QoL [23]
Plans for future children	No changes in the plans for future children had a positive impact on family QoL, while the deferral of the birth of later children or more care with later pregnancy had a negative impact on family QoL [23]
Family income	BRL 1500–2750 ^b : Lower maternal QoL on environmental domain ($P = 0.001$) [35]
Marital union	Stable: Higher maternal QoL on social domain ($P = 0.004$) [35]
Health care	
Communication of medical information	Information and explanation of medical terms by the medical personnel had a positive impact on family QoL during neonatal period, and the absence of important medical information had a negative impact on family QoL [23]
Financial impact	Do not having problems with the neonatal hospital bill had a positive impact on family QoL, and problems with the costs of later medical care had a negative impact on family QoL [23]
Behaviour of medical personnel	Stress due to policy of transporting hospital had a negative impact on family QoL [23]
Hospitalization in NICU	During hospitalization (vs. 6 months after discharge or 12 months after discharge): Lower maternal QoL on physical domain ($P = 0.013$) [35]
Participation in a nutrition RCT	Enrolled (vs. Not enrolled): Higher parental QoL scores ($P = 0.02$) during infants hospitalization in NICU [30]

BDI Beck depression inventory, *BRL* Brazilian real, *EPDS* Edinburgh Postnatal Depression Scale, *HOT* home oxygen therapy, *HRQOL* health-related quality of life, *NICU* neonatal intensive care unit, *P* *P* value, *PT* preterm, *QoL* quality of life, *RCT* clinical randomized intervention trial, *VLBW* very low birth weight (< 1500 g)

^aDepression, anxiety, anger and cognitive disturbance

^bThe equivalent to 406–745 €

Studies reported issues related with the family, the mother and health care as positively influencing parental perception of their own QoL. Having a stable marital union, maintaining contacts with other parents of preterm children, family religious belief or optimistic philosophy of life during the neonatal period, high appreciation of the child and having few changes in life and in plans for having future children, all had a positive impact on parents' QoL [23, 35]. Women experiencing a total light exposure of 12 or more hours per day [32], as well as women self-reporting evangelical religion [35], presented higher levels of perceived physical and social QoL than those who did not. Mothers' perception of QoL on health and functioning domains also improved over time during postpartum period [27]. Parents of preterm infants who participated in a Clinical Randomized Intervention Trial (vs. non-participating) reported significantly higher levels of QoL during hospitalization in NICU [30]. Having no problems with the neonatal hospital bill and receiving information and explanation of medical terms by healthcare professionals also had a positive impact on family QoL [23].

Low levels of QoL were mainly associated with mother-, family- and health care-related factors. Severely disturbed sleep, high levels of daytime sleepiness, fatigue and stress were associated with lower maternal QoL [32–34]. Family issues, such as family income of 1500–2750 Brazilian Reals (406–745 €) [35], lack of support provided by extended family, feelings of guilt considered as a problem in adjustment, the difficult physical work to care for child, considering child more “spoiled” or more protected by parents and the birth of later children deferred or more care with later pregnancy [23], also had a negative impact on QoL. Hospitalization in NICU (vs. 6 or 12 months after discharge) [35], as well as absence of important medical information, stress due to policy of transporting hospital and problems with the financial costs of later medical care, constituted health care-related factors influencing negatively family QoL [23].

The circadian activity rhythms, parity, the number of miscarriages, night-time total sleep time and self-reported physical health, as well as maternal age, skin colour, educational level, occupation and working status, were not associated with maternal QoL [25, 26, 32, 33, 35]. Similarly, the length of infant's stay in NICU, the child's chronological age, the intrauterine growth restriction, the APGAR score at 5 min and the motor and language quotient were described as factors with no impact on parental QoL [25, 29, 31, 35]. The participation of the infant in a Clinical Randomized Intervention Trial during hospitalization had no impact on parental QoL at 3.5 years after delivery [30]. Finally, the QoL of mothers and fathers of preterm infants was not influenced by the mode of delivery, the number of prenatal care visits and the use of antenatal corticosteroids [28, 35] as well

as by the family set up, the number of adults in home and the place of family residence [25, 26, 31].

Studies addressing infant factors related with the presence of health problems, gestational age, birth weight and gender revealed inconsistent results, as well as those assessing maternal mental health and pregnancy complications, which might be explained by differences on assessment tools and timing of data collection. Some studies revealed that higher mother's depression scores [33–35], caregivers' psychiatric symptoms [25] and pregnancy complications [28] were associated with lower QoL, while other reported no association between QoL and self-reported depression/anxiety or pregnancy-related diseases [35]. Having an infant born with 24–33 weeks of gestation (vs. 34–37 or 38–41 weeks), as well as with some health problems (receiving home oxygen therapy, posthemorrhagic hydrocephalus, bronchopulmonary dysplasia, high score for neonatal acute physiology with perinatal extension) was associated with worse maternal QoL [27, 31, 35]. Maternal QoL also tended to decline with the decrease of the number of gestational weeks at birth [35]. In contrast, other studies reported no difference between the QoL of mothers of preterm and full-term infants [26] and no association between infant's gestational age and parental QoL [31]. In addition, parenting an infant with cerebral palsy or hydrocephalus (vs. neurologically normal) revealed to be associated with more stress related to the unwillingness of the paediatrician to agree that the child had a problem or needed therapy and more difficulties related to the physical work to care for child, while had no impact on the problems with the neonatal hospital bill and the importance given to the support provided by extended family [23]. One study showed that the infant's ongoing medical problems were not associated with caregivers' QoL [25]. In addition, one study referred that having a very low birth weight infant (vs. full-term) was positively associated with parental QoL [25], while three other studies reported no association between infant's birth weight and maternal QoL [26, 31, 35]. Finally, one study found that having a female infant (vs. male) had a positive impact on maternal QoL [35], while another one revealed no association between infant's gender and maternal QoL [26].

Discussion

Current state of research and future direction

This scoping review suggested that the QoL of parents of preterm infants is mainly influenced by factors related with maternal characteristics, family issues and health care environment rather than aspects related with infants, in a framework where factors from individual fathers and structural levels were not addressed. Studies were based on specific

sets of variables, for which the assessment varied among studies, with 40 out of 45 factors being analysed by only one or two studies.

Psychosocial characteristics of mothers, namely sleep disturbances, fatigue, stress and poorer mental health (in particular depression and psychiatric symptoms) proved the highest relevance as factors negatively influencing the QoL of mothers of preterm infants. Previous studies conducted during hospitalization in NICU consistently show that parents of preterm infants present high levels of depression, stress and anxiety [12, 14, 16, 36], and report a sense of uncertainty and powerlessness which conjointly impact negatively on parental sleep [37]. Thus, the findings of this scoping review emphasize the need for healthcare professionals to be aware of the impact of a preterm delivery on maternal mental and psychosocial health and sleep patterns during early years. This knowledge will help health professionals to identify groups at risk that should constitute a privileged target for early intervention, aiming to promote parental mental health and improve parents' sleep quality, especially during the first weeks' postpartum. According to our results, future research should explore the maximization of the hours of natural light exposure [32], and the coping strategies related with parents' religion [23, 35] as two possible strategies to increase parental QoL.

Five studies addressed family-related variables, but only two found any associations [23, 35]. They described the social support provided by partner, extended family and other parents of preterm children as a factor positively influencing parental mental health and QoL, reinforcing the importance of the support system also reported by parents of full-term infants [38–41]. At the same time, results coherently showed that parental QoL benefits from the fact that parents did not perceive a preterm delivery as a disruptive event for the family. In a context where a preterm delivery constitutes a risk factor for recurrence in subsequent pregnancies [42], parents tended to change their plans for reproductive trajectories when their first pregnancy ended with a preterm delivery [43], which may have a negative impact on family QoL. These findings call for the need to explore in depth the role of several coping strategies to handle adversity and to deal with a preterm delivery [44, 45] as a factor influencing positively parental and family QoL. Furthermore, there is room to explore the influence of other family-related factors on QoL of parents of preterm infants, including those which were addressed by only one study (e.g. family set up, number of adults at home and place of family residence).

Only four studies reported issues related with health care [23, 28, 30, 35]. The way medical information is communicated and the degree of parental concern with financial costs of medical care constituted two main factors related with health care environment influencing parental QoL. These

results suggest that health professionals' acknowledgement of parental needs for information, financial support and assurance [46] when dealing with mothers and fathers of preterm infants is central to the development of integrated, sustainable and quality family-centred health care services. This review also highlights the importance of further exploring the impact of medical insurance and family income on parental QoL, in a context where caregivers/families of infants with physical and mental illness reported better QoL when having a public insurance [40, 41] and parents of preterm infants reported less emotional burden when they have financial compensation for time taken off from work [47].

Studies performed with parents of infants with chronic diseases also suggest that other variables than infant-related factors influence the QoL of mothers and fathers, in particular factors related with characteristics of mothers and fathers and health care environment [41, 48, 49]. However, some of these factors were not tested by most of the studies included in this scoping review, namely those associated with parents' self-efficacy and coping strategies [41, 50], maternal and paternal educational level [51] and employment status [52], family socioeconomic status [51], quality of the marital relation [40], parental health-related behaviours such as eating habits and exercise [49], use of community-based developmental resources (e.g. early intervention programs) [47] and regulation of parental leave [48]. The assessment of these variables in future research will contribute to a better understanding of QoL of parents of preterm infants.

Methodological features

There are some methodological limitations in the studies included in this scoping review that should be taken into account when analysing the results. A considerable heterogeneity across the studies was observed regarding the operationalization of QoL and the use of different units of analysis (mothers, parents, families and caregivers). Additionally, a small number of studies conducted in few countries and specific settings, with different periods of data collection, are available.

QoL, as defined by WHO [20], has been subjected to several interpretations. Only two studies presented a definition of QoL [25, 27], and the remaining used interchangeably concepts as health-related QoL, life satisfaction, parental functioning and well-being as proxies of QoL [28–30, 35]. This translates into the use of seven different quantitative instruments to measure the construct, which assessed specific domains and proxies of QoL. The presented findings can thus be biased by the different measures used to assess QoL [29, 32–34, 53].

In the last four decades, condition-specific QoL questionnaires have been developed for caregivers of infants with several medical conditions, aiming to assess the specific

impact of each condition on caregivers' QoL [54]. However, no specific tool has been designed to assess QoL of parents of preterm infants. Although the failures of the available quantitative instruments were acknowledged in one study [26], no attempts were observed to explore whether there are dimensions or constructs specifically relevant for parents of preterm infants not addressed in the questionnaires. As pointed out in this scoping review, parents bring up some dimensions influencing their own QoL that differ from those covered by the quantitative instruments, namely the importance of the support system, the information needs and the medical, reproductive and social costs related with a preterm delivery. These findings call for the development of more mixed methods studies, which would lead to a wider understanding of the QoL of parents of preterm infants [55], assisting us to disentangle the mechanisms behind some contradictory findings, and to the identification of the issues that are missing from the available scales by involving different stakeholders (e.g. parents, health professionals and relevant community stakeholders) [53].

Finally, more detailed data about the QoL of fathers of preterm infants are required. It could serve as a basis for exploring if parenthood is more consistently linked to well-being among men than women [56]. Although fatherhood has been associated with greater life satisfaction, happiness, positive affect and less with depressive symptoms [57–59], literature suggested that fathers of preterm infants, similarly to mothers, experienced high rates of psychological distress after birth due to the simultaneously concern for the hospitalized infant, providing support to the mother, communicating with family and friends, caring for other infants and returning to work [12, 14, 60].

Conclusion

The aim of this scoping review was to synthesize the current body of knowledge on the factors influencing the QoL of mothers and fathers of preterm infants. Studies addressed mainly mother- and infant-related factors. The results suggested that parental QoL after a preterm delivery is mainly influenced by factors related with mother's characteristics, family issues and health care environment rather than infants' variables, in a context where factors regarding fathers' characteristics and structural levels were not addressed. There is a need for standardizing the operationalization of the QoL and developing a structured questionnaire adapted to the specific needs of mothers and fathers of preterm infants. Further research on parental QoL after a preterm delivery should include both mothers and fathers, invest in mixed methods approaches and be performed in

different countries and settings for allowing integration and comparison of findings.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

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