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REVIEW ARTICLE

NICU infant health severity and family outcomes: a systematic review of assessments and findings in psychosocial research

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Abstract

Many infants (7–15%) spend time in the neonatal intensive care unit (NICU) and continue to experience medical issues after discharge. Family psychological responses range widely depending on burden of care, access to resources, and parental characteristics. The current systematic review examined how infant health severity is assessed and related to family psychological (e.g., mental health) and social (e.g., parent–infant attachment) outcomes. Seventy articles were deemed relevant. Infant health was operationalized in several ways including validated assessments, indices of infant health (e.g., diagnosis, length of stay), or novel measures. Parents of infants with increased medical complications reported greater family impact, increased stress, and more intrusive parenting style. A validated assessment of infant health that utilizes parent report is warranted to allow for more accessible and easily disseminated research across medical centers. Understanding NICU infant health severity and family outcomes can be used to identify families at risk for negative psychosocial sequelae.

Introduction

About one in ten infants delivered annually in the United States will spend time in a Neonatal Intensive Care Unit [1]. About 50% of NICU infants are born prematurely, i.e., delivery occurring less than 37 weeks gestation, which may result in a variety of medical complications, however, some infants born full-term also may experience medical conditions requiring a NICU stay (e.g., gastroschesis, omphalocele, and seizures) [1]. Common NICU diagnoses include respiratory distress syndrome, chronic lung disease, congenital heart disease, necrotizing enterocolitis (NEC), periventricular leukomalacia (PVL), intraventricular hemorrhage (IVH), pulmonary hypoplasia (PHP), sepsis, transient tachypnea, and infections [1, 2]. Most NICU admissions are singleton births and about 15% are multiples [1]. The average length of stay for a NICU admission is two weeks, but admission stays range from several days to several months depending on the gestational age and medical complications of the infant [1, 3]. Parents typically describe the NICU experience as an emotional "roller coaster" because they experience a variety of emotions, including feeling overwhelmed, sad, stressed, tired, relieved, happy, angry, and helpless [4]. Because of the psychological toll that the NICU experience has on parents, it is essential to understand how infant medical issues during admission and post-discharge influence family outcomes. Given the complexity in co-morbid health conditions among infants, an examination of how NICU infant health is captured in psychosocial research and the implications for parental and child outcomes is warranted.

This paper first addresses variability in NICU infant health and gaps in the current literature. Next, the methods used to conduct this systematic review are described followed by the results of the review. Then, the results of the review are discussed as well as the research and clinical implications.

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Variability in infant health

Infants with a NICU hospitalization are a unique pediatric population with a wide range of medical complications, diagnoses, and developmental outcomes. This population includes infants with chronic medical issues and those without any long-term impairment. Efforts to understand the range of infant health issues are timely because advances in perinatal and neonatal care over the last 10–20 years have led to increased rates of survival among infants born at earlier gestational ages and among infants with severe medical complications [5]. However, infants born at earlier gestational age are at increased risk for recurrent hospitalizations, complex medical conditions, and neurodevelopmental impairments [6]. Infants with more medical issues and developmental delays require increased time, attention, and resources from parents which may contribute to higher levels of parental stress and family burden [7]. In fact, infant health severity accounts for a significant portion of variance in family psychological adjustment [8]. As a result, infant medical complications during and after NICU hospitalization are key variables to examine familial adjustment. Improved understanding of how infant medical issues influence infant development, parental mental health, parent–child interactions, and couple and family functioning is needed to identify families and children who require additional support or services during and following NICU hospitalization.

Gaps in current literature

Understanding how infant health severity has been measured in the psychosocial literature is important because infant medical issues greatly impact child development and family outcomes. It is essential to be aware of relevant and validated scoring assessments and the limitations of these assessments. This information may shed light about relationships between infant severity and psychosocial outcomes (e.g., parental stress, mental health, parent–infant attachment, family functioning) and implications for future research and clinical interventions. Although it is clear that more severe medical complications negatively impact parental stress and family burden [7], the impact of specific medical indices of the child (e.g., birth weight, gestational age, medical devices, diagnoses, medical specialists) on infant, parental, and family outcomes remain unclear and warrant attention.

There are several issues that have likely contributed to this gap in the literature. First, the developmental trajectory of NICU infants can change drastically based on physical, developmental, psychological and social factors, suggesting that the change in medical status over time is important to consider. However, there is no gold standard measure to capture NICU infant health severity across time. The majority of scoring assessments measure infant health status only during the first few days following birth rather than infants' longer term medical trajectory (e.g., Score for Neonatal Acute Physiology (SNAP); Clinical Risk Index for Babies (CRIB)). Further, given the diversity of infant health diagnoses, it is difficult to determine an aggregate scoring system to effectively assess the full range of medical complications. In fact, there is great variation among scoring systems for infant health/medical severity. For example, some psychological researchers measure infant health severity with a single index such as gestational age or birth weight [9–11], whereas others ask parents to report severity of infant health on subjective rating scales (e.g., how would you rate your infant's medical severity) [12–15]. Research focused on family emotional responses can be enhanced by collaboration with medical professionals. The current validated assessments for infant medical issues typically require indices of infant health that medical staff or charts report (e.g., blood pH, temperature, blood pressure, respiratory rate, oxygenation index, PaO_2). Inclusion of medical information about a child who has spent time in the NICU provides a more comprehensive picture of which factors contribute to infant development and psychosocial outcomes than parental self-report alone.

Because NICU infants are a heterogeneous group presenting with a wide range of diagnoses and co-morbid functional impairments, there is relatively limited research about medical fragility at various stages of NICU hospitalization and discharge that may affect later parent–infant relationships and the child's development [16]. A better understanding of family adjustment to these medical stressors could positively impact infant development and lead to more effective family interventions. The current review highlights and summarizes what has been reported in the literature regarding how NICU infant health severity is captured and related to infant development, as well as parent and family psychological and social adjustment. The current review examined how infant health severity is assessed in extant research; how infant health severity is related to parent, family, and child psychosocial outcomes; and implications of these methods and findings for researchers and clinicians.

Methods of current review

A systematic review was conducted following PRISMA guidelines utilizing PubMED, PsycINFO, and Google Scholar. The following key words were searched in each database: "NICU infant," "NICU illness severity," "NICU scoring system," "NICU developmental outcomes," "parent adjustment to NICU," "NICU parent outcomes," "NICU family." This review sought to identify empirical investigations that included any assessment of NICU infant health

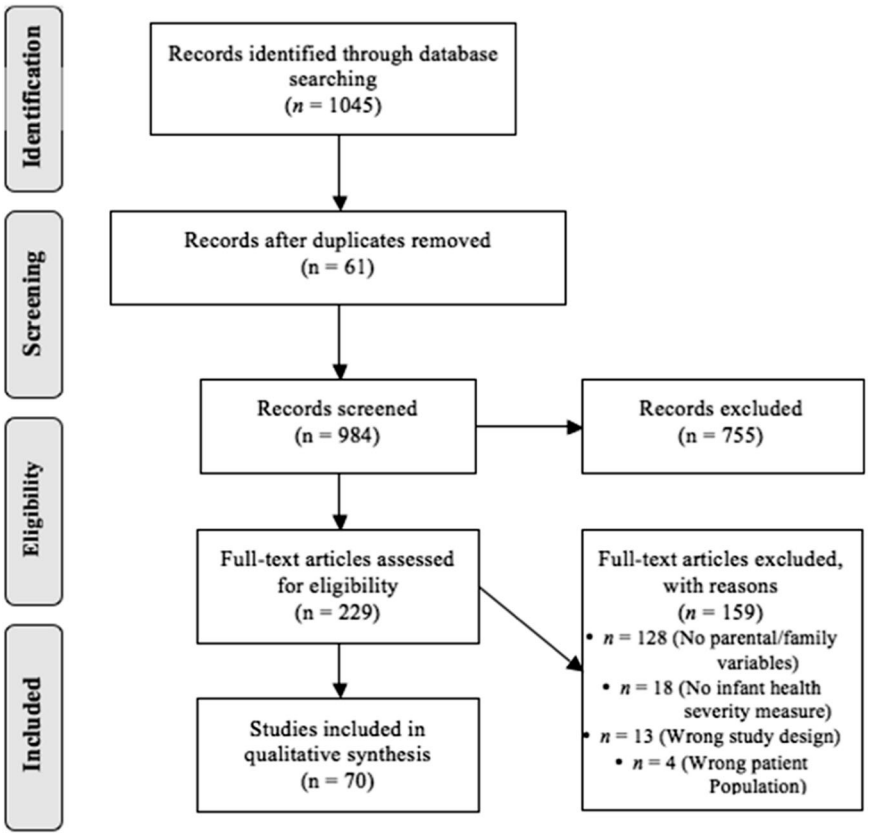

Fig. 1 PRISMA flow diagram

severity and infant, parental, or family psychosocial outcomes.

The literature searches identified 1045 articles. These articles were independently reviewed by two authors (VG and AB). Papers were excluded based on the following criteria: (1) the study focused on a population other than infants admitted to a NICU; (2) the topic did not address psychosocial issues; (3) the primary purpose of the paper was to report on measured development without including a discussion of outcomes; (4) only qualitative data were presented; or (5) assessment of parental or family psychosocial factors or measurement of infant health severity (i.e., birth weight) was not included. The independent reviewers were in complete agreement that: 61 articles were duplicates and 913 met exclusion criteria. Therefore, 70 studies were identified as relevant and included in the current review (see Fig.1).

Results of review

Infant health assessments

The 70 empirical research studies, identified separately by two authors, utilized an index of infant health severity in the context of family psychosocial adjustment. The assessments utilized for infant health severity as well as the main findings in these studies were examined and are displayed in Tables 1-7. The most common assessments are reported below.

Gestational age and birth weight

Infant birth weight and gestational age are included in every article examined in the current review; ten articles included these indices as the only measures of infant health (see Table 1). Gestational age and birth weight are accessible and easy to include because parents can report them. Researchers use infant birth weight and/or gestational age in several ways, as: inclusion criteria, a control variable, or a predictor of outcomes. These indices are essential to include given the impact that low birth weight and earlier gestational age have on neurological development and family adjustment [9, 12, 17]. Although birth weight and gestational age are known risk factors for impaired neurological development, other factors (e.g., parental interactions with infants) also affect development [8].

Nursery neurobiologic risk score (NBRS)

The NBRS [18] was utilized in eight of the articles reviewed (see Table 2). The NBRS requires information from a medical chart and/or medical team. It was developed as a predictor of neurodevelopmental issues in very low birth

Table 1 Gestational age and birth weight

Citation	Sample	Main findings	Infant health assessment
Bacharach and Baumeister [11]	453 Premature LBW children	•Maternal IQ influenced infant cognitive outcomes. •Income and home environment mediated maternal IQ and child cognition	Children were preterm (37 weeks gestational age or less), LBW (2500 g or less).
Beckwith et al. [55]	51 mothers and their preterm infants	•Maternal responsiveness to infant vocalization and infant irritability predictors of infant competence •Children born at higher birth weights and longer gestations more irritable than those born VLBW	•Gestational age of less than 36 weeks •Birth weights of less than 2500 g
Carter et al. [65]	447 NICU parents 189 parents with term infant not requiring NICU admission	•NICU parent depression and anxiety evident after infant's birth, but not at 9 months •Higher parent depression/anxiety severity and perceived quality of the couple relationship associated with improvement in symptoms	Gestation categorized into four groups; •NICU <33 weeks •NICU 33–35 weeks •NICU 36–42 weeks •Control 36–42 weeks
Cronin et al. [10]	Parents of 96 VLBWIs compared with parents of full-term matched controls	Parents of VLBWIs experienced more family impact when: •Children with functional handicap or low adaptive developmental quotient [66–81]	•Birth weight
Davis et al. [82]	62 mothers of singleton very preterm infants (<32 weeks) without congenital anomalies	High maternal depression associated with: •Lower levels of maternal education •Decreased perception of support from nursing staff	•Birth weight (grams) •Gestational age (weeks)
Gray et al. [83]	124 mothers of infants at ≤30 weeks gestation 120 mothers of term infants	•Maternal stress higher in preterm mothers than term •17% of the preterm and 9% of the term group high scores •No differences of the depression and dyadic adjustment between groups	•Preterm infants at 24–30 weeks' gestation: Singleton or twin (if both alive) No major congenital anomalies
Korja et al. [84]	125 mothers of very preterm infants	•Depression in mothers of very preterm infants was 12.6% •Number of postnatal signs of depression negatively associated with maternal interaction behavior	Very preterm infants (birth weight ≤1500 g or <32 gestation)
Magill-Evans et al. [9]	44 healthy preterm 49 full-term children	Child cognitive/motor scores explained by: •Preterm or full-term birth •Infant sex •Parental age	•Preterm or full-term birth •Infant sex
McManus et al. [84]	130 infants hospitalized in one of three neonatal intensive care units in 2002–2005	•Maternal clinically depressive symptoms at 9 months post-term associated with child lower cognitive functioning at 16 months when mothers reported low social support	•Birth weight dichotomized into low birth weight (<1500 g) or not •Gestational age (weeks)
Treyvaud et al. [67]	152 very preterm children (<30 weeks' gestation or<1250 g birth weight) and parents/guardians	Greater parent–child synchrony was associated with: •Greater social-emotional competence •Parenting that was positive, warm, and sensitive	Very preterm children (<30 weeks' gestation or <1250 g birth weight)

Table 2 Nursery neurobiologic risk score (NBRS)

Citation	Sample	Main findings	Infant health assessment
Brisch et al. [60]	79 high-risk sample of very low-birthweight preterms (≤1500 g)	•Quality of attachment in preterm infants was comparable with results of studies of term infants •Neurologically impaired infants were more often insecurely	Revised nursery neurobiologic score (NBRS)
Feeley et al. [61]	72 mother and very low birth weight (VLBW) infant dyads	More sensitive and responsive interactions by mothers associated with: •Higher maternal education •Less maternal anxious at 3 months •Higher perceived support at 3 months	Revised nursery neurobiologic score (NBRS)
Feldman et al. [68]	120 singleton premature infants	Child cognitive outcomes at 2 years predicted by: •Small-for-gestational-age status •Interaction of actual birth weight and small-for-gestational-age status •Maternal intrusive behavior	Revised nursery neurobiologic score (NBRS)
Holditch-Davis et al. [4]	177 African-American mothers	Highest stress group associated with: •More ill infants •Lower maternal education •More worry about the child	Nursery neurobiologic risk scale (NBRS)
Milgrom et al. [52]	40 depressed inpatients and 48 control (non-depressed) mothers and their infants	•Infant cognitive outcomes explained by lowered maternal responsiveness at 6 months •Increased temperamental difficulties in children of depressed mothers •Male infants of depressed mothers more vulnerable to impaired cognitive abilities associated with maternal depression	Neurobiologic risk scale (NBRS)
Thompson, Jr et al. [53]	55 very low birth weight infants (≤1500 g)	•Movement from low to poor neurobiologic risk status status at 4 years of age associated with maternal education and early levels of maternal daily stress	Neurobiologic risk score
Zelkowitz et al. [50]	56 mothers and VLBW infants	•Maternal anxiety not related to severity of neonatal illness •Maternal anxiety in NICU associated with less sensitivity and structure in interaction with toddlers at 24 months corrected age, controlling for maternal education and child birth weight	Revised nursery neurobiological risk score (NBRS)
Zelkowitz et al. [57]	88 mothers and VLBW infants 57 were followed at 24 months corrected age	•Maternal anxiety in NICU independent predictor of child cognitive development and internalizing behavior problems, controlling for maternal education and neonatal morbidity	Revised nursery neurobiological score (NBRS)

weight infants and a revised NBRS version was adapted to include seven factors [19]: blood pH, hypoglycemia, intraventricular hemorrhage, periventricular leukomalacia, seizures, infection, and need for mechanical ventilation [20]. Scores greater than 5 are associated with developmental impairments at 24 months corrected age [20]. Research indicates that 80% of 77 infants (12 months of age) with a score of 8 or higher had significant disability [19].

Perinatal risk inventory (PERI)

The PERI [21] was utilized in four of the reviewed articles (see Table 3). The PERI is an 18-item inventory that requires information from a medical professional. It includes characteristics such as Apgar scores, gestational age and appropriateness of the weight of the infant, congenital infection, seizures, infant's health growth, nature of electroencephalogram, cranial computed tomographic and ultrasonography findings, sepsis and/or meningitis, duration of ventilation and polycythemia, hypoglycemia, hyperbilirubinemia, and long-term physical disabilities [21]. The items are scored from 0 to 3 using an ordinal scale and then totaled. Higher scores indicate greater neurological impairment. A score of 10 or higher on the PERI is considered at highest risk for neurological impairment (e.g., cerebral palsy) [21]. Moreover, Schemer and Sexton reported that PERI scores of 10 or higher explained 28% of the variance in infant's intelligence quotient (IQ) or developmental quotient (DQ) scores.

Clinical risk index for babies (CRIB)

One research study used the CRIB (see Table 4) [22]. The CRIB include items such as birth weight, gestational age, congenital malformation, maximum base deficit in first 12 h, sex, and FIO_2 in first 12 h. The information for the CRIB is reported by a medical professional or extracted from a medical chart. The CRIB scoring system weights each item based on their statistical relation to likelihood of death. CRIB has mixed results with regard to ability to predict death and/or neurological impairments in infants. Doering and colleagues stated that the CRIB did not predict severe disability at 12 or 24 months of age [20]. Lago and colleagues reported that birth weight alone was similar and gestational age alone was better at predicting neurodevelopmental outcomes for infants, compared to the CRIB [23]. However, studies with smaller sample sizes have suggested that the CRIB has good predictive validity [24].

Score for neonatal acute physiology (SNAP)

The SNAP (see Table 4) [25]. an alternative to the CRIB, was utilized in four studies. The SNAP is based on 28 items

Table 3 Perinatal risk inventory (PERI)

Citation	Sample	Main findings	Infant health assessment
Forcada-Guex et al. [69]	Mother–infant dyads with: 47 Preterm infants 25 term infants ($n = 25$)	Preterm infants of controlling pattern dyads display: •More behavioral symptoms •Worse personal-social development •Worse hearing-speech development	The Perinatal Risk Inventory (PERI)
Forcada-Guex et al. [54]	47 Preterm (GA < 34 weeks) 25 full-term infants	Preterm mothers with high posttraumatic stress symptoms more likely to engage in: •"Controlling" dyadic pattern of interaction	The Perinatal Risk Inventory (PERI)
Muller-Nix e al. [70]	202 Chinese childbearing couples	Mothers who reported less decline in family and marital functioning at 6 weeks postpartum included those with: •Stronger family sense of coherence •Greater social support •Less stress during pregnancy Fathers reported less decline in family and marital functioning when they reported higher prenatal family coherence	The Perinatal Risk Inventory (PERI)
Pierrehumbert et al. [17]	50 families with a premature infant (25–33 gestation weeks) 25 families with a full term infant	•Severity of the perinatal risks only partly predicts a child's problems •Intensity of the post-traumatic reactions of the parents is an important predictor of child problems	The Perinatal Risk Inventory (PERI)

Table 4 Clinical risk index for babies (CRIB) and score for neonatal acute physiology (SNAP)

Citation	Sample	Main findings	Infant health assessment
Feldman et al. [56]	23 sets of triplets were matched with 23 sets of twins and 23 singletons ($N = 138$)	Triplets, compared twins and singletons, experienced: •Lower maternal sensitivity across infancy •Poorer cognitive competencies Most medically compromised triplet associated with: •Lowest regulation Lower maternal sensitivity	Clinical Risk Index for Babies (CRIB) score
Als et al. [44]	92 preterm infants (<1250 g and 28 weeks)	Lowered family stress associated with: •Shorter duration of parenteral feeding •Transition to full oral feeding •Lower incidence of necrotizing enterocolitis •Reduced discharge ages and hospital charges	•Score for Neonatal Acute Physiology (SNAP) •Gestational age •Birth weight and head circumference •Apgar scores at 1 and 5 min •Mean levels of fractions of inspired oxygen (FIO2)
Brummelte et al. [32]	152 children (98 preterm born ≤ 32 weeks gestation and 54 full-term)	•Parenting stress higher in preterm than full-term children at 8 and 18 months •Controlling for neonatal risk, number of children in home, child interactive behavior and maternal education, decreasing child cognition scores from 8-18 months predicted higher parenting stress for preterm children	•Score for Neonatal Acute Physiology II (SNAP-II) •Birth weight •Gestational age •Days of mechanical ventilation •Daily dosage of intravenous (iv) morphine and other med •Skin breaking procedures
Mackley et al. [70]	35 fathers of infants born less than 30 weeks gestation and hospitalized in NICU	•Paternal stress scores unchanged over time •Depressive scores decreased over time •Objective measurement of infant illness did not influence paternal symptoms	Score for Neonatal Acute Physiology (SNAP)
Vinall et al. [71]	96 infants born very preterm (≤ 32 weeks gestational age) 49 full-term controls	Lower internalizing problems in preterm children (adjusting for neonatal medical issues, gender, and cognition) associated with: •Higher parent education •Lower parenting stress •Fewer children in the home	•Score for Neonatal Acute Physiology II (SNAP-II) •Gestational age and gender •Number skin-breaking procedures •Days of mechanical ventilation •Cumulative morphine exposure

Table 5 Study specific assessments developed by researchers

Citation	Sample	Main findings	Infant health assessment
DeMier et al. [59]	354 Medical records of preterm births	Postnatal emotional distress in high-risk mothers associated with: •Infant maturity •Apgar ratings •Postnatal complications	Postnatal complications rating from six perinatal stressors: •Gestational age and birth weight •Length of the baby's hospital stay in days •Apgar scores at 1 and 5 min
Howe et al. [47]	297 with preterm children (239 mothers, 58 fathers) 208 with full-term children (181 mothers, 27 fathers)	•Fathers, compared to mothers, of preterm infants reported higher stress scores •Mothers, compared to fathers, reported more health related difficulties, depression, social isolation and role restriction, and less support from spouses	The Neonatal Medical Index (NMI)
Lefkowitz et al. [26]	86 Mothers and 41 fathers of NICU infants	•35% of mothers and 24% of fathers met ASD diagnostic criteria at T1 15% of mothers and 8% of fathers met PTSD diagnostic criteria at T2	6-item rating scale of infant physiological risk and intensity of medical intervention was developed
Litt et al. [31]	Parents of 51 infants < 32 weeks' gestation	Child adverse outcomes at 44 weeks postnatal associated with: •Poorer transition home •Feeding problems •Special health care needs Child adverse outcomes at 6 months correct age associated with: •Feeding problems •Maternal depression	Emailed questionnaires developed for study after NICU discharge to families
Miceli et al. [27]	30 Infants and their mothers in Level III NICU	•Medical complications mediated birth status-outcome relationship at 4 and 13 months, but not at 36 months •36-month outcomes predicted by 4-month maternal distress and social support	Infant's birth status formed •Birth weight and gestational age Medical complications composite included: •5-min Apgar score •Number of days the received ventilator support and oxygen •Number of days infant on intravenous and gavage feedings
Miles et al. [72]	31 Black and 38 White mothers of infants hospitalized for a serious life-threatening illness	•All mothers reported high levels of stress with the appearance of their infants •All mothers reported moderately high stress with their altered parental role and infants' health problems	•Parental Perception of Severity Scale (i.e., rate perception of severity of infant's illness) •Child Health Worry Scale (i.e., parents' degree of worry about aspects of the child's health)
Moore et al. [28]	88 Preterm children with intraventricular hemorrhage	•Higher rates of responsiveness on all measures were associated with favorable developmental outcomes •Greater amounts of directiveness related to less favorable outcomes	Medical Problems Index (MPI) assigned1 point each for the presence of: •Bronchopulmonary dysplasia •Respirator distress •Retinopathy of prematurity •Apnea, Seizure
Poehlmann et al. [30]	42 Preterm, low birth weight infants and 42 full-term infants at 12 months post-term	Preterm birth moderated the relation between maternal depression and quality of infant-mother attachment, even controlling for neonatal health complications	Health complications composite from: •Gestational age •Birth weight and length, head circumference

Table 5 (continued)

Citation	Sample	Main findings	Infant health assessment
			•Hospitalized (days), intubated (days) •1-min and 5-min Apgar
Taylor et al. [43]	Families of 60 children with birth weights less than 750 g Families of 55 with birth weights between 750 and 1499 g Families of 49 normal birth weight full-term controls	•Families with children with birth weights less than 750 g reported greater stress than families of controls •Higher neonatal medical risk predicted more negative impact on the family, but only in advantaged families	Neonatal Risk Index
Treyvaud et al. [7]	184 very preterm children and parents 71 term children and parents	•Families with very preterm children reported poorer family functioning compared with families with term children •Parental mental health problems were associated with higher parenting stress •Parents of children with a neurodevelopmental disability report higher burden	General Health Questionnaire
Zerach et al. [15]	78 Israeli mothers of extremely premature infants (24–27 weeks) born 4–16 years earlier	•Mothers of ELBW children with normal development reported lower stress compared with mothers of ELBW children with developmental difficulties •25.6% of mothers had PTSD following the birth of an ELBW child	Questionnaire constructed for ELBW children: •Gestational age and birth weight •Medical condition

in the first 24 h of life and is weighted based on expert opinion rather than statistics [20]. It requires information from a medical professional and/or medical chart. There are several versions of the SNAP and a few items include birth weight, Apgar score, mean blood pressure, lowest temperature, and seizures. The SNAP predicted infants with poorer motor and psychomotor development [20]; however, it requires a high number of complex indices.

Study specific assessments

Other researchers created their own assessment tools and/or utilized specific individual or multiple indices (e.g., diagnosis, medical devices, length of stay) of infant health beyond gestational age and birth weight. These indices ranged in terms of whether they required information from medical charts, staff, or parents. In this review, 18 of the studies included assessments of infant health severity developed by researchers for their studies (see Table 5). The assessments included a combination of indices and typically utilized: gestational age, birth weight, length of time in the NICU, Apgar scores, medical technology, specific chronic diagnoses (e.g., bronchopulmonary dysplasia, chronic lung disease), and/or neurological injuries (i.e., seizures) [12, 13, 26–28]. In seven of the 18 studies, researchers created categories of high and low risk groups of infants (see Table 6). Researchers operationalized high and low risk differently, but examples of high risk infants included those diagnosed with bronchopulmonary dysplasia (or a chronic illness throughout first year of life) and/or very low birth weight (<1500 g at birth), and those who required supplementary oxygen for more than 28 days (or being dependent on medical technology), and/or radiographic evidence of chronic lung disease [12–14, 16, 29]. In four of the 18 studies, researchers assigned one point for each health issue (e.g., presence of broncopulmonary dysplasia, respiratory distress, retinopathy of prematurity, apnea, or seizure) to create a severity rating [28, 30]. These aggregate scores were created without regard for variability in severity of each health issue (i.e., each issue equally weighted). Three of research teams developed their own study measures and scoring systems that were not validated [7, 15, 31].

Twenty-four of the studies in this review used specific indices (e.g., diagnosis, medical devices, rehospitalizations) to define infant health severity (see Table 7). These researchers did not create an overall index score, but used the indices as individual variables. Given the variability among diagnoses, medical devices, and time spent in the NICU, it is reasonable to keep these indices separate and not assume that more time, devices, or diagnoses is necessarily associated with increasing health impairment. These researchers included indices such as: infant sex, gestational age, length of stay, technology dependence (e.g., extracorporeal membrane oxygenation), severe central nervous system injury, congenital or

Table 6 High and/or low risk groups

Citation	Sample	Main findings	Infant health assessment
Baron et al. [29]	470 Participants born in 2004–2008	•Gestational age most important predictor of infant cognitive outcomes •No differences were found between groups	Late preterm infants assigned to groups: •NICU-admitted "complicated" LPT •Well-baby unit-admitted "uncomplicated" LPT
Doucette et al. [42]	71 Couples, 18 to 24 months following the birth of infant	•Family adjustment improved over time for mothers but decreased for fathers •Fathers of infants with health problems reported poorer family adjustment •Family resources related to family adjustment	Infants' health status rated by parents as either: •"Mostly healthy" •"Very healthy"
Holditch-Davis et al. [16]	41 Medically fragile premature 20 Medically fragile full-terms 28 Premature infants without chronic illnesses	Compared to mothers of medically fragile children, mothers of non-chronically ill premature infants: •Gestured to and touched their infants less •Uninvolved with them for a longer time •Spent less time interacting and looking at their infants	Infants were classified as medically fragile: •Diagnosed with a medical illness that created extended hospitalization •Dependent on medical technology •Chronic illness throughout first year of life
Singer et al. [14]	122 VLBW high-risk infants and mothers 84 VLBW low-risk infants and mothers	•Mothers of VLBW infants reported more distress at 1 month and stress at 3 years •Severity of maternal depression related to lower child developmental outcomes in both VLBW groups	•High-risk included VLBW infants with bronchopulmonary dysplasia •Low-risk included VLBW infants without bronchopulmonary dysplasia •Term infants (>36 weeks, >2500 g)
Singer et al. [29]	103 High-risk VLBW with BPD 68 Low-risk VLBW without BPD dysplasia 117 Healthy term infants	•VLBW infants displayed fewer responsive, clear interactions, with differences from term infants increasing over time •Maternal distress related to less cognitive growth fostering for all mothers	High-risk VLBW infants included: •Bronchopulmonary dysplasia •Weight < 1500 g at birth •Supplementary oxygen for more than 28 days •Chronic lung disease
Singer et al. [13]	315 Mother-infant dyads	Mothers of high-risk VLBW children reported more: •Personal stress and family stress under conditions of low social support •Child-related stress •Parenting satisfaction at 14 years	High risk children with VLBW (HR-VLBW) had: •Diagnosis of BPD •Birth weight less than 1500 g •Supplementary oxygen more than 28 days •Chronic lung disease
Smith et al. [73]	212 High-risk (HR) and low-risk (LR) preterm infants 128 Full-term infants	•Higher levels of maternal attention positively related to infant development •Attention-maintaining related to expressive language skills for HR infants •Attention-maintaining related to cognitive and language skills for all groups	•Infants divided into medically High Risk and Low Risk groups •VLBW infants included if weighed ^ 1600 g and had a gestational age ^36 weeks at birth

Table 7 Study specific assessments (i.e., Individual or multiple indices of infant health)

Citation	Main findings	Infant health assessment
Auslander et al. [49]	Maternal anxiety influenced by: •Infant's weight, and central nervous system complications •Informational support, warm, caring attitude by hospital staff Paternal anxiety influenced by: Age, infant gender, availability of child support	•Gestational age and birth weight •Need for breathing assistance during the NICU •Central nervous system complications •Child gender
Balakrishnan et al. [2]	Greater family impact associated with: •Neonatal medical risk factors •Longer hospitalization, lower gestational age •Lower social support, less family resources	•Gestational age and birth weight •Length of hospitalization •Days on supplemental oxygen or ventilator •Discharge on oxygen, cardiorespiratory monitor •Singleton or multiple birth •Rates of morbidities
Busse et al. [74]	•Parent stress in NICU (PSS: NICU) correlated with anxiety, depression, and sleep disturbance •Sights and sounds not correlated with parents' outcomes •Alteration in parenting role correlated with outcomes •Infant appearance correlated with all except fatigue	Parents reported of: •Infant's birth and health status
Cusson et al. [33]	•By 26 months corrected age, infant development was within the normal range •Language influenced by LOS, birth weight, Apgar scores, infant irritability, and maternal sensitivity	•Length of hospital stay, birth weight, Apgar scores •Infant irritability and state regulation at hospital discharge
Dudek-Shriber et al. [34]	Highest levels of stress experienced by parents were: •Baby-parental role and how baby looked and behaved Parental stress predicted by child: •Length of stay, extreme prematurity, cardiovascular diagnosis	•Gestational age •Birth weight •Diagnosis •Length of stay
Feldman et al. [75]	•Cognitive development showed a substantial growth-spurt between 2 and 5 years •Social engagement increased rapidly across the first year and more gradually thereafter •Maternal depressive symptoms interfered with growth from 2-5	•Healthy low-risk premature infants •No neurological or genetic conditions
Gangi et al. [35]	•Alteration of parental role and history of anxiety influenced PTSD in preterm parents •Familiarization with NICU environment and increasing participation of parents in care during the first weeks of life improves parental role perception	Neonatal characteristics collected by a medical researcher
Gray et al. [76]	•No group difference on depression or temperament •Disability greater in the preterm infants Among preterm mothers, maternal stress predicted by: •Maternal depression, infant temperament	Infant diagnoses by pediatricians with neurological assessment
Holditch-Davis et al. [36]	•First-time mothers and mothers of singletons provided more developmental stimulation to infants •Less maternal education and shorter period of mechanical ventilation associated with greater developmental maturity •Greater maternal worry was related to more child irritability	•Child sex •Multiple •Birth weight •Days of mechanical ventilation
Hughes et al. [48]	•Differences between mothers and fathers in the number and types of stressors •Both mothers and fathers chose stressors related to the infant's health and the physical separation due to the hospitalization as most stressful	Parents qualitatively reported stressors related to NICU, including: •Child's procedures, hospital course •Medical complications
Huhtala et al. [78]	•Parental symptoms of depression, parenting stress, and sense of coherence associated with more behavioral problems of the VLBW infants	•Birth weight and gestational age •Days in hospital •Multiple birth, infant sex •Presence of neurodevelopmental impairment
Kersting et al. [37]	•At all timepoints (except 6 months), mothers of the premature infants reported higher trauma, depression, anxiety •Mothers of the premature infants displayed no significant reduction in posttraumatic symptoms, even 14 months	•Gestational weeks, birth weight •Respiratory support, continuous positive airway pressure (CPAP) •Respiratory distress syndrome, cerebral hemorrhage, sepsis

Table 7 (continued)

Citation	Main findings	Infant health assessment
Landry et al. [58]	LBW children social competence associated with: Medical complications Children's cognitive status Mothers' interactive behaviors	LBW children with histories of: •Intraventricular hemorrhage (IVH) •Respiratory distress syndrome (RDS) •Bronchopulmonary dys plasia (BPD)
Lee et al. [38]	Families with developmentally normal VLBW infants perceived more positive family impact For the VLBW, parental attitudes toward saving VLBW infants related to family impact	•Child sex, gestational age, birth weight, medical problems
Lee et al. [78]	Neither number of technologies nor birthweight related to maternal perceptions of paternal support	•Technology Dependence Scale •Birth weight
Lee et al. [39]	Less maternal positive involvement at 6 months, but greater involvement at 12 months associated with: •More infant technological dependence, lower birth weights Higher paternal helpfulness facilitated positive involvement in mothers with low depressive symptoms	•Technology dependence. •Birth weight
Miles et al. [79]	•Alterations in the parental role stressful for both mothers and fathers •Mothers reported greater stress in this parental role than fathers	•Birth weight •Diagnosis
Miles et al. [40]	More maternal depressive symptoms in first year associated more likely to be: •Unmarried mothers •Mothers of infants who were rehospitalized •Mothers who reported more maternal role alteration stress and worry about the child's health	•Birth weight •Days on mechanical ventilation •Multiple birth •Rehospitalization (maternal report)
Montirosso et al. [80]	Maternal depressive symptoms and higher infant dysregulation predicted more internalizing problems at 18 months	•Gestational age, birth weight, length of stay •Vermont Oxford Network Risk Adjustment index
Mulder et al. [81]	•In mothers, relationship between psychological distress and the child's mental development (most significant in infants with severe developmental delay)	•Gestational age, birth weight •Singleton/twin/triplet •Diagnosis
Singer et al. [14]	More depressed mothers reported: •Family functioning to be further from the ideal, lower levels of partner support	•Medical issues gathered, but no index of medical risk calculated
Poehlmann et al. [41]	•Quality of parent-infant interaction mediated neonatal risk and cognitive development	Level of neonatal risk coded based on: •Birth weight, Apgar scores, length of hospitalization, intubation •Presence of respiratory complications
Treyvaud et al. [8]	•Home environment had less effect on dysregulation for children	•Length of hospital stay
Veddovi et al. [85]	Better infant development, maternal adjustment, and mother-child relationship associated with maternal: •Positive reappraisal •Planful coping style •More knowledge of child development	Infants met following criteria: •Gestation of 28–34 weeks •Apgar score of 4 or greater at 1 or 5 min

chromosome abnormalities, specific diagnoses (e.g., pulmonary hypoplasia (PHP), necrotizing enterocolitis (NEC)), or Apgar scores [2, 30, 32–41].

Infant health and psychosocial findings

Various attempts to capture infant health severity were found within literature presented in this review, suggesting that this is an important construct to identify and measure. Understanding whether, and to what extent, infant health severity influences family dynamics, parental psychosocial adjustment, and infant development highlights the need to include this construct in research and clinical settings. These findings would assist in identifying families who would benefit from additional support and accommodations during and following NICU hospitalization.

Family impact

Infant health severity and ongoing medical complications greatly impact the family. Family impact was most often defined with the Impact on Family Scale, Revised which conceptualizes it as the perceived burden the child on the family (e.g., My child's illness is a strain on our family). An

aspect of the parent-child relationship, couple, or family functioning was assessed in 21 of the studies. Parents of infants with lower birth weights and increased medical complications report greater family impact [2, 7, 10, 42, 43]. Parents of very low birth weight (VLBW) with a neurodevelopmental impairment, functional disability, or low developmental quotient reported more family impact than developmentally normal VLBW infants [7, 10, 38]. Lower gestational ages, longer hospitalizations, more days on ventilator or oxygen, higher incidence of necrotizing enterocolitis, and longer duration of parenteral feeding were associated with increased impact on families [2, 44]. Overall, families of infants with more medical issues and greater functional impairments report greater family impact.

Family impact also varies as a function of family resources (e.g., money, access to basic needs). Families with less resources report greater stress and family burden [2, 42]. Caring for a medically complex infant adds an extra burden to already stressed parents. Parents must learn to manage their child's health issues, the cost of care, and medical appointments, in addition to their existing parenting responsibilities. Siblings in the home, higher hospital fees, and increased need for support from the medical team are all associated with increased family stress [2, 44]. Interestingly, Taylor and colleagues reported that although decreased family resources is a risk factor for greater family burden, higher neonatal medical risk did not predict a more negative impact on the family among disadvantaged families compared to more advantaged families [43]. Further, high infant health issues predicted a more negative impact only among advantaged families [43]. Although families with fewer resources report a higher level of family burden, infant medical issues may play a larger role among families with more resources. Not surprisingly, mothers of preterm infants with greater social support, greater sense of family cohesiveness, and less stress reported less decline in family and marital functioning at 6 weeks postpartum [45]. Fathers of preterm infants with higher prenatal family sense of cohesiveness and family and marital functioning also reported better family and marital functioning at 6 weeks postpartum [45]. Increased infant responsiveness is associated with better cohesion and adaptability for the family [46]. Findings highlight how neurobiological, health, psychological, and social variables all play a role in family functioning.

Parental adjustment

Twenty-nine of the studies assessed parental mental health or parenting stress. Overall, parents of infants with lower gestational ages and birth weights reported increased stress, especially within the first three years following discharge, compared to parents of term and normal birth weight infants [14, 32, 47]. Mothers of premature infants reported higher levels of traumatic, depressive, and anxiety symptoms compared with controls [37]. Additional medical complications of a preterm child also influence parental functioning. When parents were asked to identify a primary stressor, a majority chose their infants' health and physical separation due to hospitalization [48]. Central nervous system complications and infant weight have been associated with maternal anxiety whereas perception of the infant as problematic and infant biological sex impacted paternal anxiety levels [49]. Mothers of extremely low birth weight (ELBW) children with developmental impairments report greater perceived stress compared to mothers of ELBW children with typical development [15]. Longer length of stay in the NICU, extreme prematurity, and a cardiovascular diagnosis were consistent predictors of parenting stress [34]. Surprisingly, one study reported that maternal anxiety was not associated with infant severity of illness [50]. These results suggest that infant medical issues and development explain some portion of the variability in mental health outcomes among NICU parents.

Infant health also has important implications for parental interactions with the infant. Mothers of preterm infants and/or more neurologically impaired infants tend to engage in more intrusive behaviors and report more worries related to their child [51–53, 64]. Preterm mothers with high posttraumatic stress symptoms were more likely to engage in a "controlling" dyadic pattern of interaction [54]. Mothers of medically fragile premature infants spent more time interacting, touching, and looking at their infants compared to mothers of non-chronically ill premature infants [16]. Mothers with higher levels of depressive symptoms who had a preterm infant demonstrated a poorer quality of attachment with their infant, controlling for level of neonatal health complications [30]. Findings suggest that the infant gestational age, birth weight, neurological impairment as well as maternal mental health play a critical role in maternal-infant attachment. Notably, 14 attachment studies included in this review exclusively examined maternal-infant attachment and three studies included parental-infant interactions.

Infant development

Medical issues resulting in a NICU admission influence child development. Twenty-one of the studies included in this review assessed infant cognitive, behavioral, or socio-emotional outcomes. Gestational age, birth weight, length of hospitalization, and Apgar score all have been associated with infant cognitive outcomes, irritability, and language development [29, 33, 55]. However, there are several other important factors to consider including socio-demographic variables, parental mental health, and parent–infant

interactions. With regard to socio-demographics, male infants are at increased risk for developmental impairment. Preterm birth, infant sex, and parental age accounted for 30–32% of the variance in infant cognitive and motor scores [9]. Further, triplets are at increased risk for negative cognitive outcomes, compared to twins and singletons [56]. Maternal IQ directly has been associated with infant cognitive outcomes and income and the home environment also mediated the relationship [11].

Parental mental health is another key variable that may have an influence on a NICU infant's development. Zelkowitz and colleagues reported that when controlling for neonatal morbidity and maternal education, maternal anxiety was associated with adverse cognitive development and an increase in internalizing behaviors among children [50, 57]. Maternal depression and worry also have been associated with poorer developmental outcomes and increased irritability in premature infants [14, 36]. Additionally, medical complications, child's cognitive status, and mothers' interactive behaviors are significantly associated with low birth weight and children's social competence [58].

Parent–infant attachment is critical for a child's development. Poehlmann and colleagues reported that the quality of parent-infant interaction mediated the relation between neonatal risk and cognitive development [30]. Decreased maternal responsiveness to infant vocalization and irritability as well as controlling patterns of attachment were associated with later infant behavioral problems (i.e., eating problems) and social competence [54, 55]. Various combinations of birth status, medical issues, and parent–child relationships, explain about a third of the variance in the development of very low birth weight infants at 1–2 years of age [59]. Findings highlight the powerful role of parent-child interactions, suggesting that the combination of medical complications, parent reactions to stress, and parent–child synchrony are significant for explaining an infant's cognitive and socio-emotional development.

Discussion

The current review examined how infant health severity is assessed in the literature and reviewed relevant findings regarding associations between infant health severity and psychosocial outcomes. Seventy articles were identified that include an index of infant health severity and relationship to psychological and social outcomes. Some researchers utilize validated measures of infant health [44, 60, 61], whereas others did not [29, 33, 49]. Studies included in this review utilized assessments such as the Nursery Neurobiologic Risk Score (NBRS), Perinatal Risk Inventory (PERI), specific indices of infant health severity (i.e., gestational age, birth weight, length of time in NICU, Apgar scores, medical devices), and/or created a new measure specific to their study. Within this literature, the researchers who created their own scoring systems is concerning given that these scoring systems were not validated and not comparable to existing measures. Finally, infant health can vary over time and these assessments typically captured infant's health at one point in time. This gap could be addressed by combining infant medical severity at discharge with information from follow-up clinics that utilize developmental assessments (cognitive, social-emotional, motor). For example, the NBRS as neurological status at discharge and information about developmental milestones from Neonatal Follow-Up Clinics could be correlated to determine whether these cognitive, motor, and language assessments can be used to track child health status over time. The variability in the measures utilized for assessing infant health limits generalizability and eliminates the possibility of making comparisons across different studies. Barriers for measuring NICU infant health severity the complex nature of NICU infant health given diverse disorders, the changes in infant health over time, and confounding variables such as experience with the medical team, access to resources, and family psychosocial functioning.

Results of the review indicate that infant health severity has important implications for infant and family outcomes. Parents of infants with lower birth weights and increased medical complications report greater family impact [2, 7, 10, 42, 43]. Lower birth weights and increased functional and/or neurological impairments are associated with increased parenting stress and more intrusive parenting styles [15, 51–53]. Infant health severity (e.g., gestational age, birth weight, length of hospitalization), parental depression, anxiety, posttraumatic stress disorder (PTSD), and parent-infant interaction impact an infant's cognitive and socio-emotional development [14, 29, 33, 36]. It is important to note that factors such as education, income, parental mental health, social support, and parent-child interaction also play important roles.

Research and clinical implications

The NBRS assessment holds the most promise as an assessment tool given its predictive validity and feasibility. The PERI also was effective at capturing an infant's medical issues; however, it is slightly more intensive and may result in greater participant burden. Both of these assessments require information from the medical chart and/or assistance from a medical professional, which can be a challenge across settings as this information may not be readily available. A more accessible and valid tool that utilizes parental self-report while also capturing the infant health severity across time may be especially useful for

researchers. An assessment that includes parental report would allow for the tool to be more accessible to researchers and more easily disseminated across multi-site studies. Parental report does not require that infants be at specific institutions and would allow for Internet-based studies to capture infant health severity across more diverse samples of infants from a variety of locations. Further, developing a composite score that correlates with NBRS, PERI, and infant neurological outcomes would ensure the tool's validity. It is clear that infant health severity, parent mental health, family resources, parent-infant interactions all influence outcomes, but more research is needed to understand the relative impact of each of these factors and how the medical experience, support from medical staff, and access to care may contribute.

Clinically, the results suggest that the NICU experience and subsequent stressors are crucial elements that influence future family adjustment. Given the fact that both medical issues and psychosocial functioning affect outcomes, it seems optimal for physicians, nurses, psychologists, social workers, and other health care providers to work together in a collaborative care model within the NICU. The growing inclusion of psychologists and other dedicated mental health providers integrated in the NICU is a recent development and these results highlight the critical role of psychological support [62]. While parents are always important to consider in pediatric populations, parents are essential for a child's prognosis within the NICU population. Psychological support in the NICU setting should be provided routinely for parents, along with continued monitoring following discharge [62, 63]. Integrating mental health services for parents in the NICU, as well as screening measures and the provision of resources following discharge, are pertinent to ensure optimal development for NICU children.

Conclusion

The NICU journey is a stressful experience for families, and infant medical issues are important to understand and predict parental and family adjustment. Current assessment tools addressing infant health severity are varied and generally include information that only medical staff can report. Preterm birth, medical issues, infant sex, family education and income, parent mental health, and parent–child interactions may explain the variability in psychosocial outcomes. Additional work is needed to develop an infant health severity measure that is feasible, valid, and easily disseminated. Researchers should identify and quantify the dynamic relationship among infant health and parental functioning. A multidisciplinary collaborative care model that includes a professional psychological support is recommended within the NICU given the contribution of medical, neurological, psychological, and social variables that impact parent and infant outcomes.

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Compliance with ethical standards

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

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