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Interventions to improve quantitative measures of parent satisfaction in neonatal care: a systematic review

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ABSTRACT

Objective Interventions improving parent satisfaction can reduce parent stress, may improve parent-infant bonding and infant outcomes. Our objective was to systematically review neonatal interventions relating to parents of infants of all gestations where an outcome was parent satisfaction.

Methods We searched the databases MEDLINE. EMBASE, PsychINFO, Cochrane Central Register of Controlled Trials, CINAHL, HMIC, Maternity and Infant Care between 1 January 1946 and 1 October 2017. Inclusion criteria were randomised controlled trials (RCT), cohort studies and other non-randomised studies if participants were parents of infants receiving neonatal care, interventions were implemented in neonatal units (of any care level) and ≥1 quantitative outcome of parent satisfaction was measured. Included studies were limited to the English language only. We extracted study characteristics, interventions, outcomes and parent involvement in intervention design. Included studies were not sufficiently homogenous to enable quantitative synthesis. We assessed quality with the Cochrane Collaboration risk of bias tool (randomised) and the ROBINS-I tool (Risk Of Bias In Non-randomised Studies - of Interventions) (non-randomised studies).

Results We identified 32 studies with satisfaction measures from over 2800 parents and grouped interventions into 5 themes. Most studies were nonrandomised involving preterm infants. Parent satisfaction was measured by 334 different questions in 29 questionnaires (only 6/29 fully validated). 18/32 studies reported higher parent satisfaction in the intervention group. The intervention theme with most studies reporting higher satisfaction was parent involvement (10/14). Five (5/32) studies reported involving parents in intervention design. All studies had high risk of bias.

Conclusions Many interventions, commonly relating to parent involvement, are reported to improve parent satisfaction. Inconsistency in satisfaction measurements and high risk of bias makes this low-quality evidence. Standardised, validated parent satisfaction measures are needed, as well as higher quality trials of parent experience involving parents in intervention design. PROSPERO registration number CRD42017072388.

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INTRODUCTION

One in 10 newborn babies in high-income countries require neonatal care. This is

What is known about the subject?

- Neonatal care significantly affects parents' mental health; parent satisfaction is increasingly being used as a parent experience measure.
- Parent satisfaction is inversely related to parent stress; interventions improving parent satisfaction have the potential to reduce parent stress, improve parent-infant bonding and infant outcomes.
- Use of interventions measuring parent satisfaction as an outcome in neonatal units is increasing, although few are formally evaluated and wider uptake is limited; it is not known the degree to which parents are involved in intervention design.

What this study adds?

- ► There is inconsistency in how parent satisfaction in neonatal care is defined and measured, and the majority of studies do not include parents in intervention design.
- There is low-quality evidence that interventions relating to parent involvement may improve parent satisfaction with neonatal care.
- Standardised, validated measures of parent satisfaction and higher quality trials, involving parents in intervention design, are needed.

stressful for parents, who often develop anxiety, depression and post-traumatic stress disorder symptoms.²⁻⁴ Parental stress interferes with parent-child bonding⁵ and there is a well-established link between maternal mental health and infant development.⁶ Parent satisfaction, defined as 'the perception of parents' needs and expectations being met' is inversely related to parental stress.⁷ As such, it is increasingly being used as a parent experience measure and neonatal service quality indicator. Interventions aimed at improving parent satisfaction have the potential to reduce parent stress, improve parent-infant bonding⁸ and infant outcomes.⁹



A range of parent-centred interventions, such as including parents on ward rounds, have recently become widespread in neonatal practice. Many are implemented on a small scale, without evaluating their impact on parent experience, making long-term integration into neonatal services challenging, while many others are using parent questionnaires. 'Parent satisfaction' as an outcome is gaining momentum, as neonatal trusts attempt to match more 'business-like models' where effectiveness of interventions (and evidence for change) is measured by quantitative outcomes. Moreover, where parent experience is measured as 'parent satisfaction', some studies include it as a primary outcome, whereas others use it as a secondary indicator to explore the parent point of view.

Furthermore, there are multiple experience measures available in addition to parent satisfaction, including parent stress, anxiety and depression scales; both quantitative and qualitative. Finally, it is not known the degree to which parents are involved in the design of such interventions. There have been no previous systematic evaluations focused on interventions measuring parent satisfaction with neonatal care as an outcome.

The aim of this review is to identify and describe neonatal interventions relating to parents of infants of all gestations where an outcome was parent satisfaction. For the reasons outlined above, we have only included studies that reported ≥1 quantitative measure of parent satisfaction. We aim to report each intervention's effect on parent satisfaction, as well as parent input in intervention design.

METHODS

We reported this study using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. ¹⁰ ¹¹ We searched MEDLINE, EMBASE, PsychINFO, Cochrane Central Register of Controlled Trials, CINAHL, HMIC, Maternity and Infant Care (online supplementary file 1) for English papers published between 1 January 1946 and 1 October 2017, with update searches on 1 September 2018.

Inclusion criteria were: randomised controlled trials (RCT) and non-randomised studies (non-RCT) if participants were parents of infants receiving neonatal care, interventions were implemented in neonatal units and ≥1 quantitative outcome of parent satisfaction was measured. We have restricted our review to studies where ≥1 quantitative outcome of parent satisfaction was measured, in order to enable comparison of interventions, which has previously not been possible in any published review. Including studies with all available measures of parent experience (in addition to parent satisfaction), as well as those only qualitatively evaluated, would make any comparison very difficult. By using these preregistered search criteria, we also ensured we would capture studies measuring parent satisfaction both as primary and as secondary outcomes. We included studies from all neonatal care level units and all healthcare

settings, without excluding studies in low-income or middle-income settings. This was because definitions of neonatal care levels differ between different countries and healthcare settings, making them not easily comparable. Moreover, different levels of care are found within the same hospital settings. We excluded systematic reviews, entirely qualitative studies, grey literature (eg, conference abstracts), studies only reporting protocols or abstracts and full reports not in English.

Two authors (SS, IA) independently double-screened titles and abstracts, reviewed full texts for eligibility and resolved any discrepancies with a third reviewer (JW). We extracted data using a pilot-tested, standardised data extraction form including study characteristics, interventions, outcomes and parent input into interventions' design. We assessed methodological quality with the Cochrane Collaboration risk of bias tool¹² for RCT and the ROBINS-I tool (Risk Of Bias In Non-randomised Studies - of Interventions)¹³ for non-RCT.

We presented individual study aggregate data in a narrative synthesis, grouped studies into themes using a Grounded Theory Approach¹⁴ and planned meta-analysis where data were appropriate for quantitative synthesis.

Patient and public involvement

This review was conceived in response to the clinical need identified by parents with neonatal care experience; a partnership including families with experience of preterm birth identified 'what emotional and practical support improves attachment and bonding, and does the provision of such support improve outcomes for premature babies and their families?' as a top 10 research priority. ¹⁵ Additionally, this review was conceived as part of planning a wider project to pilot a neonatal intervention, with parents' full input. ¹⁶ Patients were not directly involved in the design, conduct, reporting or dissemination plans of our research.

RESULTS

We identified 8362 studies for screening and assessed 73 full-text articles for eligibility (figure 1). A total of 32 studies describing interventions that measured parent satisfaction in neonatal care as an outcome met the inclusion criteria, reporting data from over 2866 parents, 1 study did not report number of parents. Our analysis included 10 RCT and 22 non-RCT: 3 cohort trials, 18 unspecified designs and 1 implementation project (tables 1–3). We further classified the unspecified non-RCT into two types, depending on how they defined their control groups and how they evaluated parent satisfaction (table 3).

'Unit-level effect': studies that assessed parent satisfaction during a period of routine care (control group) and introduced the intervention at a later time, with a different group of parents. In these studies, improvement in parent satisfaction was evaluated between different parent groups, on a unit level.

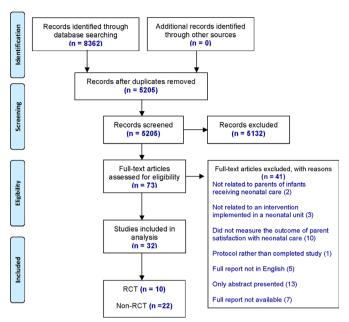


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of selected studies.

2. 'Group level effect': studies that formed intervention and control groups using convenience sampling during the same time period. Both groups (or sometimes only the intervention group) had satisfaction measured after the intervention period (postintervention testing). Baseline parent satisfaction was also measured in both groups (preintervention testing) in some studies. Improvement in parent satisfaction was demonstrated either by comparing outcomes between intervention/control groups following the intervention, or in comparison with the preintervention data.

Parent participants included mothers (14 studies), mothers and fathers (10 studies) or were not specified (7 studies). One study defined parent participants as a dyad of the mother with her designated support person. Median parent sample size was 63, ranging 7–482. This was higher for RCT (108 studies) compared with non-RCT (61 studies).

Study participants included parents of babies across the full range of gestations (23–42 weeks). Overall, 24/32 (75%) of studies involved preterm infants, 5/32 (16%) term infants and 7 studies did not state the gestational age of infants involved. Most studies (19, 59%) involved only preterm infants (up to 37 weeks); only one study (3%) involved only term infants and five studies (16%) involved both preterm and term infants. Preterm infants were included in 44% of RCT vs 63% of non-RCT.

Most studies were reported as conducted in level III neonatal units (17 studies), followed by level not stated (9 studies), level II–III (3 studies), level II (2 studies) and level I (1 study). Definitions of neonatal levels of care are not standardised but vary across different countries; none of the included studies have explicitly stated which definition applies to them.

Tables 1–3 show the key characteristics of included studies. They include a description of each study's parent and infant sample, study design and intervention, outcome measures (timing and methods), results, parent input into intervention design and study impact on parent satisfaction.

Parent satisfaction

Outcome measures

All 32 studies reported they measured parent satisfaction as an a priori outcome. Only one study confirmed this through a protocol. Overall, 18/32 (56%) of studies (4/10, 40% RCT and 14/22, 64% non-RCT) reported a higher level of parent satisfaction associated with the intervention studied. Multiple different outcome measures within the domain of parent satisfaction were used; we grouped these into four categories: i) parent satisfaction (no additional description); ii) parent satisfaction with NICU care; iii) parent satisfaction related to specific components such as communication, staff or information; iv) parent satisfaction with a specific intervention.

Timing of measurement

Parent satisfaction was mostly measured 'during infant admission only' (24 studies; between 1 and 4 times), followed by 'after infant discharge only' (5 studies; 1 time) and 'both during admission and after discharge' (3 studies; between 1 and 3 times). In the majority of studies (19/32, 59%), no preintervention parent satisfaction measurements were conducted in the same parent groups with available postintervention data (ie, paired parent data for satisfaction levels did not exist). Instead, impact of interventions was determined comparing intervention/control group measurements in different time periods (tables 1–3).

Method of measurement

Parent satisfaction was assessed using 32 different methods: 29 different questionnaires, 2 different single questions and by structured interview in 1 study; in total, 334 different questions were used to assess parent satisfaction. Only 6/29 (21%) of questionnaires were reported to be fully validated (both content validation and reliability testing); 23/29 (79%) questionnaires were partially or completely unvalidated. The most commonly used questionnaire was the validated *Neonatal Index of Parent Satisfaction*¹⁷ questionnaire (three studies).

Interventions and impact on parent satisfaction

We grouped included studies into five intervention themes: parent involvement (14 studies); information provision/communication (8 studies); clinical care (7 studies); parent emotional support (2 studies); other (1 study). Parent involvement interventions were more commonly assessed in RCT compared with non-RCT.

We categorised interventions as effective or not effective based on whether a statistically significant difference between intervention and control groups was reported for parent satisfaction (boxes 1 and 2). None of the

Continued

		Improved parent satisfacti	а	-
		Parent co- design?	° 2	2
		Results	The groups did not differ significantly with respect to satisfaction. Intervention Control P value NICU support Mean (SD) 30 (2.7) 28.7 (3.7) 0.07 Emotional connection 12.3 (1.7) 12.3 (1.7) 0.96 Family involvement 'Just right' 81.4%-85% 0.07	PPCBR had significantly higher adjusted mean (95% CI) scores for some questions from domains 1 and 2. Domain 3 was comparable between the two study groups. Intervention Control p-value Domain 1 question: "I have received adequate information about my baby's condition and management" Mean 4.321 3.947 0.03 Domain 2 questions: "In the last week I have been able to communicate effectively with my baby's healthcare team." Mean 4.407 4.250 0.05 "In the last week I have collaborated with my baby's healthcare team in the planning of care for my baby." Mean 3.843 3.426 0.02 "In the last week I have been able to ask the healthcare team questions about my baby's care."
		Method of measurement	Satisfaction questionnaire Validation: no content validity or reliability testing reported. Eleven questions: Seven items were summed (score 7-35) to measure 'support' (eg, information sharing). Three items measured 'emotional connection' to the infant (score 3-15). One item assessed 'family involvement in infant care' (responses: not enough, just right, too much). Greater scores indicated higher	
		Timing of measurement	After babies were discharged (once) During the first high-risk infant clinic visit after discharge. No preintervention parent satisfaction data available for comparison.	During babies' admission (once): At the end of each study arm, separated by a washout period. No preintervention parent satisfaction data available for comparison.
		Outcome measures	with NICU care.	Parent satisfaction assessed by questions of three domains: 1. Knowledge and understanding. 2. Communication and collaboration. 3. Privacy and confidentiality.
s (RCTs)		Intervention	Intervention: free parking. Parents received seven parking vouchers at a time (value. US\$10 each) and continued to receive vouchers until infant dischange. Each voucher allowed free enty and exit for 24 hours. Control: parents received the standard care and did not receive vouchers.	Intervention: parental Presence at Clinical Bedside Rounds (PPCBR). Parents attended bedside clinical rounds. Parents had opportunity to ask questions about their baby's condition and management. Control: parents received the standard care with no parental presence at bedside clinical rounds.
ontrolled trial		Study design	PCT	Cross-over RCT
Included randomised controlled trials (RCTs)		Infants' gestation age in weeks/ NICU level	<28/level III	25–42/level III
Included	cation year	Parents' gender/ sample size	Mothers and fathers //116	Mothers and fathers /63
Table 1	RCT by publication year	Author (date), country	1. Northrup et al (2016), USA	2. Abdel-Latif et al (2015), Australia

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Table 1	Continued									
RCT by publication year	cation year									
Author (date), country	Parents' gender/ sample size	Infants' gestation age in weeks/ NICU level	Study design	Intervention	Outcome measures	Timing of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
3. Bastani <i>et al</i> (2015), Iran	Mothers /100	30–37 Mean (SD) Control: 33.90 (2.33) Intervention: 34 (1.9) Alevel not stated	RCT (block randomisation)	Intervention: family centred care (FCC). Mothers allowed access to their baby at any time, participated in the care provided with information about neonatal care. Control: mothers received the standard care where they were only allowed to be present at the time of the infant's entry to the NICU, and were only routinely informed.	Maternal satisfaction relating to three themes: 1. Parental presence. 2. Participation in neonatal care. 3. Information about neonatal care. care.	During bables' admission (twice): 24 hours after admission. At the time of discharge.	Satisfaction questionnaire (validated) A modified satisfaction questionnaire was used, based on a parental satisfaction instrument developed for measuring satisfaction in paediatric intensive care units. 18 questions Graded 0 (very dissatisfied) to 4 (very satisfied). The overall satisfaction rate was classified based on the mean scores (score <50%, between 75%–50% and >75%).	In the FCC group, preintervention and postintervention difference in maternal satisfaction was statistically significant postinition of the control P value Mean (\$D) At 24 hours 22.36 (8.90) 22.06 (9.77) 0.87 At discharge 59.28 (6.86) 30.18 (14.09)<0.01	Mothers determined the reliability of the satisfaction tool and approved the educational pamphlet. Authors did not report if mothers input in the intervention design.	-
4. Clarke-Pounder et al (2015), USA (2015), USA	Mothers and fathers /19 families	Mothers and 23–39/level III families	RCT	Intervention: sharing information obtained from parent interviews with the primary NICU provider. Parents interviewed becision-Making Tool Octained was placed in the electronic medical record (EMP) and shared with the primary neonatal provider via email. Daily rounds on all infants were audio-recorded for 3 adys after enrolment to see if information from the N-DMT was incorporated into daily care planning. Control: the content of a recent social work note was communicated with the primary provider was communicated with the primary provider was communicated with the primary provider was email, creating an attentional control group.	Parent satisfaction with care.	During babies' admission (once): 2 weeks after study entry. No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire An N-DMT-specific questionnaire was used. Validation: partially reported. Authors stated reliability testing took place; no information on content validity provided. Eight questions: for example, "My baby's doctors considered my goals and hopes for my baby during decision-making". Likert scale (1 strongly agree-4 strongly disagree). Total N-DMT score range 8-32.	There was no significant difference in satisfactor with care as measured by the N-DMT scale between the control group and intervention groups in a univariable model or multiple variable model or multiple variable model controlling for gestational age. Intervention Control Median (range) 26 (15–28) 28.8 (19–32) No P value reported. There was, however, a pattern of decreased satisfaction with care among the intervention group compared with the control group across the N-DMT-specific survey questions, although the differences were not statistically significant.	Ves Information Debtained from paretris using the N-DMT was placed in the EMR and shared with the primary NICU provider via email (forming the intervention).	a

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Author (date), country	Parents' gender/ sample size	Infants' gestation age in weeks/ NICU level	Study design	Intervention	Outcome measures	Timing of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
5. Holditch- Davis et al (2013), USA	Mothers /208	Preterm infants Mean (SD) Overall group 27.2 (3.0) /4 centres, levels II-III	HCT three groups (two intervention and one control) Postintervention testing only	Interventions: 1. Mothers were taught how to massage infans with auditory, tactile, visual and vestibular stimulation. 2. Kangaroo care. Control group. Mothers spent a similar amount of time with the study nurse discussing the equipment needed for preterm infant care at home. Study nurses provided education and support for all three groups. Mothers were mot prevented from engaging in interventions of the other groups but did not receive formal education from the education from the education from the study nurse on the other interventions.	1. Parent (mother) satisfaction with the intervention. 2. Satisfaction with the helpfulness of the study nurse. 3. Whether would recommend the study to others and the degree of change in the mother wand as a person and as a mother as a result of being in the study.	During admission period and postdischarge: At the time of discharge. At 2 months corrected age. No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire The questionnaire was designed by the study team. Validation: partially reported. Authors stated reliability testing took place; no information on content validity provided. 26 questions: relating to three dimensions of satisfaction: efficacy, caring and technical quality. Likert (1 least satisfied–5 most satisfied).	No significant differences occurred between the groups. Mothers in all three groups were satisfied with the intervention (mean scores of 3.3 or higher on a 5-point scale) and the helpfulness of the nurse (mean scores of 4.6 or higher on a 5-point scale).	° Z	α
6. Franck <i>et al</i> (2011), UK	fathers (SD) fathers (Control: 3 /169 (S.17) Interv: 29, //4 centres	Mean (SD) Control: 31.94 (5.17) Interv: 29.40 (3.17) /4 centres, level III	Cluster RCT	Intervention: increasing parental involvement in infant patin management in the NCU. Parents received a booklet providing evidence-based information about pain and comforting infants in the NICU setting. Parents received two visits from a research wists them booklet. Control: as part of usual care, parents in both the booklet. Control: as part of usual care, parents in both the intervention and control groups received a detailed booklet with generic information and control groups received a detailed booklet with generic information about NICU care. Parents in the control group also received two visits from a research nurse listening to what parents had to say about their NICU experience (attention placebo).	At baseline: Parent satisfaction with NICU care. One week after the intervention: 1. Satisfaction with information about pain control. 2. Satisfied namke infant control and set infant make infant make infant make infant infant infant. 3. Satisfied pain medicines help infant.	During babies' Individual quee admission (twice): At baseline (within 3-7 reliability testif admission). 1 week after the 1. At baseline: intervention. 1 week after the 1. Satisfaction we satisfaction we satisfaction we satisfaction and the baseline questionnaire. 2. One week a 2. One week a Nociception sistisfied were validated Pares Nociception sistisfied—6 ver	Individual questions Validation: no content validity or reliability testing reported. 1. At baseline: parent satisfaction was measured by one question: satisfaction with NICU care' (1 very satisfied-6 very unsatisfied) as part of the baseline parent characteristics questionnaire. 2. One week after the intervention: Three questions using the word 'satisfied' were selected from the validated Parent Attitudes About Infant Nociception survey (Likert scale 1 very satisfied-6 very unsatisfied).	At baseline: there was no significant difference in satisfaction between intervention and control group. Intervention Control Mean 1.45 (0.71) 1.51 (0.76) (SD) P value missing 1 week after the intervention: intervention parents were more satisfied with the information about pain control received than control parents. Intervention Control Mean 2.10 (0.97) 3.28 (1.27) (SD) P value<0.001	Yes The booklet was reviewed by 12 parents of infants who had been cared for in NICUs in the UK.	-

Table 1 Continued

Table 1	Continued	70								
RCT by publication year	cation year									
Author (date), country	Parents' gender/ sample size	Infants' gestation age in weeks/ NICU level	Study design	Intervention	Outcome measures	Timing of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
7. Livingston et al (2009), USA	Mothers /12	Mean (SD) Control: 33.4 (6.4) Intervention: 38.5 (3.1) /level III	POT .	massage. Mothers attended a 1 hour massage class traught by a nurse certified infart massage instructor (CIMI) and were asked to participate in at least three bedside massage instruction sessions taught within the next week. Infants received massage for seven consecutive days, from the mother or a CIMI. The touch procedure lasted 20 min. Control: infants received all usual hospital services including medical care, physical and occupational therapy services and developmentally supportive nursing care.	1. Caregiver (mother) with their infant's care. 2. Caregiver satisfaction with the neonatal unit and the massage therapist.	During babies' admission (three times): At baseline On completing the 7 day massage programme. I month following intervention.	Satisfaction questionnaire Two questionnaires were developed by the research team. Validation: no content validity or reliability testing reported. First questionnaire (at baseline): a brief self-report questionnaire about caregiver satisfaction with their infant's care until that moment. No further details reported. Second questionnaire (on completing the 7-day massage programme and 1 month following intervention): a 10 min satisfaction questionnaire relating to infant's response and caregiver satisfaction with the neonatal unit and the massage therapist. Number of questions: not stated. Likert scale (1 very dissatisfied-4 very satisfied). Sample statements: "How satisfied do you feel giving massage to your infant?", "I feel that massage to your infant?", "I feel that massage improved my infant's hospital stay"."	It is unclear in the report if specific between-group comparisons and statistical analysis were conducted. At baseline and day 7: All caregivers were highly satisfied with the medical treatment their infant received. At day 7 and 1 month follow-up: All caregivers participating in the massage group reported high levels of satisfaction regarding their relationship. With their infant and the massage programme's impact on that relationship. Slight improvements in satisfaction regarding time the caregiver spent with the infant and time the caregiver spent with the infant and time the caregiver spent with the infant and involvement in the infant's care were observed between day 7 and and the 1 month follow-up (no further information reported).	°Z	м
8. Koh et al (2007), Australia	Mothers /200	Not stated/not stated	ТО	Intervention: provision of taped conversations with neonatologists to mothers. The initial conversation and subsequent conversations of significance with a neonatologist were taped and analysed (for both groups). Mothers received a tape of each conversation and a tape recorder. Control: usual care. Mothers were not given the tape or recorder.	Satisfaction with conversations held with the neonatologist. Satisfaction with the fape.	During admission period and postdischarge: At 10 days. At 4 months. At 0 months. No preintervention parent satisfaction data available for comparison.	Individual questions and a satisfaction scale Validation: no content validity or reliability testing reported. Number of questions: not stated. Likert scale (1–5 most satisfied) Questions related to: satisfaction with amount and quality of information presented, doctors' communication skills, patient's participation in the conversation. A satisfaction scale was used to assess: satisfaction with the tape.	No differences were found between the two groups in satisfaction with conversations. Mothers of babies with a poor outcome in the tape group were, however, significantly more satisfied with the conversations: Intervention Control Mean (95% CI) 115 (104–123.2) 100.5 (94.1–109.4) P value 0.0051 Most (71%–92%) of the mothers given the tapes stated that they helped their understanding, reminded them of what understanding, reminded them of what understand and recall information.	°N	-

Table 1	Continued									
RCT by publication year	cation year									
Author (date), country	Parents' gender/ sample size	Infants' gestation age in weeks/ NICU level	Study design	Intervention	Outcome measures	Timing of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
9. Mirchell- DiCenso et al (1996), Canada	Mothers and fathers/ 482	Mean (SD) Intervention: 35.1 (4.5) Control: 35 (4.3) Aevel III	LOT TO T	Intervention: clinical nurse specialist/neonatal practitioner team (CNS/NP) care. Infants of intervention parents were assigned to be cared for by the CNS/NP team during the day and by paediatric residents during the night. Control: paediatric residents cared for infants of control paediatric residents are of control parents around the clock. Neonatologists supervised both teams.	Parent satisfaction with care.	During admission period and postdischarge (twice): On fifth day after admission (full survey): After discharge over the phone (only questions related to satisfaction with discharge process). No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire (validated) The study team developed and used the validated NIPS questionnaire. Number of questions: not stated. NIPS score range (27–189); higher scores indicating greater satisfaction with care.	No statistically significant difference between groups. Intervention Control P value NIPS 140 139 0.67 Mean Difference in means 1.0, 95% CI (-3.6 to 5.6)	°Z	α
10. Broyles et al (1992), USA	Mothers /25	Mean (SD) Control: 34 (4) Intervention: 33.4 (4) /level III	RCT	Intervention: Detailed consent. Mothers were given information about mechanical ventilation. Detailed risk/benefit disclosure was provided both verbally and in writing. Control: Control: mothers were given a brief verbal description about mechanical with defailed verbal and written disclosure if desired by them (flexible consent).	Maternal satisfaction with the information provided about mechanical ventilation.	During babies' admission (once): 24-48 hours after the intervention No preintervention parent satisfaction data available for comparison.	An interview evaluating maternal satisfaction with the information provided about mechanical ventilation. Validation: a psychiatrist with a special interest in interviewing techniques was consulted in designing and standardising this assessment. A research nurse conducted the interview, 'checking' each mother against one option regarding: Amount of information: Might amount-too much-too little. Information made coping: more difficult-easier-no effect-uncertain.	This study is measuring and comparing satisfaction with two different interventions (detailed vs flaxible consent process), neither of which formally represent the usual routine care for all babies (no control). Small numbers. No data indicating statistical analysis conducted or evidence of statistically significant results. Detailed Flexible Right 75% mothers 100% amount of information Too 25% mothers little information	o Z	ო

NICU, neonatal intensive care unit; NIPS, Neonatal Index of Parent Satisfaction.

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Table 2		Included prospective cohort studies	ort studies							
Prospective	Prospective cohort studies by publication year	' publication year								
Author (date), country	Parents' gender/ sample size	Infants' gestation age in weeks/NICU level	Study design	Intervention	Outcome measures	Outcome measures Timing of measurement Method of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
1. De Bernardo et al (2017), Italy	Mothers and fathers/96	Mean (SD) Control: 34.2 (5.25) Intervention: 32.7 (5.25) Alevel III	Non-randomised, prospective cohort pilot study Unit level effect: Two different time periods	Intervention: FCC. Parents had access to NICU sor Shours/day. The NICU was videned and paediatric nurses taught parents procedures/ practices for 10 days. Parents could observe clinical beddish counds, hold meetings with the physicians, use the rooms and kitchen. Control: parents were permitted to visit their baby in NICU for 1 hour a day.	Parent satisfaction relating to three specific domains: 1. Knowledge and Understanding. 2. Communication and collaboration. 3. Privacy and confidentiality.	During bables' admission (once) At discharge (pre-FCC cohort and post-FCC cohort). No preintervention parent satisfaction data available for comparison (different parent groups printervention and postintervention).	During babies' admission Satisfaction questionnaire. (once) At discharge (pre-FC cohort) and post-FCC cohort). No preintervention data available for comparison (different parent groups preintervention and postintervention). Interequestions: Related to adequate and timely information preintervention and postintervention and collaboration with the healthcare team.	7/9 individual statements in the parent satisfaction questionnaire scored higher in the FCC compared with the MFCC (statistically significant difference). Example statement: "I have received adequate information about my baby's condition and management". Intervention Control Median 5 (3.45–5) 4 (3–5) P value<0.05	2	-
							Three questions: Related to respect of patient privacy. Likert (1 strongly disagree—5 strongly agree).			
2. Petteys et al (2015), USA	Not stated/10 parents included in sample analysis	24-36+/level III	A prospective cohort design. A feasibility study. Group level effect: Intervention/ Control groups Postintervention testing only	Intervention: PC. PC nurses provided important continuity of care for NICU infants clinically requiring PC and at least weekly verbal support of parents. The PC conferences, provided or requested orders to improve infant symptom management and comfort and addressed parental coping and self-care. Control: usual clinical care for infants not requiring PC.	Overall satisfaction with care received.	During babies' admission (once) At discharge (or study closure for infants who remained hospitalised). No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire A researcher-created questionnaire based on extensive current literature review. Validation: Partially reported. Authors stated content validity testing took place; no information on reliability testing provided. One question Likert (1 extremely dissatisfied-4 to extremely satisfied). Optional free text (description of specific experiences impacting satisfaction with care).	Parent satisfaction response numbers were small (n=10), thus statistical comparison of parental satisfaction between cohorts was not possible. However, 100% of Satisfied with care, whereas only 50% of responding usual care parents (n=4) reported extreme satisfaction.	ર	n



Prospectiv	Prospective cohort studies by publication year	y publication year								
Author (date), country	Parents' gender/ sample size	Infants' gestation Parents' gender/age in weeks/NICU sample size level	Study design	Intervention	Outcome measures	Timing of measurement	Outcome measures Timing of measurement Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
3. Stevens et al (2011), USA	3. Stevens Mothers/147. For Mean (SD) et al (2011), the OPBY NICU, 58 surveys were Control: 3f sternmed. For the SFR NICU, 89 Interventio were returned /level not stern sterns and stern sterns and s	Mean (SD) Control: 35 (4) Intervention: 34 (3) /level not stated	Cohort trial. This research was part of a large prospective evaluation. Unit level effect: Two different time periods	Intervention: SFR NICU for neonatal care. Parents could visit their baby, room-in, do kangaroo care and breast feed at any time, in individual rooms (containing bed, desk, closet, talephone, chair, refrigerator for breastmilk storage). Control: OPBY NICU. The traditional OPBY NICU was traditional OPBY NICU was traditional OPBY NICU was requipment were visible for all neonates, staff, monitors and equipment were visible for all neonates in each room. Portable partitions were placed around the incubator kangaroo care.	with different elements of NICU: elements of NICU: Environment. Nurses. Physicians. Physicians. Presonal. Overall assessment.	After babies were discharged (once) and all and within 60 days of discharge of parents' infants from the NICU. No preintervention data available for comparison (different parent groups preintervention and postintervention).	Satisfaction questionnaire Statistics improver for the st. A questionnaire from Press for innounded were three questions added by the investigators. The original questionnaire but no content validated questionnaire but no content validates reported aquestions added by the study team. 16 items 16 items 17 items 18 items 19 items 10 items 10 items 10 items 10 items 11 items 12 items 13 items 14 items 14 items 15 items 16 items 16 items 16 items 17 items 18 items 19 items 19 items 10 items 10 items 10 items 10 items 11 items 12 items 13 items 14 items 15 items 16 items 16 items 17 items 18 items 18 items 19 items 10 item	Statistically significant improvement was found for the survey categories of Environment, Overall and the Total survey. Estimated numbers from report's figures as numbers not provided): Median SFR OPBY P value Environment 4.7 3.7<0.001 Overall 5.4.8 0.018 Total 4.7 4.5 0.045 16 items composite score for FCC: 4.4 4.0.0.017	Yes Former NICU parents were mivolived in all phases of planning for the new SFR NICU.	-
ECC. family of	antred care. NICII people	atal intensive care unit: OPB	, oviteillen OG ned-ned /	F.C. family centred care: NICLI mannatal intensive care unit: OPRY Onen-hay. P.C. nalliative care: SER_sincle_family.com						

studies reported statistically significantly lower parent satisfaction in the intervention group compared with the control group. We classified studies as *unclear if effective* if they included small sample numbers or if statistical analysis was not performed (box 3). Finally, we highlighted studies where *only the intervention group was assessed and only postintervention*, where comparison to a control group was not possible (box 4).

Overall, 18/32 studies (56%) reported higher parent satisfaction in the intervention group; 4/10 RCT and 14/22 non-RCT. The intervention theme where higher satisfaction was most consistently reported was parent involvement (10/14 studies). Due to the large heterogeneity of outcome measure scales, a quantitative synthesis and meta-analysis was not possible.

Parent input into design of interventions

Five studies (5/32, 16%) reported involving parents in intervention design, of which two reported improvement of parent satisfaction. The number of included studies was too small to estimate any effect of parent co-design on the success of interventions at study level.

Methodological quality

For the majority of RCT, key study characteristics, such as randomisation, allocation concealment and blinding of outcome assessment, were either not stated or unclear (figure 2). Only one RCT had an available study protocol (retrospectively registered) and none described blinding of study participants and/or personnel. All RCT scored a high/unclear risk of bias in at least 4/6 Cochrane tool categories, except for one, which scored a high/unclear risk in 3/6 categories.

We assessed 21/22 non-RCT studies using the ROBINS-I tool¹³, excluding the implementation project. All 21 studies were assessed as having an overall *serious* risk of bias and 7/21 of studies (33%) were further categorised as having *critical* risk of bias (figure 3). Blinding of participants, personnel and outcome assessment was poorly reported across all non-RCT and no study reported a published study protocol. None of the included non-RCT measured or corrected for important parent/infant confounding variables, or other relevant neonatal unit co-interventions taking place at the same time as the intervention.

We were unable to use the *Standards for Reporting Implementation Studies (StaRI) Statement Tool*¹⁸ for assessing the implementation project, as the reporting was incomplete.

There was no association between methodological quality assessments and the studies' reported effect on parent satisfaction. All 4/10 RCT that reported a higher level of parent satisfaction associated with their intervention, scored a high/unclear risk of bias in at least 4/6 Cochrane tool categories, one of which scored high/unclear risk in all categories. Out of the 14/22 non-RCT reporting an improved parent satisfaction, two were deemed to be at *critical risk* of bias on the ROBINS- I tool, while the rest we assessed to be at *serious risk* of bias.

Continued

Table 2

Table 3 Included 'other' non-randomised controlled trials (non-RCT)

	Improved parent satisfaction?	-	-	4
	Parent co- design?	ž	g.	9
	Results	There was a significant difference in the mean score of satisfaction between cases and controls while the mean score of satisfaction increased in both groups. Comparison of the mean score between the two groups showed that the level of satisfaction was againfraintly higher in the case group is set econtrol group. Intervention Control before intervention Mean (SD) 81.62 (13.50) 85.71 (3.6) P value 0.933 After intervention Mean (SD) 93.88 (5.38) 90.12 (7.78)	The satisfaction level of the mothers in the intervention group increased significantly during the study. The results of independent t-test showed a significant difference in the satisfaction changes of the mothers on the 3rd and 10th days of NICUS daminssion between intervention and control groups, and of the most satisfaction level of and the forth day in the intervention group. After intervention Mann 137 (15.2) 102.3 (25.6) P value 0.001	Only the intervention group posture as assessed and only posturervention. The authors reported that the parents surveyed were stratified with their expension accordable lating to the OFFSN on the mobile robot and would on the mobile robot and would with their lating to the OFFSN on the mobile robot and would with their limiting to the OFFSN on the mobile robot and would with their limiting to the offset of the careful for by a physician via tielemedicine in the future.
	Timing of measurement Method of measurement	Satisfaction questionnaire (Validated) The 'What Being The Parent of a Bab's Life-Revised' Questionnaire was used. The original English version by Pricham and Chang was translated to Persian. Eleven questions. Total satisfaction score range (11–99).	Satisfaction questionnaire (Validated) The NIPS questionnaire by Mitchell et al was used and Mitchell et al was used and translated to Persian. 24 questions (Liket scale) Liker (1 always or not satisfact—7 hever or completely satisfied), A higher score indicates more satisfaction.	Satisfaction questionnaire Validation: no content validity or reliability testing reported. Number of questions: not stated. Likert (1 excellent-5 very poor).
	Timing of measurement	During bables' admission (twice): Day 1 of intervention. Day 10 of intervention.	During babies' admission (twice): Day 3 of Day 10 of intervention. Day 10 of intervention.	During babies' admission (once): At the time of discharge. No preintervention parent satisfaction data available for comparison.
	Outcome measures	Maternal satisfaction	Mothers' satisfaction with macked sea medical sea modical students and nurses during neonatal admission to the NICU.	Satisfaction with telemedicine.
	Intervention	Intervention: Internet-based education. Mothers used an educational website set up by the research team (files and clips). Mothers could visit the website from 17 700 to 1800 for 10 days. They were also allowed to use the website outside of the above hours and to respont the duration of using the website to the researcher. Mothers had to use the website at least 3 flines during 10 days, each time for at least 3 dmin. Control: mothers in the control group received the routine education provided in the NUCU.	Intervention: narrative writing. Mothers clid narrative writing at least three times until the 10th day of admission. Control: mothers in the control group received the routine NICU treatment and care.	Intervention: tele-rounding. Infants of intervention parents were araref for by an OFFSN who was present via a remote-controlled robot. The OFFSN assessed infants via the robot's integrated stehoscope, with assistance from the nursing staff. Dung routhe house, the OFFSN was called to discuss any issues with the patient. Emergencies out of hours were covered by an ONSN. Control: Infants of control parents received ONSN care. The attending nonatologist made daily patient rounds with the NICU team. After patient rounds with the attending on anatomodist made daily patient rounds with the attending on patient or ounds with the ANCU staff, under the supervision of the attending neonatologist made larger.
	Study design	Non-randomised, convenience sampling, Goup level effect intervention/control groups. Preintervention and postint ervention testing.	Non-randomised, convenience sampling. Unit level affect: Two different time periods.	Non-randomised, convenience sampling. Group level effect: Intervention/control groups Postintervention group testing only.
	Infants' gestation age in weeks/NICU level	≤30-36 /level not stated	Mean (SD) Control 31.6 (2.4) Interv: 32.9 (3.1) /level not stated	23–39/level III
by publication year	Parents' gender/sample Size	Mothers/68	Mothers/70	Not stated/9
'Other' non-RCT by publication year	Author (date), country	(2017), Iran (2017), Iran	2. Kadivar et al. (2017), Iran	3. Garingo et al. (2016), USA

Continued

Table 3 (Continued									
Other' non-RCT I	'Other' non-RCT by publication year									
Author (date), country	Parents' gender/sample Size	Infants' gestation age in weeks/NICU level	Study design	Intervention	Outcome measures	Timing of measurement Method of measurement	Vethod of measurement	Results C	Parent co- design?	Improved parent satisfaction?
4. Globus <i>et al.</i> (2016), Israel	Mothers and fathers/ total surveys returned: 178	~40% in each group <32/level III	Non-randomised, convenience sampling. Unit level effect: Two different time periods.	Intervention: SMSi. Parents were updated daily regarding the health status of their infant wis SMS from the EMR. All SMS. Including one-earlience sections with updated information of equations with underd information of equations with the infants crib and current weight, including one-earlients card events, derivoration of the infant an exist of the infant and south of the parents in real time. Control: routine care pre-SMS implementation.	Parent satisfaction related to paent communication with the medical staff colored parent satisfaction with rearries from the with rearries throughout hospitalisation. An object of the parent satisfaction with rearries throughout hospitalisation.	During bables' admission (once): P pe-SNS cohort and 1 post-SNS cohort. No preintervention are available for comparison (difficent parent groups preintervention and postintervention).	Satisfaction questionnaire prevaints and the reparation that when the regarding their experience in regarding their experience in regarding their inflants of mospilalisation in the MUCU questionnaire was used, as well as selected tiems from a literature review of similar questionnaires, including that by York Hospital and by Conner and helson. Wallodinor: no content validity or reliability testing reported. Selected tiems related to four aspects of the NICU expended terms related to four aspects of the NICU assessed parent their communication with the medical staff. Liket scale (1 do not agree at all-5 strongly agree). 2. Overall satisfaction with resument and staff attitudes attitudes stafford the staff assessed parent and staff attitudes trongly agree).	Overall, in both periods, parents expressed a high degree of satisfaction regarding the medical gastestation regarding the medical gastestation with seatment and with the information satisfaction with treatment and with staff attitudes throughout thospitalisation was slightly greater in the post-SMS cohort, a statistical significant improvement was noted regarding physician and truesse and regarding physician and ruses and regarding physician and ruses and regarding the infants' medical status from the physicians. Post-SMS Pre-SMS Post-SMS Pre-SMS Post-SMS Pre-SMS Post-SMS Pre-SMS Walto 0.03 Specific question: "I was pleased with the frequency with which I received information regarding purply and part of the physicians. Although improvement in all other received information regarding my hard:"	2	-
5. Kazemian et al. (2016), Iran	Mothers/220 mothers) mothers)	>37/level not stated	Non-randomised, convenience sampling. Group level effect: Intervention/control groups Postintervention testing only.	Mothers and bables were admitted to a different atmosphere to the routine and heart atmosphere to the routine care. This facilitated the mothers and neomates with separate beds along with photoherapy devices and nursing clinical supervision. Control: the routine care practised in this neomatal unit supported partial stay of mothers beside their neomatal unit supported partial stay of mothers beside their neomatal units upon chains; however, most of the time the mother-infant dyad was separated.	Maternal satisfaction with the neonatal care services and hospital stay comfort.	During babies admission sections. (oncol): No stated exactly when when the satisfaction data available 1 for comparison.	Satisfaction questionnaire Maidation: no content validity or reliability testing reported. The authors state, 'a validated self-made questionnaire was self-made questionnaire was pu sone trained midwires', No further information on walication processes, number questions or name of the questionnaire was provided. Likert (5 very satisfied—1 dissatisfied).	The level of satisfaction was significantly higher in the intervention group, compared with that in the control group. Interv Control Satisfaction % 26.6 18.8 P	Q	-

Table 3 Continued

'Other' non-RCT by publication year	y publication year									
Author (date), country	Parents' gender/sample Size	Infants' gestation age in weeks/NICU level	Study design	Intervention	Outcome measures	Timing of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
6 . Van de Vijver and Not stated/105 Evans (2015), UK	Not stated/105	Not stated/not stated	Non-randomised, converience sampling. Unit level effect: Three different time periods.	Intervention: baby diany. Each parent received a communication diany on their infant's admission to the unit. Staff worder-in infant infants dianopates and kept an infant infantsorin to parents, parents worde in memories and a questions for staff to address during face-to-face communication. Control: routine care, before implementation of the diaries.	Satisfaction with communication from neonatal staff.	During babies' admission (three times): On the day of babies' discharge at study baseline. Pon the day of babies' discharge at 1 month. On the day of babies' discharge at 15 months.	Satisfaction questionnaire The study team designed a questionnaire, based on the Department of Health and the National Institute for Health and Care Excellence quality standards for specialist neonatal care. Validation: no content validity or reliability testing reported. Five questions ('yes or no').	Small numbers. No data indicating statistical analysis conducted or evidence of statistically significant results. I was receiving regular communication from staff" 94%—I month postdiary cohort 98%—I month postdiary cohort 17%—prediary cohort 17%—prediary cohort 18%—I month sostdiary cohort 17%—prediary cohort 17%—prediary cohort 17%—prediary cohort 18%—prediary cohort 19%—prediary cohort 19%—prediary cohort 19%—prediary cohort 19%—prediary cohort 10%—I month postdiary cohort 10%—I month postdiary cohort 10%—I month postdiary cohort 10%—I month spostdiary cohort 10%—I months postdiary 10%—I months postdiary cohort 10%—I months postdiary 10%—I months I months I months I months postdiary 10%—I months I mo	The intervention concept was concept was areaded by the project leaders following analysis following analysis following analysis with used after mutidiscipling and used after mutidiscipling after mutidiscipling and input and input and input and input and parents.	ю.
7. Voos and Park. (2014), USA	Not stated/62	Not stated/level III	Non-randomised, convenience sampling. Unit level effect: Two different time periods.	Intervention: Oupolicy. Parents were allowed access to their baby 24 hours a day, 7 days a week. Control: parents pre-OU implementation received routine care. The unit was closed to parents duning nurse change of shift in mornings and evenings.	Parent satisfaction with how much time parents get to spend with their baby.	After bables were discharged (once): After pre-OU parents were discharged. After post-OU parents were discharged.	Single question (from a validated questionnaire). The question "Did you get to spend as much time as you wanted with your baby?"" was used from the National Research Corporation Picker parent survey.	Small numbers. No data indicated nadysis conducted or evidence of statistically significant results. "Did you get to spend as much time as you wanted with your baby?" Yes. Pre-OU 78% (18/23) Post-OU 92% (36/39)	Yes. The NICU has a Family-centred care committee including parents, which conducted this project.	n
8. Segre et al. (2013), USA	Mothers/23	Mean (SD) 31.57 (5.30)/level III	For the outcome of parent satisfaction: Non-randomised, convenience sampling. Group level effect. Intervention/control groups Postintervention group testing only.	g a 2 5	Satisfaction with the treatment and the outcome.	During babies' admission (once): Who is stated exactly when. No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire The Client Satisfaction Questionnaire was used. Validation: partially reported. Authors stared reliability testing took place; no information on content validity provided. Eight questions. Format of questions: not stated.	Only the intervention group was assessed and only postintervention. The authors reported: "The majority of women who received Lis were righty satisfied with the intervention". "The average score for the Cilient Satisfied to Journal of Satisfied on Questionnaire was 289 91, comparable to levels of satisfied or peopret of by clients receiving depression treatment from a mertal health professional". "91,3% of our participants rated the quality of help they received as excellent."	2	4
9. Palma et al. (2012), USA	Not stated/26 families returned the survey containing the satisfaction measure)	Not stated/level II	Non-randomised, convenience sampling. Unit level effect: Two different time periods.	Intervention: YBDU. A daily parent update letter generated from the EMR. Parents were given daily YBDU exports, printed automatically from the EMR. The YBDU uncluded information about an infant's status during the past 24 hours and a hand-written update by the infant's care provider. Control, parents received routine care and usual verbal updates (6 months pre-adoption of YBDU).	Satisfaction with YBDU.	Ouring babies' admission (once): Not stated exactly when. No peintervention parent satisfaction data available for comparison (different parent groups preintervention and positntervention).	During bables' admission Satisfaction questionnaire (once): Not stated exactly thems regarding adoption of when. No perintervention parent and satisfaction with YBDU satisfaction data available was used. Or comparison Yalidation: no content validity preintervention and refliability testing reported. Pumber and format of questions: not stated.	Only the intervention group was assessed and only postintervention. The authors reported: "When asked to rate the statement I like receiving Your Baby's Daily Update; 95% of families who used YBDU as an information source responded with the highest rating, always".	8	4
										Continued

Appendix satisfaction with the NICU During babies' admission experience. Perent satisfaction with the NICU During babies' admission physician and nurse practitioner (twice): Satisfaction with treatment (le, During babies' admission headbox oxygen or CPAP). Perintervention. Perent satisfaction relating to: Parent satisfaction relating to: During babies' admission only peach satisfaction relating to: Parent satisfaction relating to: During babies' admission only peach satisfaction parent satisfaction received (once): Education received Education received Education received Proparation for the parental Morphimervention parent satisfaction with the for comparison. Preparation for the parental Morphimervention parent satisfaction data available. Overall satisfaction with the for comparison.	O
Parent satisfaction with physician and nurse practitione (twice): Satisfaction with treatment (e, positive vention.) Peintervention. Parent satisfaction relating to: Parental perceptions of staff camp staff sta	Intervention: FGRs. Glo Parents were invited to attend rounds and choose their level of involvement distend every day/not at all/periodically). For confidentiality concerns, panents were asked to step outside while rounds of others infants took place. The staff others infants took place. The staff parents again after rounds in needed. Control: parents received routine care Prior to FGR implementation parents were asked to leave the unit
(e) During babies' admission (once): Within 5 days of the babies' admission. No preint evention parent satisfaction data available for comparison. To During babies' admission (once): During babies' admission (once): During babies' admission (and available satisfaction data available satisfaction data available satisfaction data available satisfaction data available for comparison.	Pan an intervention: an intervention to increase PMP phy availability and communication confrequency. (1) A brief education module for PMPs was introduced, (2) parents received a contact card with PMP rames, job descriptions and contact information, (3) a poster of the faces, names and titles of the PMPs was placed at NICU entrance. Control: parents received routine care in the preintervention cohort, without the above.
During bables' admission (once): On the day before discharge. The No preintervention parent satisfaction data available for comparison.	Intervention 1: infants received Sati headbox oxygen treatment for hea respiratory distress. Infants received CPAP treatment for respiratory distress.
NICU experience.	Intervention: infants received Pan individualised, developmentally supportive FCC. Buportive FCC. Infants received care within the framework and philosophy of framework and philosophy of individualised, developmentally supportive family centred interventions. Control: infants received the fraditional NICU standard of care.

Table 3 Continued

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Table 3	Continued									
Other' non-RCT	'Other' non-RCT by publication year									
Author (date), country	Parents' gender/sample Size	Infants' gestation age in weeks/NICU level	Study design	Intervention	Outcome measures	Timing of measurement Method of measurement	Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
14. Mills et al. (2009), USA (2009), USA	Not stated/not stated Parents of infants from sx hospitals	Not stated/level not stated	Implementation project PDSA quality improvement testing.	Intervention: 5 PBPs in the area of discharge planning. The project team iteratively implemented 5 PBPs in cocess discharge planning tool kit. Created an easy-to-use, easy-to-old kit. Restructured communication tool kit. Restructured communication tool kit. Restructured communication tools and prosesses to reflect a 'plan for the day, the stay and the way 'to discharge. Maximised the impact and use of caregiver educational tools. Maximised the impact and use of caregiver education and updated materials and delivery systems for caregiver and updated materials and delivery systems or caregiver and updated materials and caregiver and staff satisfaction. S. Amalysed and enhanced interactions with and transfers into the community. Control: NA. No discrete control apont DEA quality improvement methodology was applied to parent participants.	General satisfaction: With care Parents' feelings about preparedness for discharge Ability and corfidence in Feeling with their infant Feeling like a parent Feeling like a parent Participation in care Adequacy of information from staff about medical and care issues.	During bables' admission (four times): What reported exactly when.	Satisfaction questionnaire The internat-based parent satisfaction survey Thowsyourbaly.com* that was developed, especially for this NICU propulation was used. Validation: no content validity or reliability to scinn profred. Number and format of questions: not stated.	Through multiple rapid-cycle profess, the projects collaborative group made changes within the 5 PBP plans. Parent satisfaction measures were used to longitudinally monitor the changes made rather than make direct group monitor the changes made rather than make direct group monitor the changes made, and ratio of attain idealing statistical malysis conducted or evidence of statistically significant results. Parent satisfaction survey results (all centres combined) were applied and yes pecific interquartiles. No specific interquartiles was reported. Parent readiness for discharge was reported. Parent readiness for discharge analysis was reported. Parents receiving just the right throughout the collaborative. Parents' receiving just the right can east thats and safe sleep demonstrated some variability throughout the collaborative.	2	ю
15. Wielenga et al. (2006), The Netherlands	Mothers and fathers/46	Mean (SD) Control: 28.5 (26.0–29.9) Interv: 28.3 (25.6– 29.9)	Non-randomised, convenience sampling Unit level effect: two different time periods.	Infants received care according to NIDCAP mindents and parents were august how to provide it. Caregining plans were designed based on the linfant's current developmental stage, macked condition and family needs. Caregivers learnt to watch sensitively and note the infant's reactions of different types of hardling and care, making continuous adjustments. Control: infants received traditional neonatal care practised at that time.	Darent satisfaction relating to: Overal rating Care of the baby Communication with staff Involvement in care -Being Support Being a parent Being a parent Being a score. Total score.	After babies were discharged (on day of discharged (on day of discharget). Pre-NIDCAP cohort. Post-NIDCAP cohort.	Satisfaction questionnaire (Validated) The NICU-PSF was used and translated from English to Duff). Sixty-two questions. Closed and open-ended questions. Different rating scales used (F-point rating scales tom 'extremely satisfied' to 'nor at all satisfied' or 'excellent' to 'poor'). Total score range (50-2-43) points).	The intervention group's mean total score was significantly ligher than the control. Interv Contol Mean (SD) 18.57 (17.74) 174.04 (20.98)	2	-

Improved parent satisfaction?

There were no statistically significant differences between control and intervention groups in satisfaction with their infants' care (1), with relationships with NICU professionals (2) and with the decisions made for infant treatment (3).

Five-point Likert scale.

Thirty questions.

Professional and Decision Input Questionnaire' was used to measure satisfaction with relationships (2).

investigator-designed Relationships with 2. A subscale of the

Validation: partially reported.
Authors stated content validity testing took place; no information on reliability

Five-point Likert scale

3. Validated.

esting provided. Iwelve questions.

The "Collaboration and sustration About Care Ouestronnaire" developed by Bags, was used to measure Satisfaction with decision input (3), with decision input (3), with decision made (5).

Nine questions.

Process of decision making (4) Mean 120.20 104.95 0.012

Validation: partially reported.
Authors stated content
validity testing took place;
no information on reliability
testing provided.

Interv Control P value Decision input amount (3) Mean 33.44 30.05 0.058

Two subscales of the investigator-designed prediction and Parents Understanding of Infant Care and Outcomes Questionnaire' were used to measure Satisfaction with Care (1).

Within 0–3 days.
9–12 days.
25–28 days of an infant's admission to the NICU.

Satisfaction with

Care

Relationships with
professionals
Decision input

The process of decision
making
Decisions made.

Both the mother and father (or the mother and her designated support person) were shown how to use the IPC and attended three CPM (with neonatologists/neonatal nurse

First 2 years (control ining group data collection).
Year 3 (staff training).
Year 4 (implementing the maintervention).
Pear 5 (collecting data thin from the intervention (w

practitioners).

Results based only on mothers' data.

Control: during the control phase, professionals carried out usual communication and interaction with control group parents.

Unit level effect: Two different time periods. group).

Continued

	-
	92
	The only significant difference for a possitrevention item was a higher score for the item. Attempts were made to create a quite environment for my baby. Interv Control P value Mean 4.80 3.89 0.033 Independent t-tests comparing the co-bedded and control group parental scores found no significant differences in their parental satisfaction scores, except for higher baseline parental consistence in their parental satisfaction scores, in their parental satisfaction scores, except for higher baseline parental co-bedded group.
7-point scale (1 strongly disagree-7 strongly agree).	During babies' admission Satisfaction questionnaire (twice): At baseline. The NICU's standard parental satisfaction tool was used. Validation: partially reported. Authors stand content validity testing took place, but because of the disparate nature of the items, survey reliability could not be assessed. Eleven questions. Spoint Likert-type scale.
	Staff concern Staff concern Support of family Staff explanations Inflant environment, Comfort with feeding Kangaroo care encouragement Staff explanation of signs of inflant stress Visiting schedule Overall statisfaction with the MICLI experience.
	Intervention: co-bedding premature Parent satisfaction related for inculators. Staff concern Staff concern Staff concern Staff concern Support of family Infants were nursed in the same incubator using a co-bedding protocol (e.g. recording all of the providing care to the second infam). Control: single-bedding premature inculators. Microl experience. Nict experience.
	For the outcome of parent satisfaction: Non-randomised, convenience sampling Group level effect; Intervention and Preintervention and positintervention testing.
	Mean (SD) Control: 29 (2.00) Interv: 28.9 (2.42) /level II-III
	Mothers/19
	17. Byers et al. (2003), USA

Table 3 Continued Other' non-RCT by publication year	Parents' Infants' gestation gender/sample age in weeks/NICU Size level Study design Intervention Outcome measures Timing of measurement Method of measurement Results design?	Dyads (both Not stated/level III A repeated measures design: Intervention: The newborn individualised IPC-CPM indi
continued	Parents' gender/sample Size	E
Table 3 Continued 'other' non-RCT by publication year	Author (date), country	16. Penticuff and Dyads (both Arheart (2005), USA parents or mother with her support person)/122

Table 3 (Continued									
'Other' non-RCT by publication year	by publication year									
Author (date), country	Parents' gender/sample Size	Infants' gestation age in weeks/NICU level	Study design	Intervention	Outcome measures	Timing of measurement	liming of measurement Method of measurement	Results	Parent co- design?	Improved parent satisfaction?
18. Polizzi et al. (2003), USA	Mothers and fathers/33	Mean (SD) Control: 32.97 (1.9) Interv: 33.06 (1.31) /level III	A retrospective, comparative, descriptive design. Unit level effect.	Intervention: co-bedding multiple-gestation infants in the NICU. Multiple-gestation infants were further in the incubator or crib. The intervention was evaluated retrospectively after implementation of a co-bedding practice protocol. Control: traditionally badded group (bebies were routinely placed in separate incubators or cribs).	Parental satisfaction as measured by time questions relating to parent perceptions and their baby's care.	After babies were discharged (once): All parents were mailed the survey. A second survey was sent to those who did not respond after 2 months. No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire The parental perception/ satisfaction tool was used. Validation: partially reported. Authors stated content Authors stated content the stating provided. 6,8 and resting provided. 6,8 questions were from a similar tool that was validated by the formout offermout of the stating provided is a similar tool that was validated by the furnor offermout NICU Quality Improvement Initiative. Nine questions (such as "y was satisfied with the care my bables received in the hospital".	Mothers reported overall and additional and staff, as well as adequacy of their ability to care for their infants after discharge, with scores ranging from 4.19 to 4.71. The only survey item score that was a required their was significantly different between hospital staff to bond with my bables." Interv Control P value Mean 4.71 4.36 0.049	2	-
							Likert (1 strongly disagree-5 strongly agree).			
19. Legault and Goulet (1995), Canada	Mothers/61 completed both tests	Mean (range) 30 (24–35) /level II	Time-series design Group level effect: Same group exposed to both methods with postmethod testing only.	of removing an infant from an incubator. Mothers were taught the 'kangaroo method' (skin-lo-skin contact): Infant wears a diaper/head cap and is placed in a vertical position on the parent's bared chest. A blann let covers the infant and the parent's cothing is basened around the infant. The parent sits in a nocking chair, inclined so that the infant's head Control: traditional method. Control: traditional method. Newborns: wearing a diaper and a head cap, are wrapped in a banket and placed in their parent's arms.	Mothers' satisfaction with: Each method of removing an intent from incubator Her feelings after each method.	During babies' admission (twice): After the intervention. After the control method. No preintervention parent satisfaction data available for comparison.	Satisfaction questionnaire The 'Maternal Satisfaction Questionnaire' was used. It was developed by integrating components described by Affonso et al and the investigators. Validation: partially reported. Authors stated content provided. Fifteen questions Liker (I very much-5 do not know). An open-ended question mixed the nowther to list and explain and the content of the content o	Regardless of the method helvels of statisfaction (if was the first time since giving birth that they could hold their infants). These statements proved more powerful in discriminating between the methods: Rated higher after the kangaroo method test: If the contact with my baby's skin" (p=0,001) Part of the contact with my baby's skin" (p=0,001) Rated higher after the traditional method test: Part of the baby" (p=0,015) Part of the baby" (p=0,015) If colled into my baby's eyes and stared at histher face" (p=0,0001)	2	-



Box 1 'Effective' interventions in themes

Theme: parent involvement

More NICU access, parents on WRs, education (De Bernardo *et al*, Italy, 2017)

Rooming-in care (Kazemian et al, Iran, 2016)

Parental presence at clinical bedside rounds (Abdel-Latif *et al*, Australia, 2015) *RCT*

More NICU access, care involvement, education (Bastani *et al*, Iran, 2015) *RCT*

Education regarding pain management (Franck et al, UK, 2011) RCT

Single-family NICU rooms (Stevens et al, USA, 2011)

Family centered rounds (Voos et al, USA, 2011)

Newborn Individualised Developmental Care and Assessment

Programme (Wielenga et al. The Netherlands, 2006)

Infant progress charts filled by parents and three care planning meetings (Penticuff and Arheart, USA, 2005)

Kangaroo care (Legault and Goulet, Canada, 1995)

Theme: information provision / communication

Internet-based education (Kadivar et al, Iran, 2017)

Daily SMS from electronic patient record (Globus *et al*, Israel, 2016) Staff education, staff contact card given to parents, staff poster at NICU reception (Weiss *et al*, USA, 2010)

Provision of taped conversations with neonatologists to mothers (Koh *et al*, Australia, 2007) *RCT*

Theme: clinical care

- a. Headbox oxygen for respiratory distress
- Continuous oxygen positive airway pressure for respiratory distress (Foster et al. Australia, 2008)

Co-bedding infants in incubators (prospective) (Byers *et al*, USA, 2003) Co-bedding infants in incubators (retrospective) (Polizzi *et al*, USA, 2003)

Theme: parent emotional support

Narrative writing (Kadivar et al, Iran, 2017)

Interventions where parent satisfaction was reported to be statistically significantly higher in the intervention group.

NICU, neonatal intensive care unit; RCT, randomised controlled trial; WR, ward round

Box 2 'Ineffective' interventions in themes

Theme: parent involvement

- a. Massage with auditory, tactile, visual and vestibular stimulation
- b. Kangaroo care (Holditch-Davis *et al*, USA, 2013) *RCT* Individualised, developmentally supportive family centred care interventions (Byers *et al*, USA, 2006)

Theme: information provision/communication

Sharing information obtained from parent interviews with the primary NICU provider (Clarke-Pounder *et al*, USA, 2015) *RCT*

Theme: clinical care

Clinical nurse specialist/neonatal practitioner team care (Mitchell-DiCenso et al. Canada, 1996) RCT

Theme: other

Free parking (Northrup et al, USA, 2016) RCT

Interventions where parent satisfaction was not reported to be statistically significantly different in the intervention group.

RCT, randomised controlled trial.

Box 3 *'Unclear if effective'* **interventions in themes**

Theme: parent involvement

Open unit policy: 24/7 NICU access (Voos and Park, USA, 2014)
Touch and massage for 7 days (Livingston *et al*, USA, 2009) *RCT*

Theme: information provision/communication

Clinical staff enter updates in baby diary (Van de Vijver and Evans, UK, 2015)

Detailed information provided during consenting (Broyles *et al*, USA, 1992) *RCT*

Theme: clinical care

Palliative care (Petteys et al, USA, 2015)

Five potentially better practices in the area of discharge planning (Mills *et al.* USA, 2006)

Interventions where small study numbers and/or no statistical analysis performed).

RCT, randomised controlled trial.

DISCUSSION

Parent satisfaction with neonatal care is increasingly recognised as an important measure of parent experience and is being used to evaluate hospitals and health-care providers; use of interventions to improve parent satisfaction in neonatal units is increasing. This is the largest review of interventions where an outcome was parent satisfaction with neonatal care and includes 32 studies. We find low-quality evidence that interventions targeting 'parent involvement' may improve parent satisfaction with neonatal care, but this result must be interpreted cautiously in view of the high risk of bias in included studies.

Overall, our review highlights the complexity of evaluating parent satisfaction. As a multidimensional construct, parent satisfaction can be affected just as much by interventions directly relating to infant care (eg, Kangaroo care) as well as interventions relating to neonatal care facilities (eg, Free parking). By grouping included interventions into themes (boxes 1–4), we have highlighted the variety of interventions available, as well as the majority of interventions being those relating to 'parent involvement'.

A key reason for only selecting parent satisfaction as the outcome of interest was to focus on a single component of parent experience, in order to reduce outcome heterogeneity and allow direct comparison. Despite this approach, the key methodological limitation identified

Box 4 Interventions in themes where 'only the intervention group was assessed and only postintervention'

Theme: information provision/communication

Daily parent update letter from electronic patient record (Palma $\it et al$, USA, 2012)

Theme: clinical care

Tele-rounding robot, off-site neonatologist (Garingo et al, USA, 2016)

Theme: parent emotional support

Listening visits (Segre et al, USA, 2013)

Risk of Bias (Cochrane)

Author by publication year	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
1. Northrup (2016)	?	+	-	?	+	?
2. Abdel-Latif (2015)	+	+	-	-	-	?
3. Bastani (2015)	?	?	-	?	+	?
4. Clarke-Pounder (2015)	?	?	-	?	+	?
5. Holditch-Davis (2013)	+	+	-	+	?	?
6. Franck (2011)	-	?	-	?	-	+
7. Livingston (2009)	?	?	-	?	+	?
8. Koh (2007)	?	?	-	?	?	?
9. Mitchell-DiCenso (1996)	+	?	?	?	?	?
10. Broyles (1992)	?	?	-	+	+	?

Figure 2 Cochrane Collaboration risk of bias tool assessment (randomised controlled trial). Green: low risk of bias; yellow: unclear risk of bias; red: high risk of bias.

in this review was inconsistency in how parent satisfaction is defined and measured; it is notable that the majority of questionnaires (23/29) lack validation. In keeping with neonatal studies more widely, ¹⁹ this study confirms inconsistent outcome selection as a major source of research waste in neonatal studies examining parent experience, and further finds that there is limited involvement of parents in study design.

Strengths of our review include identifying studies with both mother and father participants, inclusion of the full range of infant gestations and a wide range of interventions. We followed a preregistered protocol and report this review in line with PRISMA guidelines. To further aid direct comparison of interventions, we only included studies that evaluated parent experience using 21 quantitative outcome of parent satisfaction. One limitation of this approach is that by excluding studies which evaluated parent experience using other measures (eg, stress, anxiety and depression scales), we are unable to comment on interventions that targeted these other components of parent experience.

Risk of Bias (ROBINS-I)

Author	Bias due to	Bias in	Bias in	Bias due to	Bias due to	Bias in	Bias in	OVERALL
by publication year	confounding	selection of participants into the study	classification of interventions	deviations from intended interventions	missing data	measurement of outcomes	selection of the reported result	risk of bias
1. De Bernardo (2017)	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	SERIOUS	SERIOUS
2. Kadivar (2017) Internet-based education	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	MODERATE	SERIOUS
3. Kadivar (2017) Narrative writing	SERIOUS	SERIOUS	LOW	SERIOUS	LOW	SERIOUS	MODERATE	SERIOUS
4. Garingo (2016)	CRITICAL	LOW	LOW	SERIOUS	SERIOUS	SERIOUS	SERIOUS	CRITICAL
5. Globus (2016)	SERIOUS	LOW	LOW	NO INFO	SERIOUS	SERIOUS	SERIOUS	SERIOUS
6. Kazemian (2016)	SERIOUS	NO INFO	LOW	SERIOUS	NO INFO	SERIOUS	SERIOUS	SERIOUS
7. Petteys (2015)	SERIOUS	LOW	LOW	SERIOUS	MODERATE	SERIOUS	MODERATE	SERIOUS
8. Van de Vijver (2015)	CRITICAL	LOW	LOW	SERIOUS	MODERATE	SERIOUS	MODERATE	CRITICAL
9. Voos (2013)	CRITICAL	LOW	LOW	SERIOUS	NO INFO	SERIOUS	SERIOUS	CRITICAL
10. Segre (2013)	CRITICAL	NO INFO	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	CRITICAL
11. Palma (2012)	CRITICAL	NO INFO	LOW	SERIOUS	SERIOUS	SERIOUS	CRITICAL	CRITICAL
12. Stevens (2011)	SERIOUS	LOW	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	SERIOUS
13. Voos (2011)	SERIOUS	LOW	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	SERIOUS
14. Weiss (2010)	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	MODERATE	SERIOUS
15. Foster (2008)	SERIOUS	CRITICAL	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	CRITICAL
16. Byers (2006)	SERIOUS	LOW	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	SERIOUS
18. Wielenga (2006)	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	MODERATE	SERIOUS
19. Penticuff (2005)	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	MODERATE	SERIOUS
20. Byers (2003)	SERIOUS	LOW	LOW	SERIOUS	LOW	SERIOUS	SERIOUS	SERIOUS
21. Polizzi (2003)	SERIOUS	MODERATE	LOW	SERIOUS	SERIOUS	SERIOUS	MODERATE	SERIOUS
22. Legault (1995)	SERIOUS	CRITICAL	LOW	CRITICAL	LOW	SERIOUS	MODERATE	CRITICAL

Figure 3 ROBINS-I risk of bias assessment (non-randomised controlled trial).

Another limitation is that we have only included studies in the English language, due to resource and time constraints. By not including studies in other languages, it is possible our results are more focused on work conducted in specific countries. Furthermore, we acknowledge that much of the research in parent experience is qualitatively evaluated. By restricting our review to studies where ≥1 quantitative outcome of parent satisfaction is measured, we have not included any interventions with solely qualitative outcomes. This was in an attempt to enable direct comparison of interventions, which has previously not been possible in any published review. By not including studies evaluated by qualitative measures only, it is possible our results are more focused on a particular type of interventions where quantitative evaluation would be preferable and/or easier. It also means we may not have included all studies ever conducted on a particular intervention, where some were only evaluated qualitatively, making some interventions appear more 'widespread' than others.

Brett et al^{20} systematically reviewed interventions aimed at improving the parent experience more widely, but only included parents of preterm infants. Their large number of outcome domains and heterogeneity of outcome measures (including studies that reported only qualitative outcomes) meant the authors we unable to draw firm conclusions about the efficacy of interventions and that comparison and meta-analysis was not possible. The majority of our review's studies have been published in the 7 years since the review by Brett et al, highlighting the increasing interest in this area. However, despite including all gestations and focusing on a specific aspect of parent experience, heterogeneity in measurement of parent satisfaction meant we were also unable to conduct a quantitative synthesis. Inconsistency and lack of validation of instruments measuring parent satisfaction in neonatal care (specifically with family centred care) has also previously been highlighted by Dall'Oglio et al.²¹

Although 31% of included studies were RCT, all were assessed as having a high risk of bias. RCTs are traditionally considered the highest-ranking form of evidence, however it is worth considering whether such a design is feasible or desirable to evaluate interventions targeting parent satisfaction. Parents in neonatal care talk to each other, compare notes and invariably create parentsupport communities; hence it is inherently difficult to avoid contamination between parents receiving an intervention and those who are not, meaning that blinding of parents or health professionals is near impossible. Furthermore, parent satisfaction is likely to be particularly susceptible to the Hawthorne effect,²² requiring longer-term follow-up. These factors may explain the low number of RCT identified in our review and the high risk of bias seen in those that were included. In non-RCT studies, the main methodological concern is the degree to which unmeasured and uncontrolled confounders may explain any differences seen between groups. The non-RCT studies included in this review were classed as



having either a serious or critical risk of bias. The overwhelming majority of studies did not adequately report baseline variables or report other interventions during the study period, making it impossible to assess studies for selection bias or treatment bias. Furthermore, limitations such as contamination bias and the Hawthorne effect affect non-RCT as well. Only two non-RCT studies evaluated the outcome of interest (parent satisfaction) both before and after the intervention, in the same group of parents (group level effect), with most studies evaluating different parent groups preintervention and postintervention (unit level effect). An inherent weakness of this latter approach is that it assumes parent satisfaction is a static measure at the unit level, which is unlikely to be true. As a result of these numerous important limitations identified across all included studies, we find only lowquality evidence in support of interventions to improve parent satisfaction with neonatal care, despite a majority of studies reporting a beneficial effect of interventions. These limitations may explain the limited uptake of these interventions by the wider neonatal community.

Changing neonatal unit practices to incorporate any new intervention requires robust evidence. We demonstrate here that such evidence is not currently available for improving parent satisfaction. We highlight the use of non-randomised study designs, inconsistency in definition and measurement of parent satisfaction, the use of unvalidated questionnaires, methodological limitations and a lack of parent involvement as contributors. Our review empirically documents the extent of these issues in studies that use quantitative parent satisfaction surveys, and their contribution to research waste in neonatology.

Given the importance of parent satisfaction for both parent and offspring well-being, higher quality trials that involve parents, use of standardised definitions and validated parent satisfaction measures are needed. Given the nature and challenges of the neonatal care environment and the limitations we have identified in existing research, a cluster RCT may be the most appropriate study design to rigorously evaluate interventions to improve parent satisfaction with neonatal care.

CONCLUSIONS

Many interventions, commonly relating to parent involvement, are reported to improve parent satisfaction with neonatal care but inconsistency in definition and measurement of parent satisfaction and high risk of bias in all studies makes this low-quality evidence. Standardised definitions and validated parent satisfaction measures are needed, as well as higher quality trials of parent experience, involving parents in intervention design.

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REFERENCES

- 1 Neonatal Data Analysis Unit. Neonatal data analysis unit annual report 2017, 2018. Available: https://www.rcpch.ac.uk/sites/default/ files/2018-10/2018_nnap_report_on_2017_data_final_v8.pdf
- 2 Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). J Clin Psychol Med Settings 2010;17:230–7.
- 3 Shaw RJ, Bernard RS, DeBlois T, et al. The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. Psychosomatics 2009;50:131–7.
- 4 Beck CT, Woynar J. Posttraumatic stress in mothers while their preterm infants are in the newborn intensive care unit. Advances in Nursing Science 2017;40:337–55.
- 5 Lee SK, O'Brien K. Parents as primary caregivers in the neonatal intensive care unit. Can Med Assoc J 2014;186:845–7.
- 6 Grace SL, Evindar A, Stewart DE. The effect of postpartum depression on child cognitive development and behavior: a review and critical analysis of the literature. *Arch Womens Ment Health* 2003;6:263–74.
- 7 Rocha G, Candeias L, Ramos M, et al. Stress and satisfaction of mothers in neonatal intensive care. Acta Med Port 2011;24:157–66.
- 8 López-Maestro M, Sierra-Garcia P, Diaz-Gonzalez C, et al. Quality of attachment in infants less than 1500g or less than 32weeks. related factors. Early Hum Dev 2017;104:1–6.



- 9 Charpak N, Tessier R, Ruiz JG, et al. Twenty-Year follow-up of kangaroo mother care versus traditional care. *Pediatrics* 2017;139:e20162063.
- 10 Prospero database. Available: http://www.crd.york.ac.uk/prospero/ display_record.asp?ID=CRD42016042110
- 11 Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. J Clin Epidemiol 2009;62:1006–12.
- 12 Higgins JPT, Altman DG, Gotzsche PC, et al. The Cochrane collaboration's tool for assessing risk of bias in randomised trials. BMJ 2011;343:d5928.
- 13 Sterne JAC, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. BMJ 2016:355:i4919
- 14 Green JTN. Qualitative methods for health research. SAGE 2014.
- 15 Duley L, Uhm S, Oliver S, et al. Top 15 UK research priorities for preterm birth. The Lancet 2014;383:2041–2.
- 16 Sakonidou S, Andrzejewska I, Kotzamanis S, et al. Better use of data to improve parent satisfaction (buds): protocol for a prospective before-and-after pilot study employing mixed methods

- to improve parent experience of neonatal care. *BMJ Paediatr Open* 2019:3:e000515
- Mitchell-DiCenso A, Guyatt G, Paes B, et al. A new measure of parent satisfaction with medical care provided in the neonatal intensive care unit. J Clin Epidemiol 1996;49:313–8.
- 18 Pinnock H, Barwick M, Carpenter CR, et al. Standards for reporting implementation studies (STARI) statement. BMJ 2017;356:i6795.
- 19 Webbe JWH, Ali S, Sakonidou S, et al. Inconsistent outcome reporting in large neonatal trials: a systematic review. Arch Dis Child Fetal Neonatal Ed 2019. [Epub ahead of print].
- 20 Brett J, Staniszewska S, Newburn M, et al. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. BMJ Open 2011;1:e000023.
- 21 Dall'Óglio I, Mascolo R, Gawronski O, et al. A systematic review of instruments for assessing parent satisfaction with familycentred care in neonatal intensive care units. Acta Paediatr 2018;107:391–402.
- 22 McCambridge J, Witton J, Elbourne DR. Systematic review of the Hawthorne effect: new concepts are needed to study research participation effects. J Clin Epidemiol 2014;67:267–77.