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Effectiveness and family experiences of interventions promoting partnerships between families and pediatric and neonatal intensive care units: a mixed methods systematic review

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ABSTRACT

Objective: The objective of this mixed methods review was to examine the effectiveness and family experiences of interventions promoting partnerships between families and the multidisciplinary health care team in pediatric and neonatal intensive care units.

Introduction: Hospitalization of infants and children in neonatal intensive care units and pediatric intensive care units has a significant effect on their families, including increased stress, anxiety, and depression. Available evidence syntheses focused on specific family-centered care, but not on partnership, which is another aspect that may improve families' outcomes and experiences.

Inclusion criteria: This review considered studies that focused on effectiveness or family experiences of interventions by health professionals in partnership with families of infants or children hospitalized in an intensive care unit. For the quantitative component of the review, the type of intervention was a partnership between the health care team and the family, and focused on outcomes of stress, anxiety, depression, quality of life, attachment, or satisfaction with family-centered care. For the qualitative component, the phenomenon of interest was family experiences of interventions that included collaboration and partnering with the health care team in the pediatric or neonatal intensive care unit. Quantitative, qualitative, and mixed methods studies, published from 2000 to August 2022 in English or French, were eligible for inclusion.

Methods: The JBI methodology for convergent segregated mixed methods systematic reviews was followed using the standardized JBI critical appraisal and data extraction tools. Ten databases were searched in December 2019 and again in August 2022. Study selection, critical appraisal, and data extraction were performed by 2 reviewers independently. Findings of quantitative studies were statistically pooled through meta-analysis and those that could not be pooled were reported narratively. Qualitative studies were pooled through meta-synthesis.

Results: This review included 6 qualitative and 42 quantitative studies. The methodological quality varied, and all studies were included regardless of methodological quality. Meta-analyses showed improvements in anxiety, satisfaction with family-centered care, and stress, yet no conclusive effects in attachment and depression. These results should be interpreted with caution due to high heterogeneity. Qualitative analysis resulted in 2 synthesized findings: "Interventions that incorporate partnerships between families and the health care team can improve the family's experience and capacity to care for the child" and "Having a child in intensive care can be an experience of

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significant impact for families." Integration of quantitative and qualitative evidence revealed some congruence between findings; however, the paucity of qualitative evidence minimized the depth of this integration.

Conclusions: Partnership interventions can have a positive impact on parents of children in intensive care units, with improvements reported in stress, anxiety, and satisfaction with family-centered care.

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Supplemental digital content: A Chinese-language version of the abstract of this review is available at http://links.lww.com/SRX/A50. A French-language version of the abstract of this review is available at http://links.lww.com/SRX/A51.

Keywords: critical care; partnership; pediatrics; psychosocial; systematic review

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Introduction

Hospitalization of infants and children in intensive care units (ICUs) can have negative short- and long-term consequences for children, their parents, and families. The negative experience of hospitalization can cause stress, anxiety, and depression in family members.[1] These psychological symptoms may persist even after discharge and can have considerable effects on the whole family. They may occur because of concerns associated with the diagnosis and prognosis, as well as the impact of disturbed family routines, altered roles of family members, or the loss of control and power when caring for their sick child. Additionally, the experience of an ICU is associated with unfamiliar interventions, equipment, and processes where the language can be difficult to understand.[2–4]

Family-centered care (FCC) is a practice framework that has long been discussed in the literature and used to some level in neonatal and pediatric health care.[5] Despite its long history, there have been inconsistencies in its definition and implementation. FCC aims to address the needs of the patient and their family members. A commonly used definition from the Institute for Patient- and Family-Centered Care is "Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families."[6(para.1)] The quality of a child's care hinges on the ability of families and health care professionals to partner together to address the needs of the children and the family.

While the use of FCC or concepts of FCC (eg, shared decision-making) have varied across studies, there is a consensus that partnership with families has a positive impact on patient care.[7] The focus on FCC has evolved from focusing only on the patient to more inclusivity, including allowing some family members to be present during health care of the child. It progressed to including families in the patient's care and, in 2012, focusing on both patients and their families.[8,9] In addition, the Family Integrated Care model by Franck *et al.*[7] focuses on enhancing information sharing, support, flexibility, and collaboration between health care providers and families, in addition to giving families choice and empowering families while respecting diversity. In order to recognize the diversity of definitions around family-centered or integrated care, this review will focus on partnerships between health care teams and families. A true partnership between the health care team and families requires shared knowledge, influence, and decision-making.[7] It can be characterized by communication and cooperation.[10]

FCC facilitates family empowerment, which can be enhanced through family education, information sharing, and promoting patient and family involvement in care activities.[11] There are varied interventions to reduce anxiety, depression, and stress, and to improve satisfaction with care among families of patients hospitalized in intensive care.[12] Increased family presence and involvement, positive reinforcement for staff, educational programs, use of diaries, structured communication, interdisciplinary family conferences, and family navigators have been identified as potential interventions.

A preliminary search was conducted in PROSPERO, PubMed, the Cochrane Database of Systematic Reviews, and the *JBI Database of Systematic*

Reviews and Implementation Reports to identify existing reviews on this topic. A systematic review by Kutahyalioglu and Scafide[13] focused on the effect of parental presence and involvement in neonatal intensive care unit (NICU) care on bonding (most interventions were kangaroo care). Another systematic review by Ding *et al.*[14] demonstrated the positive effect of FCC interventions on premature infants and their parents; FCC interventions included partnership in care (ie, empowerment and involvement in care), but focused on premature infants only. A review by Segers *et al.*[15] on the impact of FCC interventions in NICUs and pediatric intensive care units (PICUs) was explorative in nature and included any type of quantitative design; however, the operational definition of partnership in these reviews varied. Despite evidence of the benefits of FCC in the NICU and PICU, implementation of FCC interventions has been challenging in both settings. Little is known about the best way to partner with families and how families experience FCC. One qualitative review reported that co-creation of mutual knowledge, development of competencies, and negotiation of roles are key elements for successful relationships between parents and nurses in the NICU.[16] No evidence synthesis of parents' or families' experiences of partnership in the PICU was found. Our systematic review aimed to address this gap by focusing on i) the effectiveness of partnership interventions between the health care team and families in the context of pediatric and neonatal ICUs and ii) families' experiences of these interventions.

Review questions

i) What is the effect of interventions where the health care team collaborates with families as partners in the PICU and NICU on family psychological and satisfaction outcomes?
ii) What are families' experiences of interventions where the health care team collaborates with families as partners in the PICU and NICU, including benefits and challenges?

Inclusion criteria

Population

This mixed methods review considered studies conducted in PICUs and NICUs that include families of patients, regardless of the patient's length of stay, diagnosis, or treatment outcome. To recognize the diversity of contemporary family types across cultures, in this review, family was defined by the patient's surrogates. The family members could be biologically related or unrelated to the patient, and could include parents or other people with whom the patient has a significant relationship.[12] There were no limitations placed on the age of participants.

Intervention

The quantitative component of this review considered studies with partnership interventions between the health care team (including medical practitioners; nurses; allied health professionals, such as social workers; child life specialists; psychologists; and support staff, such as chaplains) and families of patients in the NICU or PICU. This review excluded volunteers, parents of other children, and student health professionals. It included family interventions fostering FCC components, such as collaboration,[7] empowerment,[11] active participation, information sharing, choice, respect, and dignity.[17] Interventions needed to occur during intensive care hospitalization but could extend before or after this time. The interventions were compared with all existing alternative interventions as included in the studies.

Phenomena of interest

The qualitative component of this review considered studies exploring family experiences of interventions that included collaboration and partnering with families. This included the benefits and challenges of these interventions as well as the acceptability or other experiences of the intervention.

Outcomes

The quantitative component of this review considered studies that included psychosocial or satisfaction outcome measures, such as (but not limited to) stress, anxiety, depression,[12] quality of life,[18] family functioning, family empowerment,[11] or satisfaction with FCC. These outcomes needed to be measured with a validated instrument. Outcomes focused on those of the family; however, patient outcomes were reported when available.

Context

The qualitative component of this review considered studies that were associated with hospitalization in a PICU or NICU. An ICU was defined as "an organized system for the provision of care to critically ill

patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency."[19(p.274)] This could take the form of separate or combined PICUs and NICUs located in any type of hospital. There were no geographical limitations on the studies.

Types of studies

This review considered quantitative, qualitative, and mixed methods studies. Quantitative studies could include both experimental and quasi-experimental study designs, including randomized controlled trials (RCTs), non-randomized controlled trials, before and after studies, and interrupted time-series studies. Qualitative studies could include designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Mixed method studies were only considered if data from the quantitative or qualitative components could be clearly extracted.

Studies published in English or French were eligible for inclusion as these are the languages the authors are proficient in. Publication year was limited from 2000 to current publications. This was to accommodate the changes in FCC, including increased visiting times, that occurred around this time.[9,16,20]

Methods

This review was conducted using the JBI methodology for convergent segregated mixed methods systematic reviews.[21,22] The methods used in this review were documented and published in an a priori protocol.[23] The protocol was registered with PROSPERO (CRD42019137834).

Search strategy

The search strategy aimed to locate both published and unpublished studies. Following an initial search of PubMed and CINAHL to identify index and free terms, the search strategy was updated and adapted for all databases and information sources in collaboration with a medical librarian. The search strategy, including all the identified keywords and index terms, was adapted for each information source. The search strategies are presented in Appendix I.

Sources of published literature were MEDLINE (Ovid), CINAHL (EBSCOhost), Embase, APA PsycINFO (Ovid), and Web of Science Core Collection. Sources of unpublished studies and gray literature were ProQuest Dissertations and Theses and DART Europe E-theses Portal. For quantitative studies only, ClinicalTrials.gov, Cochrane Central Register of Controlled Trials, and WHO International Clinical Trials Registry Platform were all searched via CENTRAL. All initial searches were performed on December 1, 2019, and updated in August 2022. Reference lists of included studies were searched for additional studies, and authors were contacted for supplemental information, where needed.

Study selection

Following the search, all identified citations were collated and uploaded into EndNote v.20 (Clarivate Analytics, PA, USA)[24] and organized using the Peters approach.[25] Deduplication followed the Bramer technique.[26] Unique citations were imported into Rayyan (Qatar Computing Research Institute, Doha, Qatar),[27] and titles and abstracts were screened independently and assessed against the inclusion criteria by at least 2 reviewers. Full-text articles were retrieved for potentially relevant studies and their citation details imported into JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).[28] Two reviewers from the study team independently assessed the full text of these citations in detail against the inclusion criteria. The reasons for exclusion of full-text studies that did not meet the inclusion criteria are reported in Appendix II. Any disagreements between the reviewers at each stage of the study selection and assessment process were resolved through discussion or with a third reviewer. To ensure consistency in decisions, all studies were reviewed at each stage by the first author. The results of the search are presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Figure 1).[29]

Assessment of methodological quality

Quantitative and qualitative studies selected for retrieval were assessed independently by 2 reviewers for methodological quality prior to inclusion in the review using the standardized critical appraisal instruments in JBI SUMARI.[28] Despite being eligible for inclusion, there were no mixed methods studies that met the inclusion criteria, thus no quality assessment methods specific to those were required. Disagreements between the reviewers were resolved through

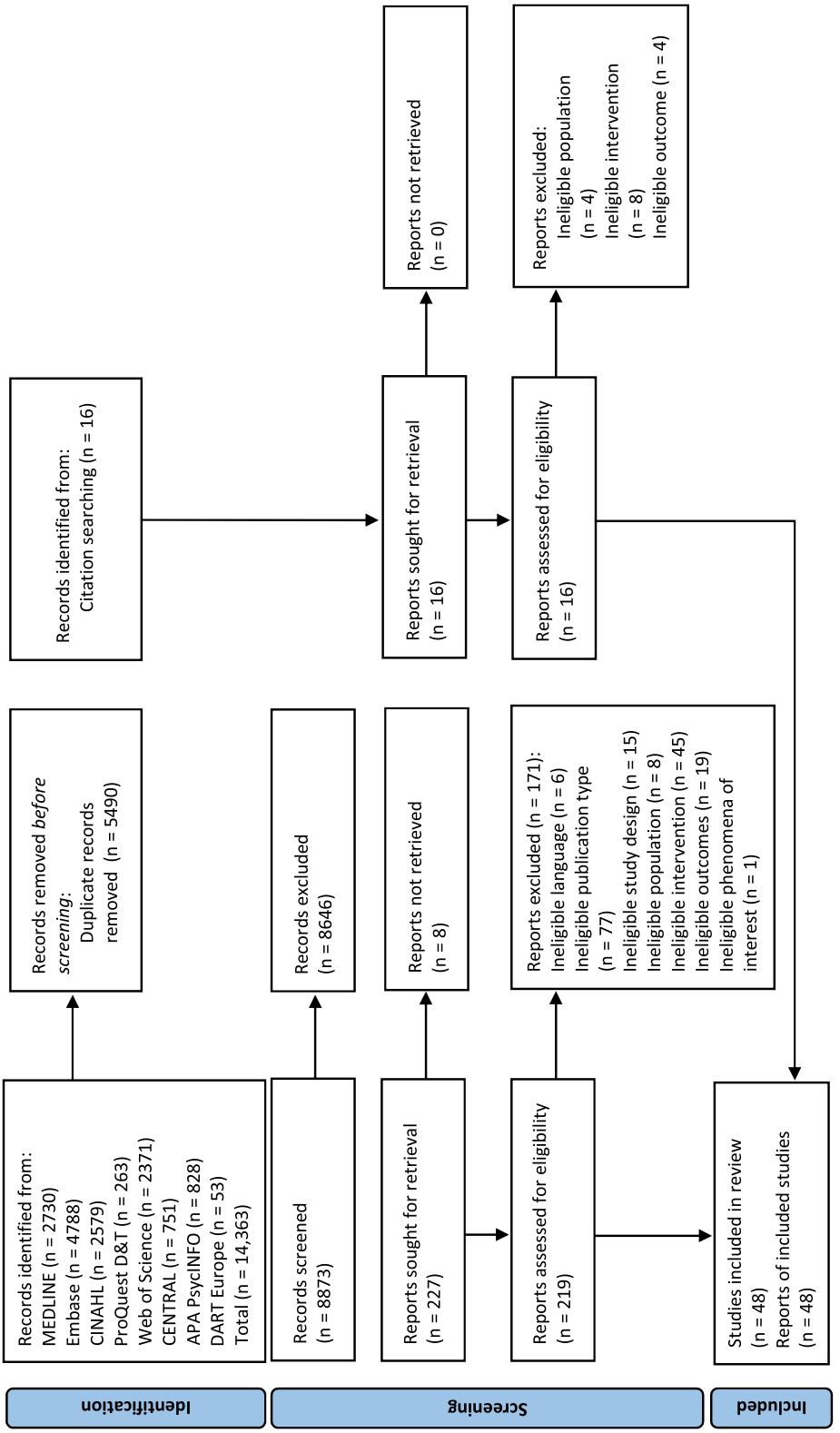

Figure 1: Search results and study selection and inclusion process[29]

discussion or with a third reviewer where needed. As specified in the published protocol, all studies, regardless of the results of their methodological quality, underwent data extraction and synthesis, where possible.

Data extraction

Quantitative data were extracted from quantitative studies included in the review by 2 independent reviewers using the standardized data extraction tool in JBI SUMARI.[28] The data extraction included specific details about the country in which the study was conducted, populations, study methods, interventions, and outcomes of significance to the review objective. Mean, SD, and sample sizes at the final measurement were also extracted, where available. Authors were contacted for additional information, where needed, and this was incorporated, when provided. Qualitative data were independently extracted from included studies by 2 reviewers using the standardized data extraction tool in JBI SUMARI.[28] The extracted data included specific details about the population, context, culture, geographical location, study methods, and the phenomena of interest relevant to the review objective.

Findings and their illustrations were extracted and assigned a level of credibility based on the quality of supporting participant quotes and discussion. This level of credibility was either unequivocal (U), credible (C), or not supported (NS). Unequivocal findings were "accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge,"[(p.183)] credible findings were "accompanied by an illustration lacking clear association with it and therefore open to challenge,"[(p.183)] and not supported findings were "not supported by the data."[30(p.183)]

Data synthesis and integration

A convergent segregated approach guided this review as per the JBI methodology for mixed methods systematic reviews.[21] There were separate quantitative and qualitative syntheses, followed by integration of the resulting quantitative and qualitative evidence.

Quantitative synthesis

To determine the effectiveness of partnership interventions on outcomes of interest, a statistical meta-analysis using JBI SUMARI was performed. Effect sizes were for continuous data and expressed as standardized final post-intervention mean differences with their 95% CI calculated for analysis. Heterogeneity was assessed statistically using the standard χ^2 and I^2 tests. Statistical analyses were performed using random effects where there were high levels of heterogeneity, and fixed effects were used when there was low heterogeneity.[31] Analyses were performed according to outcome. Where statistical pooling was not possible due to absence of mean, SD, and/or sample sizes, the findings are presented in narrative format.

Qualitative synthesis

Qualitative research findings were pooled using JBI SUMARI using the meta-aggregation approach.[30] Unequivocal and credible findings were aggregated or synthesized to generate a set of statements that represented that aggregation, through assembling the findings and categorizing these findings based on similarity in meaning. These categories were then subjected to a synthesis to produce a comprehensive set of synthesized findings that could be used as a basis for evidence-based practice. All findings were suitable for textual pooling, and no findings are presented in narrative format.

Integration of quantitative evidence and qualitative evidence

The findings of each single method synthesis included in this review were configured according to the JBI methodology for mixed methods systematic reviews.[21] Quantitative evidence and qualitative evidence were juxtaposed and linked into a line of argument to produce an overall configured analysis. The integrated analysis was used to develop recommendations for research and clinical practice. Grades of Recommendations have been used to classify recommendations for practice.[32] Using a binary system, recommendations were rated as Grade A (strong recommendation) or Grade B (conditional recommendation).

Results

Study inclusion

There were 14,363 search results identified for possible inclusion in this review. Following deduplication, 8873 unique results remained. The titles and abstracts were assessed against the inclusion criteria. Of these, 227 were selected for potential inclusion, and the full texts were retrieved where possible (8 reports were unable to be retrieved). Of the 219 full-text reports assessed for eligibility, 171 were

Table 1: Critical appraisal of randomized controlled trials

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Total
Bastani *et al.* 2015[38]	U	U	Y	U	N	U	Y	N	Y	Y	Y	Y	U	6/13
Borghini *et al.* 2014[39]	Y	N	Y	N	N	N	Y	N	Y	Y	Y	Y	N	7/13
Cheng *et al.* 2021[40]	N	U	N	U	U	U	U	N	Y	Y	Y	Y	N	4/13
Glazebrook *et al.* 2007[41]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	9/13
Heo and Oh 2019[42]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	9/13
Hoffenkamp *et al.* 2015[43]	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13
Holditch-Davis *et al.* 2014[45]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	9/13
Holditch-Davis *et al.* 2013[44]	Y	N	Y	N	N	Y	Y	U	Y	Y	Y	Y	Y	9/13
Kaaresen *et al.* 2006[46]	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	10/13
Lee *et al.* 2019[47]	Y	Y	Y	N	N	Y	Y	N	Y	Y	Y	Y	Y	10/13
Matricardi *et al.* 2013[48]	N	U	Y	N	N	N	Y	Y	N/A	Y	Y	Y	U	6/12
O'Brien *et al.* 2018[49]	Y	N	Y	U	N	N/A	Y	U	Y	Y	Y	Y	Y	8/12
Samra *et al.* 2015[50]	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	Y	U	8/13
Weis *et al.* 2013[51]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	9/13
Welch *et al.* 2016[52]	U	U	Y	N	N	N	Y	Y	Y	Y	Y	Y	U	7/13
Xie *et al.* 2019[56]	U	U	Y	N	N	N	U	N	N	Y	Y	N	U	3/13
Yilmaz and Küçük Alemdar 2022[53]	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	Y	Y	9/13
Zelkowitz *et al.* 2011[54]	Y	Y	U	N	N	Y	Y	Y	Y	Y	Y	Y	Y	10/13
Zhang *et al.* 2018[55]	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	9/13

Y, yes; N, no; NA, not applicable; U, unclear.
JBI critical appraisal checklist for randomized controlled trials.
Q1: Was true randomization used for assignment of participants to treatment groups?
Q2: Was allocation to treatment groups concealed?
Q3: Were treatment groups similar at the baseline?
Q4: Were participants blind to treatment assignment?
Q5: Were those delivering treatment blind to treatment assignment?
Q6: Were outcomes assessors blind to treatment assignment?
Q7: Were treatment groups treated identically other than the intervention of interest?
Q8: Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?
Q9: Were participants analyzed in the groups to which they were randomized?
Q10: Were outcomes measured in the same way for treatment groups?
Q11: Were outcomes measured in a reliable way?
Q12: Was appropriate statistical analysis used?
Q13: Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?

excluded (see Appendix II). There were 48 full-text studies that met the inclusion criteria and underwent critical appraisal for methodological quality. Aligning with the protocol, studies were not excluded based on critical appraisal. Reference lists of included studies were searched, and an additional 16 records were identified as potentially meeting the inclusion criteria and were retrieved for full-text review; however, all 16 were excluded. The results of the search and selection process are outlined in a PRISMA flow diagram (Figure 1).[29]

Methodological quality

The critical appraisal of the 19 included RCTs (see Table 1) found scores ranging between 3 and 11 out of 13 criteria; 15 studies scored 7 or greater. All studies reported outcomes measured in the same way for treatment groups, and that outcomes were measured in a reliable way. No studies reported blinding of participants or those delivering treatment.

The critical appraisal of the 23 included quasi-experimental studies (see Table 2) found scores ranging between 4 and 8 out of 9 criteria. All except 3 studies[33–35] measured outcomes in a reliable way. Only 1 study[36] obtained multiple measures pre- and post-intervention.

The critical appraisal of the 6 included qualitative studies (see Table 3) found scores ranging between 1 and 8 out of 10 criteria. All studies had ethical approval. Only 1 study[37] reported the influence of

Table 2: Critical appraisal of quasi-experimental studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Total
Cano Gimenez *et al.* 2015[57]	Y	Y	Y	Y	N	Y	Y	Y	N	7/9
Cho *et al.* 2016[73]	Y	N	U	Y	U	Y	Y	Y	Y	6/9
De Bernardo *et al.* 2017[75]	N	Y	U	Y	N	U	Y	Y	Y	5/9
Genesoni 2012[36]	Y	N	N	Y	Y	Y	Y	Y	Y	7/9
Ghomi *et al.* 2019[58]	Y	Y	Y	N	N	Y	Y	Y	Y	7/9
Gustafson *et al.* 2016[59]	Y	Y	Y	Y	N	Y	Y	Y	Y	8/9
Kardas Ozdemir *et al.* 2017[60]	Y	Y	N	N	N	U	Y	Y	Y	5/9
Kuntaros *et al.* 2007[61]	Y	U	Y	Y	N	U	Y	Y	Y	6/9
Ladak *et al.* 2013[33]	Y	Y	Y	Y	N	N/A	Y	N	Y	6/8
Lee *et al.* 2013[62]	Y	Y	Y	Y	N	N/A	Y	Y	Y	7/8
Luu *et al.* 2017[63]	Y	U	Y	Y	N	N	Y	Y	Y	6/9
Mansson *et al.* 2019[64]	N	U	Y	N	N	U	Y	Y	Y	4/9
Michelson *et al.* 2020[65]	Y	U	Y	Y	N	Y	Y	Y	U	6/9
Miles *et al.* 2006[74]	Y	Y	Y	Y	N	N	Y	Y	Y	7/9
Ong *et al.* 2019[66]	Y	N	Y	Y	N	Y	Y	Y	Y	7/9
Penticuff and Arheart 2005[67]	Y	N	U	Y	N	U	Y	Y	Y	5/9
Piris-Borregas *et al.* 2018[68]	Y	Y	Y	Y	N	U	Y	Y	Y	7/9
Salmani and Champiri 2016[69]	Y	Y	Y	N	N	Y	Y	Y	Y	7/9
Simphronio Balbino *et al.* 2016[70]	Y	N	Y	Y	N	Y	Y	Y	Y	7/9
Sweeney *et al.* 2017[34]	Y	Y	Y	N	N	U	Y	U	Y	5/9
Turan *et al.* 2008[35]	Y	Y	Y	Y	N	N	N	N	Y	5/9
Uhm and Kim 2019[71]	Y	Y	Y	Y	N	Y	Y	Y	Y	8/9
Voos *et al.* 2011[72]	Y	Y	Y	Y	N	Y	Y	Y	Y	8/9

Y, yes; N, no; U, unclear; NA, not applicable.
JBI critical appraisal checklist for quasi-experimental studies.
Q1: Is it clear in the study what is the "cause" and what is the "'effect" (ie, there is no confusion about which variable comes first)?
Q2: Were the participants included in any comparisons similar?
Q3: Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?
Q4: Was there a control group?
Q5: Were there multiple measurements of the outcome both pre and post the intervention/exposure?
Q6: Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?
Q7: Were the outcomes of participants included in any comparisons measured in the same way?
Q8: Were outcomes measured in a reliable way?
Q9: Was appropriate statistical analysis used?

the researcher and their cultural or theoretical location.

Characteristics of included studies

Further detail on the characteristics of the included studies is presented in Appendix III. There were 48 included studies, of which quantitative studies were predominant with 19 RCTs[38–56] and 23 quasi-experimental studies.[33–36,57–75] There were 6 qualitative studies included.[37,76–80] A total of 21 countries were represented in the included studies, with most studies conducted in the United States (n = 10),[34,44,45,50,52,59,65,67,72,77] Canada (n = 4),[40,49,54,63] the United Kingdom (n = 4),[36,41,74,78] Australia (n = 3),[40,49,76] Iran (n = 3),[38,58,69] Turkey (n = 3),[35,53,60] and the Republic of Korea (n = 3).[42,71,73] Studies were also conducted in China (n = 2),[55,56] Hong Kong (n = 2),[47,62] Italy (n = 2),[48,75] Netherlands (n = 2),[43,80] New Zealand (n = 2),[40,49] Norway (n = 2),[46,79] Spain (n = 2),[57,68] Sweden (n = 2),[37,64] Brazil (n = 1),[70] Denmark (n = 1),[51] Malaysia (n = 1),[66] Pakistan (n = 1),[33] Switzerland (n = 1),[39] and Thailand (n = 1).[61] Two studies were conducted in multiple countries.[40,49] Studies included both parents (n = 24),[33–36,42,43,48,49,51,55,59,63–68,70,72,75,77–80] only mothers (n = 19),[38–41,44–47,50,52–54,56–58,61,71,73,74] only fathers (n = 4),[37,60,62,69] or

Table 3: Critical appraisal of qualitative studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Broom *et al.* 2017[76]	U	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Cameron *et al.* 2009[77]	N	U	U	U	U	N	N	N	Y	U	1/10
Hemle Jerntorp *et al.* 2021[37]	Y	Y	Y	Y	Y	Y	Y	N	Y	N	8/10
Ingram *et al.* 2017[78]	U	U	U	U	U	N	N	Y	Y	Y	3/10
Kyno *et al.* 2013[79]	U	U	U	U	U	N	U	Y	Y	Y	3/10
van den Hoogen *et al.* 2021[80]	U	Y	Y	Y	Y	N	N	Y	Y	Y	7/10

Y, yes; N, no; U, unclear.
JBI critical appraisal checklist for qualitative research.
Q1: Is there congruity between the stated philosophical perspective and the research methodology?
Q2: Is there congruity between the research methodology and the research question or objectives?
Q3: Is there congruity between the research methodology and the methods used to collect data?
Q4: Is there congruity between the research methodology and the representation and analysis of data?
Q5: Is there congruity between the research methodology and the interpretation of results?
Q6: Is there a statement locating the researcher culturally or theoretically?
Q7: Is the influence of the researcher on the research, and vice-versa, addressed?
Q8: Are participants, and their voices, adequately represented?
Q9: Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?
Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

mothers and grandmothers (n = 1).[76] Studies were conducted in NICUs (n = 43)[34–60,62–64,66–70,72–76,78–80] and PICUs (n = 5).[33,61,65,71,77]

Outcomes

The predominant psychosocial or satisfaction outcomes assessed in the included studies were stress (n = 30),[35, 36, 39–41, 43, 46–51, 53–55, 57, 59, 60, 62–66, 68–70, 72, 73, 75, 79] satisfaction with FCC (n = 12),[33,38,44,55,61,65,67,68,71,72,75,80] anxiety (n = 15),[34–37,40,49,52–55,57,59,65,71,77] and depression (n = 6).[36,52,54,56,57,65] Other outcomes included attachment (n = 5),[36,42,43,73,74] partnership (n = 4),[37,42,71,80] psychological well-being/distress (n = 4),[43–45,74] self-efficacy (n = 4),[58,61,63,71] parenting ability (n = 3),[53,62,66] knowledge (n = 3),[54,58,67] breastfeeding (n = 2),[49,55] empowerment (n = 1),[58] perceptions (n = 3),[65,76,78] support (n = 2),[51,62] decision-making/conflict (n = 2),[65,67] adjustment (n = 1),[56] competence (n = 1),[47] coping (n = 1),[59] discharge readiness (n = 1),[78] FCC (n = 1),[70] home environment (n = 1),[41] motivation (n = 1),[52] quality of life (n = 1),[65] trauma (n = 1),[43] and worry (n = 1).[79] Infant measures were also assessed in 10 studies.[36,41,42,49,54–56,63,71,74] Some studies assessed multiple outcomes. Outcome measures not relevant to the review outcomes in the a priori protocol, such as health care team outcomes, were not extracted or analyzed. All qualitative studies were included in the qualitative synthesis. Where possible, results of quantitative studies were meta-analyzed.

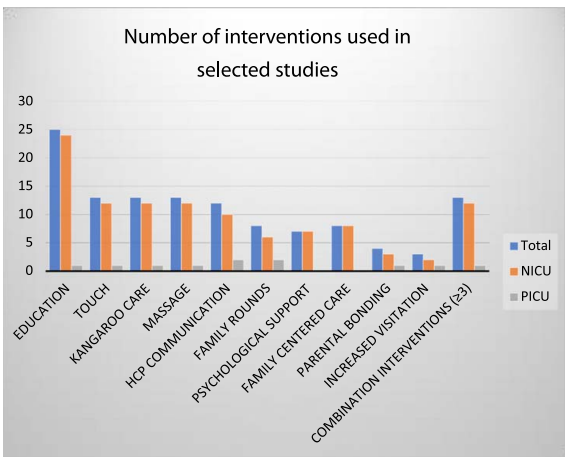

Figure 2: Components of partnership interventions between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit, and the number of interventions in the included studies. (HCP, health care professional)

Interventions

The partnership interventions between families and the health care team described in the included studies were education (n = 25)[35,39–43,46–49,52–54,56–58,60,62,63,66,69,71,76,78,80]; touch, including skin-to-skin, kangaroo care, or infant massage (n = 13)[34,36,41,44,45,48,50,52,56,69,71,73,74]; increased health professional communication (n = 12)[41,46–48,53,57,64,65,67,71,78,80]; family participation in rounds (n = 8)[33,40,49,59,68,72,76,77]; FCC (n = 8)[38,51,55,68,70,75,78,80];

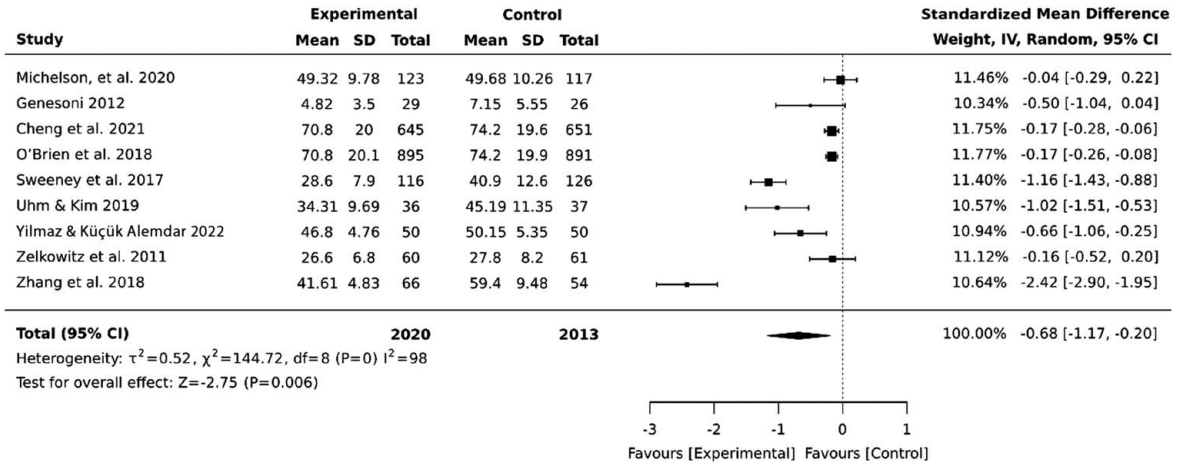

Figure 3: Effect of partnership interventions on anxiety. Partnerships were between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit. Family members' anxiety was measured using 4 different scales. The interval between baseline/intervention completion and post-intervention outcome ranged from 12 hours pre-discharge to 3-5 weeks post-discharge.

psychological support (n = 7)[39,40,46,49,53,57,76]; parental bonding (n = 4)[43,52,71,79]; and increased visitation (n = 3).[37,60,61] The number of studies that used these interventions, and their use in either the NICU or PICU setting, are highlighted in Figure 2.

Some studies used combinations of interventions, with 13 studies having 3 or more interventions.[39–41,46,48,49,52,53,57,71,76,78,80] High variability in the studies prevented subgroup analysis matching similar interventions components with similar outcomes.

Review findings

Quantitative evidence

Anxiety

Pooled results from 5 RCTs[40,49,53–55] and 4 quasi-experimental studies,[34,36,65,71] with 4033 total participants, favored the experimental groups, suggesting that partnership interventions can improve anxiety in parents with an infant or child hospitalized in intensive care (Figure 3). Meta-analysis using random effects found a standardized mean difference of –0.68 (–1.17, –0.2). The effect size in this meta-analysis is moderately large. High heterogeneity was seen, with $I^2 = 98$. Heterogeneity may have resulted from differences in outcome measurement, and duration and type of intervention. While all studies used partnership strategies as interventions, the interventions were quite different and included skin-to-skin contact,[34,36] family in medical rounds,[40,49] increased communication,[53,65] education,[40,53,54,55,65] psychological support,[53,65] and parents performing infant care.[40,55] The control group of the outlying study[55] (Figure 3) had usual care that meant no contact with the infant during intensive care hospitalization, which may have compounded the effect of the partnership intervention.

The measurement tools used were the Emotional Distress-Anxiety Short Form 8a,[65] the Beck Anxiety Inventory,[36] the Spielberger State-Trait Anxiety Inventory (STAI),[34,40,49,53,54,71] and the Zung Self-Rating Anxiety Scale.[55] The interval between baseline/intervention completion and post-intervention outcome measurement ranged from 12 hours before discharge[36] to 3-5 weeks post-discharge.[65]

Of the studies unable to undergo meta-analysis, 2 studies[52,57] did not report mean and standard deviation, and 2 studies[35,59] did not assess the outcome post-intervention. One of these studies used the Inventory of Situations and Responses of Anxiety to measure the impact of an individualized psychological intervention on parents at day 15 of NICU hospitalization.[57] Following the intervention, there were significant differences in anxiety between the experimental and control groups. Parents in the experimental group reported no anxiety while in the control

group, 98% of mothers and 90% of fathers reported the presence of anxiety. Baseline measures of anxiety prior to the intervention were not reported and, therefore, could not be measured. This patient group differs from other NICU studies where the infants are commonly born with low-birth-weight or preterm gestational age.

Another study used the STAI to measure the impact of a Family Nurture Intervention on anxiety in mothers at the infant's 4-month corrected age.[52] Following the intervention, the experimental group had significantly lower STAI scores than the control group. Two other studies used the STAI to measure anxiety prior to the inclusion of parents in multidisciplinary rounds[59] or education interventions.[35] The studies found similar results in parents in the intervention and control groups, but did not retest STAI results after the intervention.

Attachment

Pooled results from 3 quasi-experimental studies[36,73,74] and 1 RCT,[42] with a total of 270 participants, may favor experimental groups; however, no conclusive effect of the intervention on attachment could be determined (Figure 4). Meta-analysis using random effects found a standardized mean difference of 0.55 (–0.21, 1.31). The effect size in this meta-analysis was moderate with a wide CI. High heterogeneity was seen, with $I^2 = 89$. Heterogeneity may have resulted from differences in outcome measurement, duration and type of intervention, and small sample size. One study reporting on attachment was not eligible for meta-analysis due to not reporting overall attachment results and instead reporting subscale results.[43]

While all studies used partnership strategies as interventions, the interventions were quite different and included skin-to-skin contact,[36,73,74] education,[42] and parents performing infant care.[42] Measurement tools included maternal–infant attachment measurement tool,[73] Maternal Attachment Inventory,[42] Parent to Infant Attachment,[74] and Maternal Post-natal Attachment Questionnaire.[36] The interval between baseline/intervention completion and post-intervention outcome measurement ranged from 2 weeks[42] to 1 year[74] after term gestational age of infant.

Depression

There was no evidence of an effect of the intervention on parental depression as measured in 1 RCT[56] and 2 quasi-experimental studies[36,65] with a total of 447 participants (Figure 5). A meta-analysis using fixed effects found a standardized mean difference of 0.01 (–0.18, 0.19). The effect size was small with a wide CI. Interventions used in the studies reporting on depression included education, communication, and psychological support. The tools used to measure depression were the Beck Depression Inventory,[36] the Edinburgh Postnatal Depression Scale (EPDS),[56] and the Emotional Distress-Depression Short Form 8a.[65] The interval between baseline/intervention completion and post-intervention

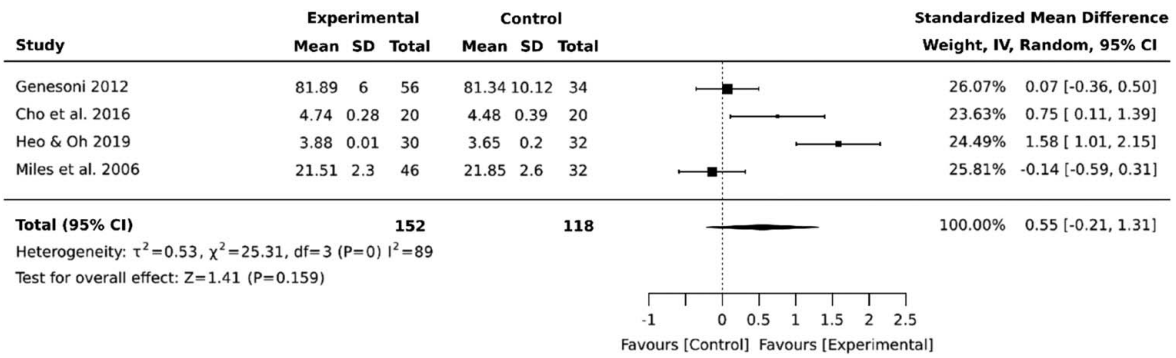

Figure 4: Effect of partnership interventions on attachment. Partnerships were between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit. Family members' attachment was measured using 4 different scales. The interval between baseline/intervention completion and post-intervention outcome measurement ranged from 2 weeks to 1 year after term gestational age of infant.

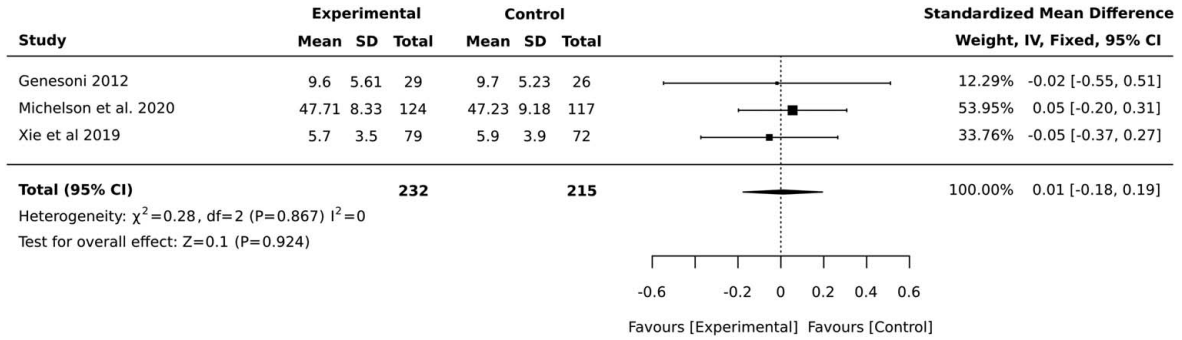

Figure 5: Effect of partnership interventions on depression. Partnerships were between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit. Family members' depression was measured using 3 different scales. The interval between baseline/intervention completion and post-intervention outcome measurement ranged from at discharge to 3-5 weeks post-discharge.

outcome measurement ranged from at discharge[36] to 3-5 weeks post-discharge.[65]

Of the studies unable to undergo meta-analysis, 2 studies[52,57] did not report mean and standard deviation, and 1 study[54] did not have the power to analyze depression. One of these studies used the EPDS to measure the impact of anxiety awareness and infant communication in mothers 2 to 4 weeks after the intervention.[54] Following the intervention, 13% of the mothers in the experimental group and 4% of the mothers in the control group scored within the clinical range suggestive of a depressive illness. There was insufficient power within the sample to analyze the difference between experimental and control groups. An additional study used the EPDS to evaluate the impact of multidisciplinary, multiphased intervention focusing on psychological support and support with infant care.[57] Following the intervention, at the time of discharge, 37.5% of mothers and 24% of fathers in the intervention group scored within the range of probable depression. In the control group, 100% of the mothers and 89.7% of the fathers scored within the range of probable depression. This study was performed with parents of full-term infants requiring NICU admission. This patient group differs from the previous NICU study where the infants had low-birth-weight or preterm gestational age.[54]

One study used the Center for Epidemiologic Studies Depression Scale (CES-D) to measure the impact of a family nurture intervention at infant full-term age and 4-month corrected gestational age on mothers' depression.[52] Following the intervention, at discharge, there were significant improvements for the intervention group in both the mean CES-D score and the number of participants who met the criteria for referral of depressive illness.

Quality of life

Only 1 study assessed parental quality of life and used the Global Health tool to measure the impact of the parents' health care navigator compared with an information brochure.[65] Following the intervention, at 3- to 5-weeks' post-PICU discharge, there were no significant differences in overall health-related quality of life between the experimental and control groups.

Satisfaction with family-centered care

Pooled results from 3 RCTs[38,44,55] and 4 quasi-experimental studies,[33,61,65,71] with a total of 938 participants, favored the experimental groups, suggesting that partnership interventions may improve satisfaction (Figure 6). A meta-analysis using random effects found a standardized mean difference of 1.09 (0.47, 1.70). The effect size in this meta-analysis is large. High heterogeneity was observed, with $I^2 = 95$. The heterogeneity may have resulted from differences in type and timing of outcome measurement, and duration and type of intervention. While all studies used partnership strategies as interventions, the interventions were quite different and included skin-to-skin,[44,71] increased communication,[65,71] parents performing care,[61,71] and family participation in rounds.[33] Measurement tools included the Pediatric Family Satisfaction in the ICU, standard hospital satisfaction survey, Empowerment

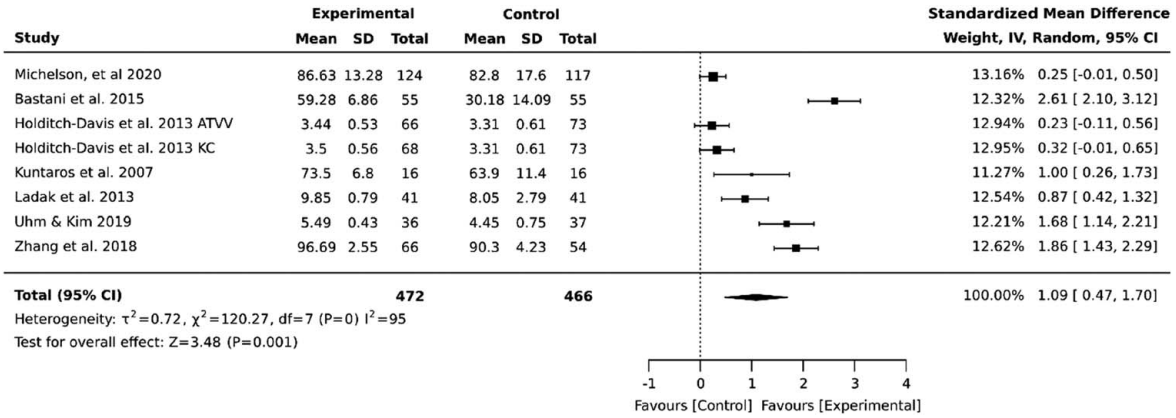

Figure 6: Effect of partnership interventions on satisfaction with family-centered care. Partnerships were between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit. Family members' satisfaction was measured using 7 different scales. The interval between baseline and post-intervention outcome measurement ranged from 2 days to 3-5 weeks post-discharge. (ATVV, auditory, tactile, visual, and vestibular simulation; KC, kangaroo care)

of Parents in the Intensive Care (EMPATHIC-30), self-developed questionnaire, modified satisfaction questionnaire, and satisfaction with nursing care questionnaire. The interval between baseline and post-intervention outcome measurement ranged from 2 days[33] to 3-5 weeks post-discharge.[65]

Of the studies unable to undergo meta-analysis, 2 studies[68,75] only reported subscale results, not overall score, and 2 studies[67,72] did not report mean and standard deviation. One study used the Neonatal Instrument of Parent Satisfaction (NIPS) tool to assess the satisfaction of parents on the seventh admission day and at discharge following their involvement in the family-centered clinical rounds,[68] and no significant differences were found. Another study used the NIPS tool to measure the impact of family-centered rounds on parents prior to discharge.[72] They found no significant changes in satisfaction between the intervention and control groups, except for 1 subscale related to communication. One study used multiple tools to measure components of satisfaction following an intervention with parents using an infant progress chart and care planning meetings.[67] The authors found no significant differences in satisfaction between the intervention and control groups. Yet another study used a satisfaction survey to measure the impact of FCC on parents at discharge.[75] Following the intervention, individual survey questions were reported, with parents in the intervention group showing significantly higher scores in 7 of the 9 questions. However, satisfaction was generally high in both the intervention and control groups, and an overall satisfaction score was not reported.

Stress

Pooled results from 10 RCTs[39–41,46,47,49–51,53,55] and 9 quasi-experimental studies,[35,36,59,60,62,64–66,73] with a total of 5000 participants, favored the experimental groups, suggesting that partnership interventions can improve stress in parents with an infant or child in the NICU or PICU (Figure 7). Meta-analysis using random effects found a standardized mean difference of –0.59 (–0.91, –0.27). The effect size in this meta-analysis is moderate. High heterogeneity was seen, with $I^2 = 96$, which may be due to differences in type and timing of outcome measurement, and duration and type of intervention. While all studies used partnership strategies and interventions, the interventions were quite different and included skin-to-skin,[36,40,41,50] increased communication,[41,46,47,53,64] parents performing care,[38,39,49] and family participation in rounds,[40,49,59] among others. Measurement tools included Parental Stressor Scale: Neonatal Intensive Care Unit,[35,40,47,49,50,51,53,59,60,62,64,66,73] Parenting Stress Index,[41,46] Perinatal Posttraumatic Stress Disorder Questionnaire,[39] Impact of Event Scale-Revised,[65] Parenting Stress Index-Short Form (Parental Distress subscale),[36] and Zung Self-Rating Anxiety Scale.[55] The interval between baseline/intervention completion and post-intervention outcome

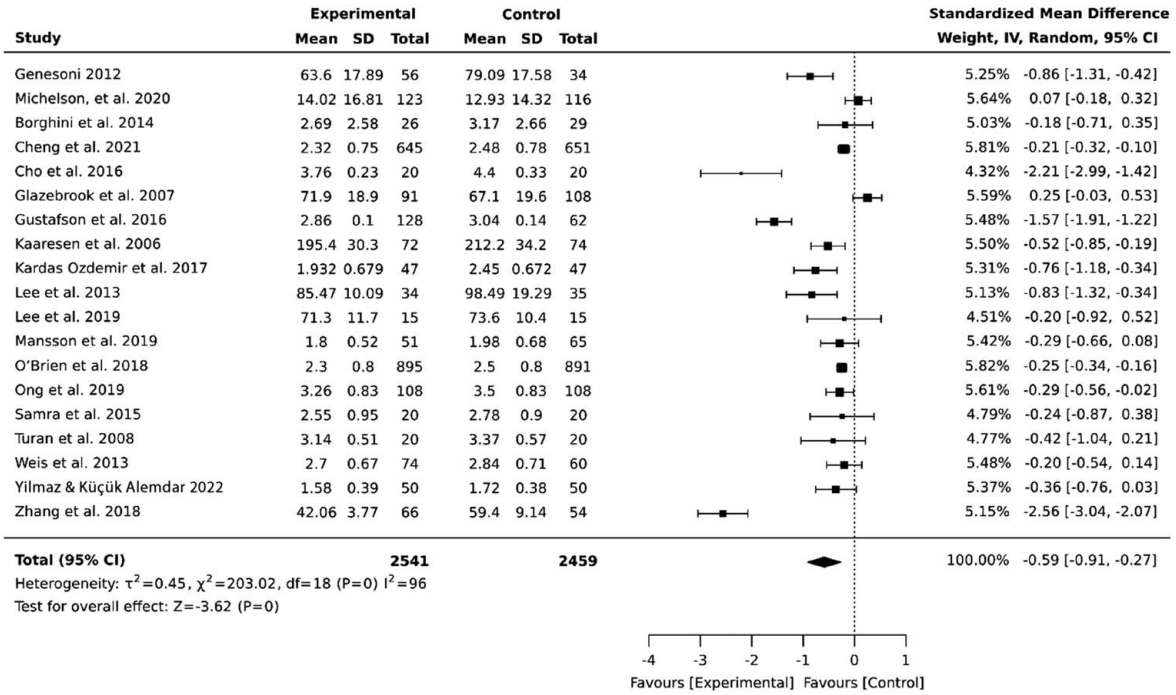

Figure 7: Effect of partnership interventions on stress. Partnerships were between the health care team and families with an infant or child in a neonatal or pediatric intensive care unit. Family members' stress was measured using 6 different scales. The interval between baseline/intervention completion and post-intervention outcome measurement ranged from straight after the intervention to 12 months.

measurement ranged from straight after the intervention[73] to 12 months.[39]

There were many studies that assessed the impact of partnership interventions on stress in parents. Mean overall scores and SD were not available for some of these studies, despite efforts to obtain these from authors. Of the studies unable to undergo meta-analysis, 4 studies only reported subscale results, not overall score,[48,54,70,75] and 6 studies did not report mean and standard deviation.[43,57,63,68,69,72] One study used the Parenting Stress Index–Short Form questionnaire to assess the impact of web-based and in-person NICU education and workshops, and discharge follow-up.[63] When the infant was 4-months corrected age, there were no significant differences in the stress index between the intervention and control groups. Another study used a parental stress scale to assess the impact of a kangaroo care intervention on fathers in the NICU.[69] Two weeks after the conclusion of the intervention, there were no significant differences in stress between the intervention and control groups.

Multiple studies used the Parental Stressor Scale-NICU (PSS-NICU) to assess stress in parents. This tool was used to measure the impact of an individualized psychological intervention on parents at day 15 of NICU hospitalization.[57] In another study, there were no significant differences between the intervention and control groups following the intervention. A video interaction guidance intervention showed no significant differences in PSS-NICU scores between parents in the intervention or control groups at 1 week after the intervention.[43]

Another study assessed stress levels in mothers and fathers 1 week after NICU hospitalization and, following a physical therapist joint intervention and infant massage intervention, at discharge.[48] The authors found that mothers in either group had significantly higher PSS-NICU scores than fathers. Additionally, the parents in the intervention group reported significantly lower PSS-NICU subscores for infants' appearance/behavior and parental role alteration. An intervention with mothers to support

understanding of infant cues found no significant differences in PSS-NICU subscales between the intervention and control groups just before discharge.[54]

A number of studies used the PSS-NICU to evaluate the impacts of interventions promoting FCC. Following an FCC intervention with parents, individual survey questions were reported at discharge, with parents in the intervention group reporting significantly better scores in 16 of the 22 questions.[75] A study exploring FCC clinical rounds intervention with parents found that, at discharge, there were no significant differences between the intervention and control groups.[68] The impact of implementation of a patient and FCC model on parents was assessed 3 months after the intervention.[70] There were no significant differences in overall stress; however, there were some significant improvements for individual questions relating to separation from, not holding, and being unable to help their child. After another FCC rounding intervention, there was no significant impact for parents at discharge when compared to a control group.[72]

Infant and child measures

There was no attempt to undertake meta-analysis of infant outcomes due to the high heterogeneity of interventions and specific measured outcomes. Studies that measured infant outcomes were undertaken in NICUs, except for 1 study[71] that was conducted with infants in a pediatric cardiac ICU. There were no significant differences in assessed infant outcomes in studies using education and follow-up,[63] skin-to-skin,[74] early parent interaction,[56] understanding infant cues,[54] Parent Participation Improvement,[42] parent-baby interaction,[41] or mother-nurse partnership interventions.[71] Some studies showed mixed results for infant outcomes. An FCC intervention found mixed results, with significant improvements in some measures, such as infant weight gain and readmission rates, but no significant differences in measures, such as length of NICU admission and rate of bronchopulmonary dysplasia.[55] A family-integrated care intervention found significant improvements in weight gain and exclusive breastfeeding, but no significant differences in mortality, length of supplemental oxygen, significant morbidity, or duration of hospitalization.[49] A kangaroo care intervention showed mixed effects, such as significant improvements on infant play and expressive communication, and non-significant results for cognitive and socio-emotional skills.[36]

Qualitative evidence

Analyses of the qualitative included studies provided 2 synthesized findings. Details of the findings and illustrations of the included qualitative studies are presented in Appendix IV.

Synthesized finding 1: Interventions that incorporate partnerships between families and the health care team can improve the family's experience and capacity to care for the child

A total of 17 findings (11 unequivocal, 6 credible) from all 6 qualitative studies[37,76–80] created the 3 categories that combined to make up the first synthesized finding (see Table 4). The synthesis highlighted the value and positive impact of partnership interventions on parents and families who have or have had a child in an ICU. For example, study findings found that families reported improved communication, increased confidence, and that

Table 4: Synthesized finding 1: Interventions that incorporate partnerships between families and the health care team can improve the family's experience and capacity to care for the child

Category 1: Education about their child's health and care can be beneficial to parents
Bedside education and participating in cares[76] (U)
Group education sessions[76] (U)
Personalized information and communication[80] (U)
Category 2: Interventions can help to give parents confidence with their child's health care
Parents' confidence and concern in everyday life[79] (U)
FICare enhances parent confidence and parental role attainment[76] (C)
"Giving us hope" and "Feeling in control"[78] (U)
Getting to know your baby[78] (U)
Role of feeding: "breastfeeding is the harder way to do it"[78] (U)
Getting the opportunity to take responsibility[37] (C)
Category 3: Partnership between families and health professionals is valued by families
Improved parent-parent and parent-staff communication[76] (C)
Medical team provides information to the parents[77] (C)
The value of staff engagement[78] (U)
Family-centered ward rounds[76] (C)
Transparency[77] (C)
Fathers and families loved it[78] (U)
Something you can visually see[78] (U)
Involvement in care[80] (U)

FICare, family-integrated care; C, credible; U, unequivocal.

education increased parental participation in care of the child.

Synthesized finding 2: Having a child in intensive care can be an experience of significant impact for families

A total of 12 findings (6 unequivocal, 6 credible) from all 6 qualitative studies[37,76–80] created the 2 categories for the second synthesized finding (see Table 5). The synthesis highlighted the considerable impact that ICU hospitalization has on parents and families who have or have had a child in an ICU. Study findings showed that this experience can affect the whole family and result in worry and anxiety. Studies reported that interventions to support anxious parents were sometimes helpful but sometimes not. They also found that parental perceptions of readiness for discharge to home were greatly influenced by the support in discharge preparation.

Table 5: Synthesized finding 2: Having a child in intensive care can be an experience of significant impact for families

Category 4: Preparation for going home is critical to parents' perceptions of readiness
"The dates prepare you for going home" so "Do it right at the beginning"[78] (U)
Coming home[79] (U)
Emotional preparation: "uncertainty, feeling rushed, motivation to get home"[78] (C)
Practical preparation: "knowledge and skills transfer, but not enough notice"[78] (C)
Transition to a parental role[80] (U)
Category 5: Interventions to support anxious parents during their child's hospitalization can be helpful but not always
Concerned and worried toward alert and vigilant[79] (U)
Decreases parental anxiety[77] (C)
Increases parental confusion and/or anxiety[77] (C)
Hospitalization – a stressful setting[79] (U)
Miracle Babies psychosocial support[76] (C)
The fathers were occupied by worries and concerns[37] (C)
Emotional support[80] (U)

C, credible; U, unequivocal

Integration of quantitative evidence and qualitative evidence

Are the results/findings from individual syntheses supportive or contradictory?

Qualitative synthesis found that having a child in intensive care can significantly impact a family. Similarly, quantitative studies showed the presence of increased stress, anxiety, and depression in parents with infants or children in intensive care prior to interventions. Furthermore, qualitative studies found that interventions that incorporate partnerships between families and the health care team can improve the families' experience and capacity to care for the child. This was also seen in quantitative studies, with improvement in some studies and across some outcomes. Similarly, the potential for partnership interventions to not be beneficial was seen in both qualitative and quantitative studies. Both qualitative and quantitative studies found positive results for satisfaction with FCC.

Does the qualitative evidence explain why the intervention is or is not effective?

There was no clear distinction in the qualitative studies between stress and anxiety, and these often overlapped in study findings.[37,77,79] There were not strong qualitative data to fully explain the effectiveness of the interventions on stress. One study discussed how the high stress nature of infant hospitalization in a NICU was present even with previous NICU hospitalization experience.[79] However, the support and advice that was received through the partnership intervention improved stress more than just having existing experience.

> *We saw a very big difference. Both of our preterm born children had the same problems. They were vulnerable and needed a lot of close contact. With our first child we didn't know how to respond. When I had my second preterm baby and got advice from the nurse, I almost cried because I realized how many mistakes I had made with the first. … The advice we got was really helpful … and the reason that it was so much better with the second was not, I think, because we had experience, but simply because we got so much good advice during the intervention that worked.*[79(p.5)]

Another study found that even though the intervention decreased stress associated with the monitoring equipment, there was then stress associated with the removal of that monitoring.[37] The authors also

found that, in addition to the focus of partnering to care for the infants, an individualized focus on the parental support would have been helpful to identify parent specific needs: "… a bit more attention to M (the mother). There is so much focus on the child already."[37(p.1147)]

Another study found that parents were not universal in their preferences for emotional support.[80] Some parents preferred and valued the involvement and support of the health care team, whereas others preferred the support of their partner, family, or peers. At times, anxiety was discussed separately from stress in qualitative studies, and it was found that parental involvement in rounding could increase anxiety due to confusion from the volume and complexity of medical information.[77] Conversely, the study also found that parental inclusion in rounding could decrease anxiety due to improved understanding about the child's health status. Additionally, 1 study suggested that parental anxiety naturally reduces with time and improved health stability.[79]

In an exploration of satisfaction, synthesis of quantitative studies suggested that parents in the intervention groups had increased satisfaction with FCC compared with parents in control groups. Qualitative studies also concurred with this finding; however, there was limited clarity about why this may be the case.[37,76,77,79] While interventions were varied, they typically resulted in increased involvement of parents, and this increased involvement seemed to support parental satisfaction.[77] Where an intervention involved education and capacity-building for the parents, it increased their confidence, which also supported parental satisfaction.[79] Other suggestions were that parents playing an active role in partnering with the health care team promoted parental satisfaction.[37] This could be because many parents want to partner in their child's care and, when this occurs, they experience increased satisfaction.

There was minimal exploration of attachment in qualitative studies. One study found that fathers appreciated the opportunity to take increased responsibility in infant care and this supported partnership.[37] Another study found that active partnership in infant care empowered the parental role, and that this was anticipated and desired by parents.[80] Partnership enabled parents to feel that they were contributing in their parental role, which included responsibilities and feelings. Having increased active partnership promoted the capacity and opportunity to fulfill this role.

Does the qualitative evidence explain differences in the direction and size of effect across the included quantitative studies?

There were insufficient qualitative data to explain differences in the direction and size of effect across the included quantitative studies.

Which aspects of the quantitative evidence were (or were not) explored in the qualitative studies?

While some quantitative studies assessed depression and quality of life, there were no qualitative studies that specifically explored these outcomes.

Which aspects of the qualitative evidence were (or were not) tested in the quantitative studies?

A qualitative study explored parental readiness,[79] but this outcome was not reported in any of the quantitative studies.

Discussion

This review presents the impact of partnership interventions between families and health care teams on multiple parental and family outcomes when they have a child in a NICU or PICU. The importance of partnership with parents and families has been highlighted in the effect on psychosocial outcomes in this review. Through various partnership interventions, positive improvement was seen in parental stress, anxiety, and satisfaction with FCC. There were few consistent interventions across the included studies, and the impact of these interventions was also varied. The heterogeneity within the interventions hindered the identification of the effectiveness of partnership interventions and affected the clarity of the degree of impact of the partnership interventions. Due to this variability, it is not possible within this review to identify the ideal partnership intervention to optimize family outcomes. This aligns with other research that, using varied types of interventions in parents of children in intensive care, was unable to identify an optimal intervention.[81] Nevertheless, it found that some types of interventions could be beneficial to parents. Within this review, a number of studies used a combination of interventions to support parents, and this may present opportunities to

leverage the benefits from different types of interventions. Partnership with parents can also help support the development of knowledge, competence, and trust.[16] While there was limited measurement of this in the studies within this review, the studies provide additional depth for the potential impact of partnership with families.

The absence of siblings from any of the interventions ignores the considerable impact that an intensive care hospitalization of a sibling can have. Siblings of a hospitalized child can experience symptoms such as stress, worry, fear, shock, or sadness.[82] This is likely to be multifactorial and could relate to the change in the home routine, exposure to an unfamiliar environment, reduced access to parents due to split location of parenting (home and hospital), effect of increased parental stressors, and concern for their sibling. It is also likely that the age of the sibling would influence the effect of having a sibling hospitalized in intensive care. For example, a non-hospitalized twin of a neonate may demonstrate altered developmental and/or physical growth, whereas an older adolescent sibling may show withdrawal, misbehavior, or changes in independence. With the exploration of the impact of intensive care hospitalization on siblings comes the question of whether a partnership intervention would be effective in improving outcomes for the siblings. The health care team may need support to effectively involve and educate siblings.[83] These approaches to sibling support should be delivered in a developmentally appropriate manner.[82] Efforts to improve health professionals' skills may extend beyond the support of the siblings and also enable the parents to better understand and support the sibling. While interventions may need to be adapted to the age of the sibling or supported by well-trained health professionals, the effect of appropriate interventions can extend to the whole family.[84]

The impact of ICU hospitalization on grandparents should also not be underestimated. A study found that when grandparents were supported and included in NICU care, not only did it support their own well-being, but they were also better able to provide understanding and support to the infant's parents.[85]

Limitations

Given the nature of the interventions relevant to this review, it is unlikely that a study could appropriately blind participants or the treating team to the allocation of control and experimental groups.

There were no exclusion criteria related to methodological quality. Given the small numbers of studies related to certain outcomes, this was appropriate. It has meant, however, that some results were obtained from studies with lower methodological quality. This has resulted in lower strength in the recommendations from the synthesis.

There was a small number of qualitative studies on this topic compared to quantitative studies. There were no mixed methods studies that met the inclusion criteria. There were multiple outcomes that had small numbers of studies examining them. These included adjustment, breastfeeding, coping, decision-making/conflict, home environment, interaction, motivation, psychological well-being/distress, rounding, support, trauma, and worry.

Studies were predominantly located in NICUs, thus results are more reflective of these environments than PICUs. Further, while there were studies from countries within Europe, Asia Pacific, and North America, there was minimal representation from South America and none from countries in Africa.

There was high methodological heterogeneity across the studies. While random effects and a standardized mean difference were used to mitigate this, there were also clinical factors contributing. There is no standardized partnership intervention and there was high clinical heterogeneity in the interventions that were undertaken in the included studies. While they all used partnerships between the health care team and families (primarily parents), they had varied complexity, duration, and components. There were some common outcome measurement tools in some of the outcome measures; however, there was still considerable variation in the tools that were used. A standardized mean difference was used to reduce this impact. There was varied timing in the assessment of intervention outcomes, and there was not always assessment of pre-intervention outcomes. This may have introduced an additional risk of bias that was not measurable.

Conclusions

This review has highlighted the considerable impact of infant or child hospitalization on families, particularly parents. While this impact can be broad, this review focused on the impact of partnerships between

the health care team and families on psychosocial outcomes. There are multiple interventions that have been examined with mixed results. There is no clear, single partnership intervention that can be recommended based on effectiveness; however, multiple interventions have demonstrated significant improvements in outcomes for parents. Family experiences of partnership interventions showed the considerable impact of hospitalization, along with the potentially positive impact that partnerships can achieve. These results highlight the importance of parents as partners within health care as well as the need for further research to clarify the optimal strategies to achieve this.

Recommendations for practice

The presence of many studies with low methodological quality along with high intervention heterogeneity affected the findings and the strength of the recommendations from this review. The effect of NICU/PICU hospitalization on parents is clear within the included studies, and interventions that partner with families can improve outcomes such as stress, anxiety, and satisfaction with FCC. It is recommended that clinicians ensure that parents and families are empowered to be active partners within their child's care in all phases of health care (Grade B).

Recommendations for research

Future research could use components of effective studies to determine the ideal type of partnership intervention in PICUs and NICUs. Due to the paucity of qualitative and mixed methods research on this topic, it is recommended that future studies incorporate a mixed methods approach to ensure that the qualitative perspective is examined alongside the quantitative. Future research could examine the impact of partnerships with families in PICU/NICU settings on other outcomes, such as breastfeeding, empowerment, psychological well-being/distress, support, adjustment, decision-making/conflict, discharge readiness, enabling, home environment, interaction, mood, motivation, rounding, trauma, and worry. Most of the available research was for NICUs, yet there are important differences in the populations and experiences of families in PICUs. Additional research to further explore the impact of partnerships in PICUs is needed. Furthermore, it is important to examine and explore whether the results observed in parents through partnerships are replicated in the siblings of the child. Additionally, research could expand to the extended family of children, such as grandparents.

Author contributions

SB: conceptualization, methodology, literature search, selection of studies, data extraction, data synthesis, writing (original draft and editing); IM, ZR: selection of studies, data extraction, data synthesis, writing (review and editing); VdG, CG: conceptualization, methodology, selection of studies, data extraction, data synthesis, writing (review and editing); CJ: literature search, writing (review and editing); ASR: conceptualization, methodology, selection of studies, data extraction, data synthesis, writing (review and editing), supervision.

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Appendix I: Search strategy

MEDLINE ALL (Ovid)

Search conducted: December 1, 2019; updated August 4, 2022 (n = 2730)

(Exp Intensive Care Units, Pediatric/ OR Exp Intensive Care, neonatal/ OR (((Pediatric OR paediatric OR neonatal OR newborn OR baby) ADJ5 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU).ab,ti,kf. OR (exp Intensive Care Units/ AND ("Adolescent"/ OR exp "Child"/ OR exp "Infant"/ OR Adolescent, Hospitalized/ OR Child, Hospitalized/ OR exp "Pediatrics"/ OR (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*).ab,ti,kf.))) AND (exp Family/ed,th OR exp Family health/ed OR ((exp Family/ OR (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR surrogate* OR sibling* OR brother* OR sister* OR gestational carrier OR Gestational Carriers OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other OR significant others OR legal guardian OR legal guardians).ab,ti,kf.) AND (Nursing process/ OR counseling/ OR exp "Psychotherapy"/ OR Self-Help Groups/ OR Peer Group/ OR Health Education/)) OR ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR surrogate* OR sibling* OR brother* OR sister* OR gestational carrier OR Gestational Carriers OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other OR significant others OR legal guardian OR legal guardians) ADJ6 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*")).ab,ti,kf.)

limit to yr = "2000 -Current"

Embase

Search conducted: December 1, 2019; updated August 4, 2022 (n = 4788)

('Intensive Care Units, Pediatric'/exp OR 'neonatal intensive care unit'/exp OR 'newborn intensive care'/de OR (((Pediatric OR paediatric OR neonatal OR newborn OR baby) NEAR/5 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU):ab,ti,kw OR (('Intensive Care Units'/exp) AND ('Adolescent'/exp OR 'Child'/exp OR 'Infant'/exp OR 'Pediatrics'/exp OR (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*):ab,ti,kw))) AND ('Family education'/exp OR 'family therapy'/exp OR ((Family/exp OR (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians"):ab,ti,kw) AND ('Nursing process'/exp OR counseling/exp OR 'Psychotherapy'/exp OR 'Self Help'/exp OR 'Peer Group'/exp OR 'Health Education'/exp)) OR ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians") NEAR/6 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*")):ab,ti,kw) AND [2000-2022]/py

CINAHL with Full text (EBSCOhost)

Search conducted: December 1, 2019; updated August 4, 2022 (n = 2579)

S1

(MH "Intensive Care Units, Pediatric+" OR MH "Intensive Care, Neonatal" OR MH "Pediatric Critical Care Nursing+" OR MH "Neonatal Intensive Care Nursing" OR AB (((Pediatric OR paediatric OR neonatal OR newborn OR baby) N4 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU) OR TI (((Pediatric OR paediatric OR neonatal OR newborn OR baby) N4 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU) OR MW (((Pediatric OR paediatric OR neonatal OR newborn OR baby) N4 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU) OR (MH "Intensive Care Units+" AND (MH "Adolescence+" OR MH "Child+" OR MH "Pediatrics+" OR TI (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*) OR AB (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*) OR MW (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*))))

S2

(MH "Family+/ed" OR ((MH "Family+" OR AB (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians") OR TI (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians") OR MW (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians")) AND (MH "Nursing process" OR MH "counseling" OR MH "Psychotherapy" OR MH "Support Groups" OR MH "peer group" OR MH "Health Education")) OR TI ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians") N5 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*")) OR AB ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR "legal guardians") N5 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*")) OR MW ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR "Gestational Carrier" OR "Gestational Carriers" OR caregiver* OR carer* OR careprovider* OR caretaker* OR "significant other" OR "significant others" OR "legal guardian" OR

"legal guardians") N5 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*")))

S1 AND S2

Publication date: 20000101-20221231

APA PsycINFO (Ovid) 1806 to April Week 1 2022

Search conducted: December 1, 2019; updated August 4, 2022 (n = 828)

(exp neonatal intensive care/ OR (((Pediatric OR paediatric OR neonatal OR newborn OR baby) ADJ5 ("intensive care" OR ICU)) OR PICU OR NICU OR PCICU).mp. OR (exp Intensive Care/ AND (exp Pediatrics/ OR (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR pediatric OR paediatric OR newborn* OR neonat*).mp.))) AND (family intervention/ OR ((parents/ or fathers/ or mothers/ OR (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR Gestational Carrier OR gestational carriers OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other OR significant others OR legal guardian OR legal guardians).mp.) AND (exp counseling/ OR exp Psychotherapy/ OR exp Health Education/ OR support groups/)) OR ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR Gestational Carrier OR gestational carriers OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other OR significant others OR legal guardian OR legal guardians) ADJ6 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR "self-help group*" OR "peer group*" OR "support groups*").mp.))

limit to yr = "2000 -Current"

*Web of Science Core Collection**

Search conducted: December 1, 2019; updated August 4, 2022 (n = 2371)

TS = (("PICU" OR "NICU" OR "PCICU" OR ("Intensive Care" AND ("prepube*" OR "preadolescen*" OR "adolescen*" OR "teenager*" OR "child*" OR "baby" OR "babies" OR "infant" OR "infants" OR "p$ediatric" OR "p$ediatrics" OR "newborn*" OR "neonat*"))) AND (("father*" OR "mother*" OR "families" OR "family" OR "familial" OR "relatives" OR "parent" OR "parents" OR "parental" OR "parenthood" OR "stepparent*" OR "stepfamily" OR "stepfamilies" OR "kinship*" OR "Surrogate*" OR "sibling*" OR "Gestational Carrier*" OR "brother*" OR "sister*" OR "caregiver*" OR "carer*" OR "careprovider*" OR "caretaker*" OR "significant other*" OR "legal guardian*") NEAR/5 ("Program*" OR "Workshop*" OR "involvement" OR "empowerment" OR "engagement" OR "communication" OR "participation" OR "partnership" OR "presence" OR "training" OR "collaboration" OR "Teach*" OR "Intervention*" OR "counsel*" OR "education*" OR "nursing process" OR psychotherap* OR "self-help group*" OR "peer group*" OR "support groups*")))

Timespan: 2000-01-01 to 2022-12-31 (Publication Date)

* The Core Collection includes the following databases: Science Citation Index Expanded (1900-present), Social Sciences Citation Index (1900-present), Arts and Humanities Citation Index (1975-present), Conference Proceedings Citation Index- Science (1990-present), Conference Proceedings Citation Index- Social Science and Humanities (1990-present), Book Citation Index–Science (2005-present), Book Citation Index–Social Sciences & Humanities (2005-present), Emerging Sources Citation Index (2015-present), Current Chemical Reactions (1985-present; i ncludes Institut National de la Propriete Industrielle structure data back to 1840), Index Chemicus (1993-present).

ProQuest Dissertations and Theses Global

Search conducted: December 1, 2019; updated August 4, 2022 (n = 263)

(TIABSU(((“Pediatric” OR “paediatric” OR “neonatal” OR “newborn” OR “baby”) NEAR/5 (“intensive care” OR “ICU”)) OR “PICU” OR “NICU” OR “PCICU”) OR (SU(“Intensive care”) AND TIABSU (“prepubescent” OR “preadolescent” OR “adolescent” OR “teenager” OR “child*“ OR “baby” OR “babies” OR “infant” OR “infants” OR “pediatric” OR “pediatrics” OR “paediatric” OR “paediatrics” OR “newborn*“ OR “neonat*“))) AND ((TIABSU(“father*“ OR “mother*“ OR “families” OR “family” OR “familial” OR “relatives” OR “parent” OR “parents” OR “parental” OR “parenthood” OR “stepparent” OR “stepfamily” OR “stepfamilies” OR “kinship*“ OR “Surrogate*“ OR “sibling*“ OR “brother*“ OR “sister*“ OR “Gestational Carrier” OR “Gestational Carriers” OR “caregiver*“ OR “carer*“ OR “careprovider*“ OR “caretaker*“ OR “significant other” OR “significant others” OR “legal guardian” OR “legal guardians”) AND SU(“Nursing process” OR “counseling” OR “Psychotherapy” OR “Self-Help Groups” OR “Peer Groups” OR “Health Education”)) OR TIABSU((“father*“ OR “mother*“ OR “families” OR “family” OR “familial” OR “relatives” OR “parent” OR “parents” OR “parental” OR “parenthood” OR “stepparent” OR “stepfamily” OR “stepfamilies” OR “kinship*“ OR “Surrogate*“ OR “sibling*“ OR “brother*“ OR “sister*“ OR “Gestational Carrier” OR “Gestational Carriers” OR “caregiver*“ OR “carer*“ OR “careprovider*“ OR “caretaker*“ OR “significant other” OR “significant others” OR “legal guardian” OR “legal guardians”) NEAR/6 (“Program*“ OR “Workshop*“ OR “involvement” OR “empowerment” OR “engagement” OR “communication” OR “participation” OR “partnership” OR “presence” OR “training” OR “collaboration” OR “Teach*“ OR “Intervention*“ OR “counsel*“ OR “education*“ OR “self-help group*“ OR “peer group*“ OR “support groups*“)))

Publication date: 01 January 2000 to 1 December 2022

Cochrane CENTRAL Register of Controlled Trials

Search conducted: December 1, 2019; updated August 4, 2022 (n = 751)

((PICU OR NICU OR PCICU OR (“Intensive Care” AND (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR baby OR babies OR infant OR infants OR p*ediatric OR p*ediatrics OR newborn* OR neonat*))) AND ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR “Gestational Carrier” OR “Gestational Carriers” OR brother* OR sister* OR caregiver* OR carer* OR careprovider* OR caretaker* OR “significant other” OR “significant others” OR “legal guardian” OR “legal guardians”) NEAR/6 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education* OR “nursing process” OR psychotherap* OR “self-help group” OR “peer group” OR “support group” OR “self-help groups” OR “peer groups” OR “support groups”))):ab,ti,kw

With Publication Year from 2000 to 2022

DART Europe E-theses Portal

Search conducted: December 1, 2019; updated August 4, 2022 (n = 53)

(“Pediatric Intensive Care” OR “Paediatric Intensive Care” OR “Neonatal Intensive Care” OR PICU OR NICU OR PCICU) AND (involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach OR Intervention OR counsel OR education) AND (father OR mother OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood)

Appendix II: Studies ineligible following full-text review

Reason for exclusion: ineligible language (n = 6)

1. Bastani F, Ali Abadi T, Haghani H. The effectiveness of participatory care program in neonatal intensive care unit on state anxiety of mothers of preterm newborns. J Babol Univ Med Sci. 2012;14(3):59–65.
2. Eun Sook K, Yong Ae C. The effect of fathers' kangaroo care experience of preterm babies on paternal attachment. J Korean Crit Care Nurs. 2017;10(2):45–55.
3. Jang YS. [Effects of a workbook program on the perceived stress level, maternal role confidence and breast feeding practice of mothers of premature infants]. Taehan Kanho Hakhoe Chi. 2005;35(2):419–27. [Chinese]
4. Khajeh M, Karimi R, Sadat Hosseini AS. The effect of parents empowerment program on their beliefs about parental role, behaviors and characteristics of their premature infants in NICU. J Urmia Nurs Midwif Faculty. 2013;11(6):419–27.
5. Martínez Gertner M. [Efficacy of a brief early intervention based on the assessment of the development of the premature neonate: effect on stress, depression and maternal perceptions] [thesis]. Universitat Autonoma de Barcelona; 2010. [Spanish]
6. Villamizar-Carvajal B, Vargas-Porras C, Garcia-Corzo JR. Decrease of premature mothers' stress levels in the intensive care unit. Enferm Intensiva. 2018;29(3):113–20.

Reason for exclusion: ineligible publication type (n = 77)

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5. Programs follow moms through pregnancy, NICU: case management is program's strongest component. Case Management Advisor. 2007;18(6):52–4.
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Reason for exclusion: Unable to retrieve full text (n = 8)

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Appendix III: Characteristics of included studies

Randomized controlled trials

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Description of main results
Bastani *et al.*,[38] 2015	Iran	Large maternity hospital NICU	Mothers aged between 18 and 35 years, with a preterm infant weighing > 2000 g and a gestational age between 30 and 37 weeks	Experimental group: FCC (n = 50) Control group: Usual care (n = 50)	Maternal satisfaction	There were no statistically significant differences in maternal satisfaction prior to the intervention. After the intervention, experimental group had significantly higher maternal satisfaction.
Borghini *et al.*,[39] 2014	Switzerland	Metropolitan university hospital NICU	Mothers with a mean age of 33–35 years of infants with a mean gestational age of 30 weeks Mothers of full-term infants in a separate control group	Preterm experimental: Joint observation and interaction guidance (n = 26) Preterm control: Usual care (n = 29) Full-term control group (n = 23)	Post-traumatic stress symptoms Mother-infant interactions	Mothers of preterm infants in experimental and control groups had statistically significant higher rates of post-traumatic stress symptoms than mothers of full-term infants at 42 weeks gestational age. This significant difference continued with the preterm control groups at 4 and 12 months. Mothers in the preterm experimental group had a significant reduction in post-traumatic stress symptoms between 42 weeks gestational age and at both 4 and 12 months.
Cheng *et al.*,[40] 2021	Canada, Australia, and New Zealand	26 tertiary NICUs	Mothers with a mean age of 31.3 years, > 90% were married	Experimental group: FICare (n = 710) Control group: Usual care (n = 673)	Stress Anxiety	There were no significant differences in stress scores prior to the intervention, but the experimental group had significantly lower scores following the intervention. The experimental group had significantly higher anxiety scores prior to the intervention and significantly lower scores following the intervention.
Glazebrook *et al.*,[41] 2007	United Kingdom	6 neonatal centers	Mothers with an average age of 30	Experimental group: Parent-baby interaction	Primary outcome: maternal stress	There were no significant differences

(*Continued*)

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Description of main results
			(experimental)/29 (control) years, predominantly first-time mothers with White European ethnicity of infants born at < 32 weeks' gestational age	program (n = 99) Control group: Described as normal care (n = 111)	Secondary outcome: caregiver-child interaction, infant neurobehavior, home environment	in maternal stress between intervention and control groups. There were no significant differences for infant outcomes between intervention and control groups.
Heo and Oh,[42] 2019	Republic of Korea	NICU in an urban hospital	Mother-father dyads with a mean age of 35 years with premature infants born at < 37 weeks' gestational age	Experimental group: Parent Participation Improvement Program (n = 60) Control group: Usual care, including unlimited visitation, general condition information, and option to deliver feeding or kangaroo care (n = 64)	Primary outcomes: nurse-parent partnership; maternal attachment Secondary outcome: infant weight	Parents in the experimental group had significantly higher partnership and attachment scores compared with the control group. There were no significant differences between infant weights.
Hoffenkamp *et al.*,[43] 2015	Netherlands	2 NICUs and 7 maternity wards	Mothers and fathers with a mean age between 30.8 and 34.1 years of infants born between 32 and 37 weeks' gestational age	Experimental group: Video interaction guidance (n = 75 families [mother +/-father]) Control group: Standard care including parent education and participation (n = 75 families [mother +/-father])	Interactive behavior, bonding, stress and psychological well-being, trauma	Parents in the experimental group had significantly higher parental sensitivity compared to the control group at mid- and post-intervention measurements, along with mid-intervention parental bonding. There were no significant differences for parental intrusiveness or parental stress. There were mixed results for parental withdrawal.
Holditch-Davis *et al.*,[44] 2013	United States	4 NICUs	Mothers with a mean age of 27 years of preterm infants with a birth weight < 1750 g	Experimental group: Auditory-Tactile-Visual-Vestibular intervention (n = 67) Experimental group: Kangaroo care (n = 68) Control group: Not prevented from intervention activities but not educated on them (n = 73)	Maternal satisfaction Psychological distress	There were no statistically significant overall differences in satisfaction between the control or experimental groups. There were some small significant improvements in some psychological outcomes.
Holditch-Davis *et al.*,[45] 2014	United States	4 hospital NICUs	Mothers with a mean age of 27.1 years of preterm infants with a birth weight < 1750 g	Experimental group: Auditory-Tactile-Visual-Vestibular intervention (n = 78) Experimental group: Kangaroo care (n = 81) Control group: Not prevented from intervention activities	Psychological distress Mother-infant relationship	There were no statistically significant overall differences in satisfaction between the control or experimental groups.

(*Continued*)

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Description of main results
				but not educated on them (n = 81)		
Kaaresen *et al.*,[46] 2006	Norway	NICU in university hospital	Mothers with a mean age of 29.4-30.7 years of infants born ≤2000 g or infants born at a gestational age ≥37 weeks	Experimental group: Preterm infants receiving a modified Mother-Infant Transaction Program, including pre- and post-discharge sessions with neonatal nurses (n = 72) Control group: Preterm infants receiving standard discharge protocol including examinations and training (n = 74) Control group: Full-term infants receiving routine clinical examination on day 3 of life (n = 75)	Parenting stress	Following the intervention, the experimental group had significantly lower stress scores at both 6 and 12 months compared with the preterm control group, with the exception of the child domain at 12 months.
Lee *et al.*,[47] 2019	Hong Kong SAR	NICU in regional teaching university	Mothers aged 23-43 years of infants born at < 32 weeks' gestational age	Experimental group: Usual care plus guided participation with nurse consultant (n = 15) Control group: Usual care with infant condition updates and follow-up with parents (n = 15)	Primary outcomes: mother's efficacy and satisfaction with parenting Secondary outcomes: mothers perceived stress	Following the intervention in the experimental group, there were initial significant improvements for mothers' regulation of negative affect and behaviors during feeding; however, this significant improvement was not sustained. Greater improvements in the C-PSOC score were observed in the experimental group than in the control group at T1 and T2, although these differences were statistically insignificant. The experimental group exhibited greater improvements than the control group in the C-PSS scores at T1, T2, and T3, although these differences were also not statistically significant.
Matricardi *et al.*,[48] 2013	Italy	NICU	Mothers and fathers with a mean age between 34.95 and 38.35 years of infants born at < 32 weeks' gestational age	Experimental group: Physical therapist joint observation and infant massage (n = 21) Control group: Standard support (n = 21)	Primary outcome: parental stress Secondary outcome: Infant condition	There were significantly higher stress levels in mothers compared with fathers. Following the intervention, stress

(*Continued*)

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Description of main results
						levels were significantly reduced in mothers but not fathers
O'Brien *et al.*,[49] 2018	Canada, Australia, and New Zealand	26 Tertiary NICUs	Parents of infants born at ≤33 weeks' gestational age	Experimental group: FICare (n = 738 mothers) Control group: Described as standard care (n = 705 mothers)	Primary outcome: infant weight gain Secondary outcomes: weight gain velocity, breastfeeding frequency, parental stress and anxiety, NICU mortality and major morbidity, safety, resource use	Prior to the intervention, there were no significant differences in mean scores for parental stress and anxiety. At day 21, both groups had lower mean scores for stress and anxiety; however, parents in the experimental group had significantly lower mean scores for stress and anxiety.
Samra *et al.*,[50] 2015	United States	NICU in a tertiary medical center	Mothers with a mean age of 25 years of infants born between 34 and <37 weeks	Experimental group: Skin-to-skin care (n = 20) Control group: Holding infant in blanket (n = 20)	Maternal stress Infant physiologic stability	Following the intervention, there were no significant differences in stress scores between the experimental and control groups. Length of time performing skin-to-skin care showed a significant correlation with improvement in overall stress scores.
Weis *et al.*,[51] 2013	Denmark	Level III NICU in university referral hospital	Parents with a mean age of 32.5 years of infants with a gestational age of ≤34 weeks	Experimental group: Guided FCC (n = 74) Control group: Standard care including unrestricted visiting, discussion in rounds, contact nurses (n = 60)	Parental stress Nurse support	Following the intervention, there were no significant differences in parental stress or nurse support between the experimental and control groups. Mothers reported significantly more stress than fathers.
Welch *et al.*,[52] 2016	United States	Level IV NICU in a children's hospital	Mothers with a mean age of 33.9 (experimental)/33.8 (control) years of infants born between 26 and 34 weeks' gestational age	Experimental group: Family nurture intervention (n = 59) Control group: Standard care with mothers able to self-initiate nurturing activities as desired (n = 56)	Depressive symptoms Anxiety Maternal motivation	Following the intervention at 4 months infant corrected age, the experimental group had significantly lower mean scores for anxiety and depressive symptoms compared with the control group.

(*Continued*)

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Description of main results
Xie *et al.*,[56] 2017	China	NICU in a children's hospital	Mothers with mean age of 31 years of infants with mean gestational age of 31 weeks	Experimental group: Early parent interaction (n = 79) Control group: Standard care, including kangaroo care, nesting, and minimal handling (n = 72)	Maternal knowledge Experience Depression Coping Infant neurodevelopmental functioning and mother-infant interaction	Following the intervention, mothers in the experimental group showed significant reductions in the risk of late postpartum depression compared with mothers in the control group. There were no significant differences between the 2 groups in early maternal adjustment, late mother-infant relationship, early or later infant development.
Yilmaz and Küçük Alemdar,[53] 2022	Turkey	NICU	Mothers aged between 15 and 30+ years of infants born between 28 and 38 weeks' gestational age	Experimental: Educational and supportive nursing intervention (n = 50) Control: Described as no other intervention (n = 50)	Stress NICU parent belief Anxiety Saliva cortisol	Following the intervention, the experimental group showed statistically significant improvements in parental belief and anxiety.
Zelkowitz *et al.*,[54] 2011	Canada	2 NICUs in tertiary care hospitals	Mothers with a mean age of 31.1 (experimental)/30.8 (control) years of infants with a birth weight < 1500 g	Experimental group: Intervention to understand infant cues (n = 60) Control group: Access to care intervener, infant care information, and standard medical care (n = 61)	Maternal anxiety Stress Post-traumatic stress symptoms Mother-infant interaction Postnatal depression Infant illness severity Knowledge of intervention	Following the intervention, there were no significant differences in psychological outcomes between the experimental and control groups. There was a significant improvement in intervention knowledge for the experimental group.
Zhang *et al.*,[55] 2018	China	NICU in a tertiary children's hospital	Parents with a mean age of 31.81 (fathers)/37.61 (mothers) [experimental]/32.6 (fathers)/28.13 (mothers) [control] years of infants born at ≤ 37 weeks' gestational age	Experimental group: FCC intervention (n = 66) Control group: Standard care with physician communication 3 times per week and visiting only in special circumstances (n = 54)	Parental stress Anxiety Satisfaction Breastfeeding rate and knowledge Infant clinical outcomes	Following the intervention, parents in the experimental group had significantly lower mean scores for stress and anxiety and higher satisfaction and knowledge. Infants in the experimental group had significantly better clinical outcomes for weight gain, length of stay, and readmission.

C-PSOC, Chinese version of Parenting Sense of Competence Scale; C-PSS, Chinese version of Perceived Stress Scale; FCC, family-centered care; FICare, family-integrated care; NICU, neonatal intensive care unit

Quasi-experimental studies

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Main description of results
Cano Gimenez *et al.*,[57] 2015	Spain	NICU in an acute care university hospital	Mothers, mean age 33.9 (experimental)/32.6 (control) years Fathers, mean age 34.9 (experimental)/36.5 (control) years Infants born at > 36 weeks' gestation	Experimental group: Face-to-face intervention program (mothers n = 40; fathers n = 25) Control group: Usual care (mothers n = 40; fathers n = 29)	Parental stress Anxiety Depression	No significant differences between control and experimental groups for stress at day 3 of admission. At day 15 of admission, significant difference in anxiety showed lower levels in parents in experimental group. There were also significantly lower levels of depression in parents in the experimental group.
Cho *et al.*,[73] 2016	South Korea	General hospital	Mothers aged between 26 and 36+ years of preterm infants > 33 weeks' corrected gestational age	Experimental group: Kangaroo care (n = 20) Control: Usual care (n = 20)	Maternal-infant attachment Maternal stress	The experimental group had significantly higher scores for maternal-infant attachment following the intervention than the control group. The experimental group also had lower maternal stress following the intervention.
De Bernardo *et al.*,[75] 2017	Italy	NICU in a tertiary hospital	Mothers and fathers with mean ages of 34.81 (experimental)/35.65 (control) years of infants with mean gestational age of 32.7 (experimental)/ 34.2 (control) weeks	Experimental group: FCC (n = 24 mothers; n = 24 fathers) Control group: Non-family-centered care (n = 24 mothers; n = 24 fathers)	Stress Satisfaction	Following the intervention, parents in the experimental group showed higher levels of satisfaction and decreased stress levels compared with the control group.
Genesoni,[36] 2012	United Kingdom	Metropolitan NICUs	Parents of infants born at < 37 weeks' gestation and 2000 g	Experimental: Kangaroo care full intervention (n = 33) Experimental: Kangaroo care limited intervention (n = 23) Control group: Described as traditional hospital care (n = 34)	Primary outcomes: Parental stress, maternal bonding, mother-infant interaction Secondary outcomes: Proximal environment, infant development	Mothers in the experimental group had significantly less stress at discharge and 6 months corrected age than the control group; however, this difference was not significantly sustained at 3, 9, or 12 months corrected age. No significant differences were seen in anxiety, bonding, or interaction; however, these improved over time for experimental and control groups. The intervention did not directly influence fathers' psychological stress and the formation of father-infant relationships.

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Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Main description of results
Ghomi *et al.*,[58] 2019	Iran	NICU	Mothers of infants born at < 37 weeks with no congenital malformation and starting oral breastfeeding	Single pre-/post-group (n = 40)	Perceptions of susceptibility, severity, benefits and barriers; cues to action, self-efficacy, knowledge, caring behaviors	There were significant differences before and after the intervention for perceptions of susceptibility, severity, and benefits, as well as self-efficacy, knowledge, and caring behaviors. There were no significant differences for perceived barriers and cues to action.
Gustafson *et al.*,[59] 2016	United States	NICU in a children's hospital	Parents with a mean age of 32 (experimental)/33 (control) years of infants hospitalized in NICU	Experimental: Routine care plus invitations to attend multidisciplinary rounds (n = 86) Control: Routine care with no inclusion in multidisciplinary rounds (n = 46)	Primary outcomes: Parental stress Secondary outcomes: Parental anxiety and coping	Following the intervention in the experimental group, there were significant reductions in stress compared to pre-intervention; however, these reductions were not significantly different to the control group. Mothers had significantly higher mean stress levels than fathers.
Kardas Ozdemir *et al.*,[60] 2017	Turkey	Level II NICU	Fathers with a mean age of 27.4 years of infants with a mean gestational age of 35.65 weeks	Experimental: Post-intervention (n = 47) Control: Pre-intervention (n = 47)	Primary outcomes: Parental stress Secondary outcomes: Parental anxiety and coping	Following the intervention in the experimental group, there were significant reductions in stress compared to pre-intervention; however, these reductions were not significantly different to the control group. Mothers had significantly higher mean stress levels than fathers.
Kuntaros *et al.*,[61] 2007	Thailand	PICU	Mothers of children hospitalized in PICU	Experimental: Mothers and families permitted to visit child as desired and have greater involvement in the child's care (mother-child dyad n = 16) Control: Described as usual care (mother-child dyad n = 16)	Primary outcomes: Parental self-efficacy Secondary outcomes: Satisfaction with nursing care	Prior to the intervention, there was no significant difference in pre-test self-efficacy scores for experimental and control groups. Following the intervention, the experimental group had a significantly higher score. Parental satisfaction was significantly higher in the experimental group.
Ladak *et al.*,[33] 2013	Pakistan	PICU and pediatric CICU	Parents (mean age 34 years) of children admitted to PICU or pediatric CICU for at least 2 days	Experimental: Family-centered rounds at the bedside (n = 41) Control: Traditional rounds with health care team, but no parental presence (n = 41)	Parental satisfaction Health care professional satisfaction	There was no statistically significant difference found in parental satisfaction with care between experimental and control groups. Parents attending the

(*Continued*)

Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Main description of results
						family-centered rounds expressed a greater sense of inclusion in discussion at rounds, as well as decision-making related to care. In addition, ratings were significantly higher on evidence of teamwork and use of simple language by doctors during rounds during family-centered rounds.
Lee *et al.*,[62] 2013	Hong Kong SAR	NICU	Fathers (mean age 36.66 [control]/35.85 [experimental] years) of infants born at < 37 weeks' gestation	Experimental: Booklet and nursing guidance (n = 34) Control: Described as routine care (n = 35)	Parental stress Fathering ability Nurse support	There were statistically significant reductions in stress and increases in fathering ability and perceptions of nurse support in fathers in the experimental group compared with the control group.
Luu *et al.*,[63] 2017	Canada	NICU	Parents of infants born at < 30 weeks' gestation that survived to 32 weeks' post-menstrual age	Experimental: Internet-based education platform, in-person workshops, and phone/ email follow-up after discharge (n = 51) Control: Standardized developmentally appropriate care, including neurodevelopmental assessment at follow-up clinic and optional skin-to-skin holding workshops (n = 45)	Parental stress Perceptions and behaviors Feasibility Acceptability Infant neurodevelopmental outcomes	There were no significant differences in overall stress, perceptions, behaviors, or in neurodevelopmental outcomes. The education platform was predominantly deemed to be acceptable by participants. Parents in the experimental group had a significantly higher median score on the coercive behavior scale.
Mansson *et al.*,[64] 2019	Sweden	NICU	Parents of infants born at < 37 weeks' gestational age and hospitalized in NICU	Experimental: Neonatal parent support program; mothers (n = 51) and fathers (n = 50) from n = 52 families Control: Pre-intervention control; mothers (n = 65), fathers (n = 65) from n = 65 families	Parental stress	There was no significant difference in total stress or as measured by subscales for experimental and control groups.
Michelson *et al.*,[65] 2020	United States	2 PICU/CICUs	Parents of children hospitalized in PICU	Experimental: PICU supports, including navigator, handbook, and communication log (n = 112) Comparator: Information brochure (n = 104) Lost to follow-up (n = 166)	Satisfaction Decision regret Anxiety Depression Post-traumatic distress Health quality of life Satisfaction with decisions, acceptability, and	Following the intervention, there were no significant effects in the experimental group in main outcome measures.

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Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Main description of results
					perceived effectiveness of intervention	
Miles *et al.*,[74] 2006	United Kingdom	2 urban tertiary NICUs	Mothers and infants born at < 32 weeks' gestational age	Experimental: Skin-to-skin intervention (n = 46) Control: Informal support (n = 32)	Primary outcomes: Psychological well-being, confidence in caregiving, maternal attachment Secondary outcomes: Infant stress and behavior	No significant differences between control and experimental groups for baseline characteristics, infant or maternal scores.
Ong *et al.*,[66] 2019	Malaysia	Level III NICU	Parents of infants with a gestational age of 27-34 weeks hospitalized in NICU	Experimental: Structural nursing intervention (n = 108) Control: Pre-intervention sample with no formal orientation or psychological support (n = 108)	Primary outcomes: Parental stress Secondary outcomes: Maternal ability	For parental stress, both the control and experimental groups had significant decreases in stress at the post-test point. For maternal ability, there were no significant differences between the control and experimental groups prior to the intervention. Following the intervention, there was significantly increased mean scores in the experimental group.
Penticuff and Arheart,[67] 2005	United States	2 NICUs	Parents predominantly aged between 20 and 29 years of premature infants with ≤ 1500 g birth weight hospitalized in NICU	Experimental: Infant progress chart and care planning meetings (n = 77) Control: Described as usual care (n = 77)	Parental comprehension Satisfaction Decision conflict Shared decision-making	Following the intervention, the experimental group had significantly different results for uncertainty, unrealistic concerns, amount of shared decision-making, infant complications, and satisfaction with decision input and process.
Piris-Borregas *et al.*,[68] 2018	Spain	Level IIIC NICU	Parents with a mean age between 32.89 and 35.54 years of infants with a mean gestational age between 31.6 and 32.6 weeks	Experimental: Parents opting into adapted FCC model, including parents on medical rounds (n = 47) Control: Parents opting out of intervention (n = 26) Historical control: Traditional rounds (prior to intervention; n = 63)	Primary outcomes: Parental stress Secondary outcomes: Parental satisfaction	Following the intervention, there were no significant differences between experimental and control for stress or satisfaction except for stress related to sights and sounds.
Salmani and Champiri,[69] 2016	Iran	NICU	Fathers with a mean age of 27.28 years of infants with a mean gestational age of 22.16 weeks	Post-intervention: Kangaroo care for 1 hour every day for 2 weeks (n = 25, 1 eliminated due to infant death) Pre-intervention (n = 26)	Parental stress	Following the intervention, there were significant improvements in overall and subscale mean scores in the experimental group.

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Study	Country	Setting/ context	Participant characteristics	Groups	Outcomes measured	Main description of results
Simphronio Balbino *et al.*,[70] 2016	Brazil	NICU in a university hospital	Parents of newborns hospitalized in the previous 72 hours or longer	Experimental non-equivalent group: Implementation of a patient and FCC model (n = 66) Control group: Pre-intervention (n = 66)	Parental perceptions of FCC Parental stress	Following the intervention, the experimental group showed significant improvements in some questions assessing parental perceptions and there were mixed results for parental stress.
Sweeney *et al.*,[34] 2017	United States	Level III NICU in a pediatric hospital	Parents of infants ≤ 34 weeks' gestational age or ≤ 2500 g birth weight	Experimental group: Initiation of kangaroo care encounters for at least 30 minutes (n = 133) Control group: Pre-intervention (n = 133)	Parental anxiety	Mean changes for state anxiety and trait anxiety were significantly lower after the intervention.
Turan *et al.*,[35] 2008	Turkey	NICU in a university hospital	Mothers and fathers of 40 premature infants	Experimental group: 30-minute individual, face-to-face education plus booklet (mothers n = 20, fathers n = 17) Control group: Described as routine unit procedures (mothers n = 20, fathers n = 19)	Parental anxiety and stress	Following the intervention, the mean stress score was significantly lower in the experimental group compared with the control group. There were no statistically significant differences between experimental and control groups in mean stress or subscales found for fathers. Fathers had significantly higher mean stress scores than mothers.
Uhm and Kim,[71] 2019	Republic of Korea	Pediatric CICU	Mothers of infants who had first-stage cardiac surgery	Experimental group: Mother-nurse partnership program (n = 36) Control group: Ordinary care with a brochure including information on extubation, feeding and discharge (n = 37)	Primary outcomes: Parental satisfaction, self-efficacy, perceived partnership, anxiety Secondary outcomes: Infant feeding and length of stay	Following the intervention, there were significant improvements in the experimental group for parental satisfaction, self-efficacy, perceived partnership, and anxiety compared with the control group. There were no significant differences in infant feeding or length of stay.
Voos *et al.*,[72] 2011	United States	NICU	Parents of infants admitted for ≥ 1 week	Experimental group: Family-centered rounds (n = 16) Control group: Pre-family-centered rounds where families were asked to leave bedside during rounds (n = 12)	Parent stress and satisfaction	Following the intervention, there were no significant changes to parental stress or satisfaction.

CICU, cardiac intensive care unit; FCC, family-centered care; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit

Qualitative studies

Study	Country	Setting/ context/ culture	Participant characteristics and sample size	Methods for data collection and analysis	Phenomena of interest	Description of main results
Broom *et al.*,[76] 2017	Australia	Regional level III NICU	Mothers (n = 4) and a grandmother (n = 1) with infants 29-32 weeks' gestational age who experienced the FICare intervention	Data collection: Focus groups Analysis: Thematic analysis	Parental perceptions of FICare	Benefits of FICare Components: FICare enhances parent confidence and parental role attainment, improved parent-parent and parent-staff communication.
Cameron *et al.*,[77] 2009	United States	PICU in a large, urban tertiary children's hospital	Parents (n = 36) who participated in medical rounds and parents (n = 16) who did not participate in medical rounds	Data collection: Semi-structured interviews Analysis: Thematic coding	Experiences of parental presence on medical rounds	Experiences, opinions, benefits, and detriments of parental presence on rounds.
Hemle Jerntorp *et al.*,[37] 2021	Sweden	NICU	Fathers (n = 7) aged between 25 and 45 years of infants born between 30 and 34 weeks' gestational age and a birth weight between 1255 and 2615 g	Data collection: Semi-structured interviews Analysis: Phenomenological analysis	Experiences of caring for their infant in NICU and at home	Main themes: The partner was constantly present in the fathers' minds; the fathers were occupied by worries and concerns; the fathers felt that they were an active partner to the professionals; getting the opportunity to take responsibility.
Ingram *et al.*,[78] 2017	United Kingdom	4 NICUs	Parents (mothers n = 37, fathers n = 3) of infants born between 27-33 weeks' gestation. Maternal median age was 32 years. Children were singletons or twins. Also neonatal consultants (n = 5).	Data collection: Telephone interviews Analysis: Thematic analysis	Parental and staff experiences and perceptions of Train-to-Home discharge process	Main themes for parents: Knowledge and skills transfer, but not enough notice; uncertainty, feeling rushed, motivation to get home; breastfeeding is the harder way to do it.
Kyno *et al.*,[79] 2013	Norway	NICU in an urban university hospital	Intervention group: Mother-Infant Transaction Program; mothers (n = 10) and fathers (n = 4) of children (n = 11) Control group: Described as standard care; mothers (n = 11) and fathers (n = 6) of children (n = 14 including 2 pairs of twins)	Data collection: Semi-structured focus group interviews Analysis: Thematic analysis	How parents describe stress and worry while raising a preterm child Parental perspectives on Mother-Infant Transaction Program	Main themes: Hospitalization - a stressful setting; coming home; parents' confidence and concern in everyday life; concerned and worried toward alert and vigilant; intervention parents' recommendations for the Mother-Infant Transaction Program.
van den Hoogen *et al.*,[80] 2021	Netherlands	NICU	Parents (mothers n = 11, fathers n = 2) with a mean age of 33 years of infants between 24 and 27 weeks' gestational age and a birth weight between 700 and 1070 g	Data collection: Semi-structured interviews Analysis: Thematic analysis	Experiences of VOICE support program	Main themes: Involvement in care; personalized information and communication; transition to a parental role; emotional support.

FICare, family-integrated care; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit

Appendix IV: Qualitative study findings with illustrations

Broom *et al.*,[76] 2017	
Finding	FICare enhances parent confidence and parental role attainment (C)
Illustration	"It was great to have someone there to hold your hand." p.e15
Finding	Improved parent-parent and parent-staff communication (C)
Illustration	"I was very much involved in what was going on at rounds, you're the one that knows her best because you're the one that's there constantly through the change of nurses and the doctors." p.e17
Finding	The changing role of nurses (NS)
Illustration	No quotes available
Finding	Bedside education and participating in cares (U)
Illustration	"The best part of the program was Kangaroo Care with my baby." p.e16 "I would stay to do care rather than go to an education session." p.e16
Finding	Group education sessions (U)
Illustration	"I deliberately [went] to meet other people. That's where the education sessions were good for us." p.e16 "Topics provided information that helped me prepare to take my baby home." p.e16
Finding	Family-centered ward rounds (C)
Illustration	"It was great to get that interaction, especially with the doctors, because they included you as part of the rounds, whereas I found before that they would kind of look at you but not talk to you." p.e16
Finding	Miracle Babies psychosocial support (C)
Illustration	"Someone who's actually come out the other side … can come in and … say that yes, okay, it is hard but you do get over this and you actually can move on." p.e16
Cameron *et al.*,[77] 2009	
Finding	Medical team provides information to the parents (C)
Illustration	"To get as much information as we can understand. To ask questions of everyone." p.526
Finding	Transparency (C)
Illustration	"I think that it makes you feel that no one is hiding anything, and you know what it going on with your child." p.524 "Hearing the complete story instead of just the good stuff. Taking out the mystery." p.526
Finding	Increases parental confusion and/or anxiety (C)
Illustration	"My wife gets overwhelmed when she hears all the details. Her head spins." p.524 "Like a foreign language. It is very technical. They are very detached. They don't sound like they are talking about your family member." p.524
Finding	Parental empowerment (NS)
Illustration	No parent quotes available
Finding	Decreases parental anxiety (C)
Illustration	"You are afraid of the unknown. If you know what you are facing, you can face it and move on. Don't tell me 'It's not so bad.' It is better to face the facts." p.526
Finding	Increases duration of rounds (NS)
Illustration	No parent quotes available
Finding	Decreases teaching (NS)
Illustration	No parent quotes available

Finding	Limits medical team discussion (NS)
Illustration	No parent quotes available
Finding	Erodes parental confidence in the house staff (NS)
Illustration	No parent quotes available
Finding	Parents provide medication information to the team (NS)
Illustration	No parent quotes available
Hemle Jerntorp *et al.*,[37] 2021	
Finding	The partner was constantly present in the fathers' minds (NS)
Illustration	No quotes available
Finding	The fathers were occupied by worries and concerns (C)
Illustration	"Even if we felt really safe the whole time, we were still worried all the time about this little vulnerability, I would say, about what could happen" p.1147
Finding	The fathers felt that they were an active partner to the professionals (NS)
Illustration	No quotes available
Finding	Getting the opportunity to take responsibility (C)
Illustration	"….the last week, they more or less only came in with the food and then I did the rest." p.1148
Ingram *et al.*,[78] 2017	
Finding	Practical preparation: "knowledge and skills transfer, but not enough notice" (C)
Illustration	"It was all very quick in the end. … we didn't really talk about going home and then all of a sudden it was, "Let's try demand feeding. You could go home in two days"… very, very sudden." p.753
Finding	Emotional preparation: "uncertainty, feeling rushed, motivation to get home" (C)
Illustration	"It came to the point where we, yeah, we were getting prepared to do it and, yeah, nervous, scared, but excited at the same time…mentally kind of preparing how we were going to do things, continuing it at home rather than having the hospital around to help." p.753
Finding	Role of feeding: "breastfeeding is the harder way to do it" (U)
Illustration	"Everybody acknowledged that breastfeeding is the harder way of doing it. And a lot of babies that were bottle-fed left sooner than us." p.754
Finding	The value of staff engagement (U)
Illustration	"We loved it [Train-to-Home], we felt like it made us feel like a part of it. We loved getting the little booklet out, and we would discuss it between the two of us and with the nurses and take pictures of it." p.755
Finding	Fathers and families loved it (U)
Illustration	"One of the nurses sat down and went through everything so that we completely understood it, and it was great because we've got a four year old,… he loved the train, he thought it was fantastic, and it was great for him to be able to understand a bit more…" p.755
Finding	"The dates prepare you for going home" so "Do it right at the beginning" (U)
Illustration	"We did think it was a really good idea that you can see him progressing, but it's just unfortunate that we didn't do it right at the beginning… So we didn't actually see much progress. That's one thing I suggest…is to do it right at the beginning so that you can see a change." p.755
Finding	"Giving us hope" and "Feeling in control" (U)
Illustration	"The doctors came round while I was there early and said that I could do the stickers myself. Something so small actually makes a big impact, you kind of feel quite good about being able to put a different colour sticker in, because you can see how she is improving." p.757

Finding	Something you can visually see (U)
Illustration	"I really liked it, I thought it was a great idea, because it's a quick easy way of seeing where they are. When my parents came, instead of having to explain everything I could show them the little train, with their colours on there." p.757
Finding	Getting to know your baby (U)
Illustration	"I did find it useful, like when we looked for the questions, and going through each stage with the nurses….especially the questions in there that you probably didn't think of yourself. So it was good to look in there and we felt that we could ask them." p.758
Kyno *et al.*,[79] 2013	
Finding	Intervention parent's recommendations for the MITP (NS)
Illustration	No parent quotes available
Finding	Hospitalization – a stressful setting (U)
Illustration	"The most stressful time was here at the hospital. To feed my baby and myself — back and forth. Never able to relax and enjoy my baby. The chase between the hotel and the NICU was the worst, and most stress related." p.5
Finding	Coming home (U)
Illustration	"… I did not bother to use my time to visit the wellbaby clinic; it is always the same, 'But everything is normal'… everything is probably normal too, but when I ask a question and am feeling a 'little' worried, it would have been nice if they had a little more to say than 'Everything is normal.'" p.6
Finding	Parents' confidence and concern in everyday life (U)
Illustration	"No, I don't think you can let go of the [focus on] prematurity completely. When you have a premature child, you don't take the development for granted like you do with term-born children. With preterms, you are always a little alert in relation to development, like in relation to kindergarten, you are maybe more concerned about a premature child … because you have a notion that he or she has a longer way to go than a child born at term. The term born children are in a way automatically there [at developmental milestones], and I think this mindset will stick with a parent at least until their child starts school. I think maybe the concern will always be there to some extent." p.7
Finding	Concerned and worried toward alert and vigilant (U)
Illustration	"Worried may not be the right word; you are perhaps more alert. They might need more follow-up … But, after a while, when I saw that my child had completely normal curves [on the growth chart], I stopped worrying. Nevertheless, I'm certainly more alert — more on my toes, I think … But it's wrong to say or to use the word worried after the 2–3 first months." p.7
van den Hoogen *et al.*,[80] 2021	
Finding	Involvement in care (U)
Illustration	"Involved as a partner in health care by caring myself for my baby made me strong."p.205
Finding	Emotional support (U)
Illustration	"We were surviving in the NICU and without the social worker we hadn't discussed feelings of mourning and anxiety. It helped us to reflect on our situation." p.205
Finding	Personalized information and communication (U)
Illustration	"Parental meetings were very informative in education about the principles of developmental care." p.205
Finding	Transition to a parental role (U)
Illustration	"As a father, I have the full responsibility for my infant. In order to fulfill my role as a father, I need to know about all the daily choices and considerations of the doctors." p.205

U, unequivocal; C, credible; NS, not supported.
FICare, family-integrated care; MITP, Mother-Infant Transaction Program; NICU, neonatal intensive care unit.

