

## **A systematic review of instruments for assessing parent satisfaction with family-centred care in neonatal intensive care units**

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## **ABSTRACT**

This systematic review synthesised and described instruments measuring parent satisfaction with the increasingly standard practice of family-centred care (FCC) in neonatal intensive care units. We evaluated 11 studies published from January 2006 to March 2016: two studies validated a parent satisfaction questionnaire and nine developed or modified previous questionnaires to use as outcome measures in their local settings. Most instruments were not tested on reliability and validity. **Conclusion:** Only two validated instruments included all six of the FCC principles and could assess parent satisfaction with FCC in neonatal intensive care units and be considered as outcome indicators for further research.

**Keywords:** Family-centred care, instruments, neonatal intensive care unit, parent satisfaction, validity.

## **Key Notes**

- This systematic review explored instruments measuring parent satisfaction with the increasingly standard practice of family-centred care (FCC) in neonatal intensive care units.
- We evaluated 11 studies from January 2006 to March 2016: two validated a parent satisfaction questionnaire and nine developed or modified previous questionnaires to use as outcome measures in local settings.
- Only two instruments included all six FCC principles and most of them did not investigate instrument validity.

## INTRODUCTION

Family-centred care (FCC) is a multifaceted concept that has been developed over the last 60 years and has become a central principle in child healthcare (1,2). It is an innovative approach to the planning, delivery and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families and providers that recognises the importance of the family in the patient's life (3). Although there is no uniform definition and comprehensive understanding about the concept of FCC practices (4), the general FCC core principles may be summarised as follows: showing respect and understanding; providing information and education to families; achieving coordinating care through effective communication; providing physical support; providing emotional support and involving parents in decision making and care (5). The opinions of patients and parents are, therefore, important for assessing FCC experiences and improving the quality of the care delivered (6-8), specifically when FCC principles are not consistently implemented in clinical practice (9-11).

The positive effects of FCC are also experienced by families and preterm infants admitted to neonatal intensive care units (NICU) (12-15). FCC in the NICU was defined in a concept analysis by Ramezani et al as applying inter-disciplinary, comprehensive and holistic care to neonates and their families while respecting the dignity of both parties (16). In complex NICU settings, evaluating parent satisfaction is important and validated instruments based on FCC principles are recommended. The path from the FCC principles of care to their application in practice and to the development of instruments that can evaluate the patients and parents' satisfaction is extremely crucial. If theoretical frameworks are not clear and are adapted to a single setting, such as the NICU, then the risk of bias in the satisfaction evaluation might be high.

Several instruments have been developed to evaluate parent satisfaction with FCC in NICU settings. A review conducted in 1999 by Conner et al focused on the description of NICU parent satisfaction questionnaires (17). They found that none of

the five identified satisfaction questionnaires had been rigorously tested for validity and, in addition, they did not comprehensively measure parent satisfaction. The integrative review by Butt et al selected 12 studies published between 1990 and 2011 and showed that many of the parent satisfaction instruments lacked strong psychometric properties (6). Unfortunately, the development of most parent satisfaction instruments have not been based on the FCC philosophy and principles. It is important to use validated instruments to evaluate patient satisfaction rigorously in a way that provides reliable outcome measures for benchmarking across different NICUs.

The way that FCC is implemented in NICU settings varies from country to country and often depends on the NICU environment (6,18-20). It is, therefore, justified to assess parents' satisfaction and experiences to identify possible shortcomings in healthcare services and to implement interventions to improve the care of families and their infants. Furthermore, most instruments might have a limited applicability in NICU settings that have implemented FCC as a standard practice.

We hypothesised that in the last decade new parent satisfaction instruments would have been developed from the FCC perspective with the aim of measuring parent satisfaction and experiences with FCC received in NICU settings.

Therefore, the aim of this study was to review, synthesise and describe the properties of instruments published during the last 10 years that measure parents' satisfaction and experiences with FCC in the NICU

## **METHODS**

A systematic literature search was conducted to identify which studies reported the use of instruments measuring parental satisfaction of FCC in NICUs (21).

## **Eligibility criteria**

The review included quantitative studies such as randomised controlled trials, observational studies, before and after design studies and validation studies published from January 2006 to March 2016. This timeframe was selected to complement two previous literature reviews on parent satisfaction in NICUs and a critical appraisal of the literature that identified studies conducted in both paediatric and neonatal intensive care settings (6,17,22). However, this review specifically focused on parent satisfaction instruments related to FCC. The FCC principles used in our review covered, as cited above, a wide range of issues, both practical and emotional or organizational (5). We included studies that aimed to develop a new instrument, studies using a satisfaction instrument to measure the study outcomes and studies using an adapted version of a previously developed instrument. Moreover, the review only included articles describing the instrument in detail. Articles were excluded if they described instruments developed before 2006 without conducting any modification to them. The review excluded qualitative studies, annotations, literature reviews and grey literature such as institutional documents, interviews with experts, unpublished data, dissertations and conference abstracts.

## **Search strategy**

The following electronic databases were used: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library and Scopus. The search strategy used medical subject headings keywords consistent with the patient or population, intervention, comparison, and outcome process: parent, newborn, infant, neonatal intensive care, assessment, family-centred care and parent satisfaction. The imposed limits were: date of publication between January 2006 and March 2016; abstract available newborn infant from birth to one month of age. The last two searches could only be specified in MEDLINE and CINAHL. The full search strategy is given in Table S1. Additional articles were identified by manual searches and reference list mapping.

## **Study selection**

Duplicate records were identified and removed. The titles and the abstracts of all the identified studies were carefully examined and if they appeared relevant the full texts were obtained and reviewed. The titles, the abstracts and the full texts were evaluated independently by two authors. Any disagreement was resolved by discussion. No attempt was made to contact the authors of the papers if the data were unclear.

## **Data extraction and synthesis**

The studies were divided among four authors to devise a synthesis using a data-extraction form developed by the authors for this review. Extracted data concerned objectives, settings, sample sizes, study designs, instruments, validity and reliability and results. The authors discussed the aims and design of the studies and the characteristics of the satisfaction instruments. Attention was given to the description of the validity and reliability process of the instruments, when reported by the authors, according with the relevant literature (23).

## **RESULTS**

Initially, 315 potentially eligible studies were retrieved from the electronic databases and free searches: 161 articles from MEDLINE, 100 from CINAHL, 43 from the Cochrane Library, nine from Scopus and two from manual searches. After removing duplicates and applying the exclusion criteria, 11 articles were included in the review, as shown in Figure 1 (14,18,24-32).

In total, 11 new instruments measuring parent satisfaction with FCC were included in the analysis.

### **Aim of included studies**

There were two studies that exclusively aimed to develop and validate a parent satisfaction assessment instrument regarding FCC in NICUs (24,25). The primary aim

of the other studies was to evaluate parent satisfaction and experiences with FCC in NICUs (14,18,24-32) and two of them aimed to compare parent satisfaction before and after moving to a different NICU environment, as shown in Table 1 (30,31).

### **Study design**

The studies included in this review used different designs. Two studies had a validation design to test the reliability and validity of the instrument (24,25). One study used a prospective design, because it evaluated the perceptions of parents during the move from an old open bay to the new family room NICU (30). Similarly, one study had a before and after design (29). Moreover, two studies used a quasi-experimental design (14,18) and only Bastani et al performed a randomised controlled trial (32). The study by Tran et al used a quantitative, descriptive study design (29), the study by Hurst was defined as programme evaluation research (26). Two other studies did not report the design used (27,28), but one could be described as a survey (27) and the other one as a comparative study (28). Finally, three out of the 11 were multicentre studies (18,27,28).

### **Population and sample size**

Most of the participants in the studies were parents (14,24-27,29,30), but two studies only considered mothers (28,32) and two studies included both families and healthcare staff in the sample (18,30). The study by Cooper et al also included NICU administrators (18). In some studies, parents whose infants had died were excluded (24,30,32). The sample size of the included studies varied from 14 to 502 study participants (Table 1).

The studies with smaller sample size were single centre studies, whereas those involving larger populations were multi-centre studies, except for the validation study by Latour et al (24). The only two studies with a validation design included 441 and 105 parents of preterm infants (24,25).



## **Data collection**

All studies used quantitative research methods to assess parent satisfaction with FCC. However, several studies also included open-ended questions or space for parents to write comments, as shown in Table 2. Most of the questionnaires were self-administered surveys (18,24,26,30). Only one study used an online form supplemented by telephone interviews (27). In the study by Punthmatharith et al, mothers were interviewed using the survey (28). The number of items in the instruments varied from 11 to 76 (Table 2). There were five instruments that used a five-point Likert-type scale (14,18,26,29,30). The other six instruments used points scales ranging from three to 10 points (24,25,27,28,31,32). Only two studies reported that the parent satisfaction instrument was anonymous (18,30). Furthermore, two studies surveyed parents of infants who were in NICU at the time of the study (28,31). In five studies, parents were recruited at discharge (14,24,25,29,30) and one study surveyed parents after varying periods of time after discharge (26). In the study by Bastani et al, the included mothers completed the questionnaire 24 hours after neonatal hospitalisation and at the moment of discharge (32). Finally, two studies measured parent satisfaction either when their infants were in the NICU or at home after being discharged (18,27).

## **Validity and reliability**

Both the studies by Latour et al and Hagen et al specifically aimed to develop and test a parent satisfaction instrument for FCC (24,25). Latour et al (24) developed and validated the parent satisfaction instrument called Empowerment of Parents in The Intensive Care Neonatology (EMPATHIC-N), performing content, face validity and psychometric analysis, as shown in Table 1. The reliability testing showed a Cronbach's alpha ranging from 0.82 to 0.95 in the five instrument domains, including repetitive measures over time with two different cohorts of parents. Latour et al (24) evaluated congruent validity and showed a significant positive correlation between the instrument domains and the four overall satisfaction indicators: that the parents would

suggest the neonatal intensive care unit to other parents; they would come back again if needed and their overall satisfaction with the physicians and with the nurses.

Hagen et al developed the instrument through focus group interviews and performed content validity with a pilot study (25). This permitted other statistical considerations, as shown in Table 1. The internal consistency of the 13 categories of the instrument was calculated by Cronbach's alpha (0.60 to 0.89). The lowest alpha was related to the domain of trust with eight individual items.

A total of four studies did not investigate validity (18,26,27,31). However, two of them reported a pilot study to test the clarity of the items and improve the questionnaire (26,27). In three studies, content validity was established by groups of experts (14,28,32). Punthmatharith et al (28) tested reliability with a pilot study of 30 mothers and one other study did not assess reliability because of the disparate nature of the items (14). Bastani et al modified the instrument developed by Latour et al (24) used in paediatric intensive care units and 10 mothers were enrolled to determine the reliability (32).

Two studies used the Nurse Parent Support Tool (NPST) (29,30), previously developed and tested by Miles et al (33). This original instrument measured parents' perception of nursing support during their child's hospitalisation. The psychometric properties of the NPST were tested through factor analysis and reliability (33). Tran et al modified the NPST by adding a second section to explore parents' satisfaction (29). Their instrument was not psychometrically tested. Domanico et al added 11 items related to physical facilities, such as privacy for bonding or breastfeeding and controlling lights, to the NPST, but did not mention if the validity of the amended version was tested (30).

### **FCC principles and parent satisfaction instruments**

The 11 instruments described in this review were analysed and we compared the items, when reported, or the topics and other instrument components with the FCC

principles listed above. Only two instruments included all six principles, whereas the remainder explored most of them (Table 3). Furthermore, three instruments also investigated parent satisfaction concerning NICU facilities, such as toilet and sleeping facilities and a breastfeeding room. The instruments included in the present review that explored FCC, with regard to parents' experiences or perceptions, and, or, their satisfaction is shown in Table 2.

## **DISCUSSION**

This review identified 11 new instruments that measured parents' satisfaction and experiences related to FCC in the NICU. In general, the primary aim of the studies included in this review was to evaluate this using different study designs. The primary aim of two of the studies was to develop and validate a new instrument. Psychometric analysis was not performed for most of the instruments, except for the two that had been developed through a specific validation study (24,25). Factor analysis was performed for both of these instruments and this supported their theoretical structure (23). These were also the only two instruments that explored all the FCC principles used in NICU settings. Information and education, as well as involvement of parents, were the FCC principles that were most frequently investigated in the other satisfaction instruments. According to Mikkelsen and Kirsten, the principles of FCC for children in hospital should be seen from a wider prospective that also considers other core values, such as mutuality, shared goals, shared responsibility, parental autonomy and control (34). However, it should be taken in account that the NICU is a unique setting in which parents and newborns are just beginning a new relationship and they need to develop and maintain it. Thus, the parents need to be assisted in this relationship and to develop their own parental role. It is possible that this could also explain why the principle of respect was not addressed so frequently by the reviewed questionnaires.

Respect is a complex concept that implies acceptance of racial, socioeconomic diversity and the uniqueness of the other (35,36). The fact that the respect principle was not addressed as often may reflect the difficulties experienced by NICU healthcare professionals when it comes to recognising parents' ethnocultural and religious differences and care preferences as essential aspects of today's care delivery. This is a point to consider in the analysis of parental perception of care. Indeed, families may be dissatisfied with the care they received because they feel that their values were not respected. Conversely, some nationalities might have a tradition of not being very critical, which could result in high satisfaction scores (37).

Some instruments focused exclusively on parents' experiences, others on parent satisfaction, while others measured both aspects. Sitzia and Wood reported that the discrepancy between expectations and actual experience was likely to be the major issue: it was only when an extremely negative event occurred that dissatisfaction was expressed (38). To avoid missing crucial elements, the provision of an open section gave parents the opportunity to describe their experiences in detail. The timing of the distribution of the questionnaires could be crucial with regard to the risk of bias. It is possible that parents were more satisfied when the questionnaire was completed at discharge. Indeed, the phenomenon of gratitude could be present at this stage (38).

We only identified one study that used an online survey to assess parent satisfaction with FCC (27). Although conducting surveys via the Internet may have several advantages, such as eliminating stationery costs and avoiding manual data input, there are also important limits to be considered, such as the need to obtain a representative sample and adequate response rate (39). Another novel way to administer questionnaires might be sending text message questions to parents' mobile phones, as used by Separation and Closeness Experiences in Neonatal Environment research group (40). However, several limitations might be considered, such as difficulties in delivering the text messages and the response rate, as noted in that

study. Therefore, a paper version of the online instrument for those without access to the Internet should be taken in account.

Most of the instruments were self-administered and the number of items varied widely. On average, the validated instruments contained more items than the non-validated instruments. Longer questionnaires enabled researchers to explore more detailed FCC features, for example, a longer list of care activities or duplicate questions that referred to both doctors and nurses (25,27,28). However, the risk of overwhelming parents, careless answers and missing data should be considered. According to Sitzia et al, the risk of lower response rates was not related to questionnaire length (41). However, Rolstad et al found that response rates were lower for longer instruments, but that this could also be due to the content of the instruments (42). Therefore, it is important to consider the delivery mode, the appearance of the instrument and the motivation for completing it. Nevertheless, developing shorter and more user-friendly instruments, and avoiding redundant items, could be especially useful for periodic monitoring or benchmarking, such as the EMPATHIC-30 questionnaires for the paediatric intensive care unit setting (43).

This systematic review showed that only two studies conducted rigorous testing of the instrument's psychometric properties (24,25). Moreover, two other studies only performed reliability tests on a small group of participants (28,32) and two instruments were adapted from the NPST that measured perceptions of nursing support. This is a psychometric validated instrument developed by Miles et al, but the adapted instruments were not tested for their validity and reliability (29,30,33). Considering the strength of the original tool, we suggest psychometric testing of these new adapted instruments.

The question about which instrument should be used in NICUs is difficult to answer. The questionnaire length, validity and reliability of each instrument are important judgment criteria to be considered. We believe that an essential criterion when adopting an instrument should be that it has been developed following the steps

in the reliability and validation process (44). Moreover today's ideal NICU parent satisfaction instrument should include items covering FCC principles.

A limitation of this review was the defined time limit in the search strategy. We did not include studies published before the start of the last decade. Furthermore, we excluded those studies that used previously developed instruments without adapting them. Therefore, the studies measuring parent satisfaction that used the original questionnaires developed by Conner and by Miles without adapting them were not reported (17,33). The NPST was developed in 1999 and measured parent perceptions of nursing support. This instrument was well designed and validated but did not specifically focus on FCC in NICU settings. In the same year, Conner et al developed the NICU Parent Satisfaction Form to measure parent perceptions of care and evaluate the quality of care, but this lacked rigorous validation methods (17). However, these instruments had the merit of stimulating interest in measuring parent satisfaction (17,33).

Conner et al (17) outlined several important points for the design of parent satisfaction survey in neonatal settings and Butt et al reported similar consideration in the limitation section of their review (6). After almost 20 years we might conclude that these recommendations were not satisfied by most of the identified questionnaires in our review. This was probably due to a lack of knowledge of research methodology related to instrument development and its validity and reliability testing. Moreover, both the revisions by Conner et al and Butt et al only focused on parent satisfaction and not on satisfaction with FCC principles (6,17). Conner et al analysed the identified instruments along the care delivery process. Instead, Butt et al mostly explored the level of parent satisfaction and the factors that were correlated with it. Our review analysed parent satisfaction questionnaires that considered the FCC principles and focused on the validity of the instruments. We consider these two points crucial, both for implementing FCC in NICUs and for assessing reliable and valid outcomes.

## **CONCLUSION**

This review showed that only two validated instruments are available to assess parent satisfaction with the six principles of FCC in NICU settings. These are Latour et al (24) and Hagen et al (25)

In terms of validity rigour, addressing all components of FCC and the number of items, the instrument developed by Latour et al (24) seems to be a preferred instrument. However, the decision about what parent satisfaction instrument to use should ultimately be guided by the study question.

Given that FCC has been ranked as the second most important nursing research domain in NICUs across Europe (45), it is important to use validated instruments to assess the satisfaction and experiences of parents of all the components of FCC in NICU settings. Further research in this field is needed to be able to use validated instruments in diverse cultural contexts, to reduce the number of items contained in lengthy instruments and to evaluate innovative ways of administering questionnaires.

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**LIST OF WORDS AND ABBREVIATIONS**

EMPATHIC-N, Empowerment of Parents in The Intensive Care Neonatology; FCC, Family-Centred Care; NICU, Neonatal Intensive Care Units; CINAHL, Cumulative Index to Nursing and Allied Health Literature; NPST, Nurse Parent Support Tool.

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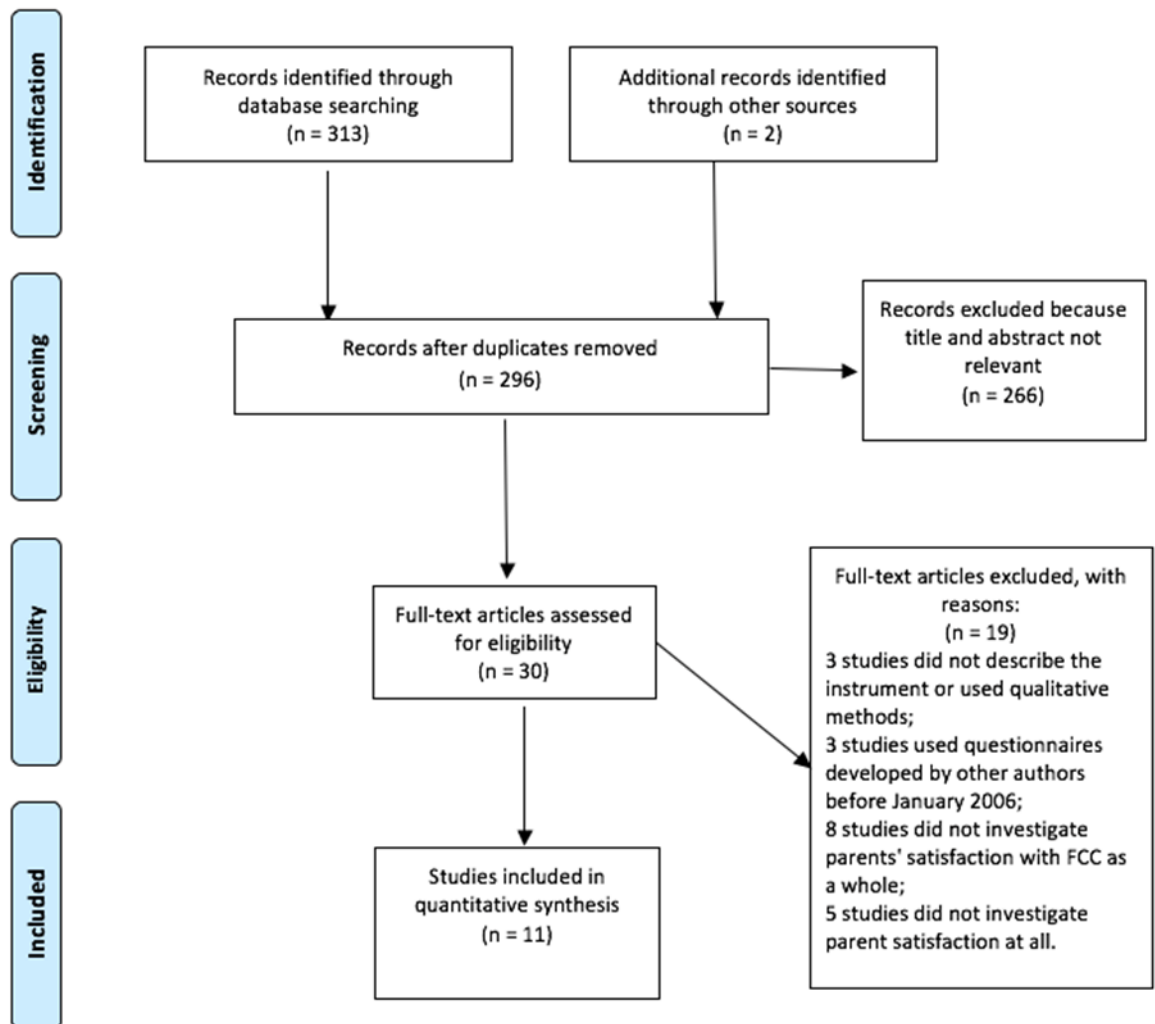
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Figure legend:



**Figure 1.** Flow-chart on selection of included studies

Table 1 Studies included in the review

Author(s) and year	Objectives	Setting	Sample size	Data collection methods	Instruments	Validity and reliability
<i>Validation study</i>						
Latour et al. (2012) (24)	To develop and test the psychometric properties of the EMPATHIC-N (EMpowerment of PArents in The Intensive Care Neonatology) questionnaire measuring parent satisfaction.	1 NICU in a university hospital. N. beds not reported. (The Netherlands)	441 parents of preterm infants divided into two cohorts.	The self-administered questionnaire was mailed to the parents 3–4 weeks after NICU discharge. Excluded were parents whose child's hospitalization was <48 hrs and whose child died in the unit. The development of the questionnaire was a structured process.	EMPATHIC-N rated scale questionnaire from 1 to 6 (1=certainly no; 6=certainly yes) and an alternative box, "not applicable". Overall satisfaction about physicians' and nurses' performances had a 10-point rating scale. 57 statements. Parent anonymity was not reported.	Content and face validity. Structural equation modelling and confirmatory factor analysis, reliability (Cronbach $\alpha$ ranged from 0.82 to 0.95) and reliability across time (it did not vary). Congruent validity; no differential validity.
Hagen et al. (2015) (25)	To develop and validate a survey investigating parents' satisfaction with neonatal wards.	1 hospital NICU with 13 beds. (Norway)	105 parents of preterm infants.	To develop the questionnaire, the literature was reviewed and three focus groups were formed: two with expert health personnel and one with parents. Survey was tested in a parent population.	Neonatal Satisfaction Survey – 13 categories (NSS-13) composed of 69 items. Parent anonymity was not reported.	A pilot study to assess content validity and statistical considerations. Cronbach's alpha is reported (it varied from 0.60 to 0.89). Factor analysis was performed but results were not reported.
<i>Studies developing or adapting an instrument and measuring the outcome</i>						
Byers et al. (2006) (14)	To evaluate the impact of FCC on infant physiological variables, growth, behavioural stress cues, return to sleep state, medical and developmental progress, complications, resource utilization, parental perception of NICU experience, and overall parental satisfaction.	A 78-bed NICU. (USA)	14 premature infants and their parents.	A parental satisfaction questionnaire was distributed by the NICU staff the day before discharge and collected on the day of discharge.	Parents' questionnaire: 11-item parental satisfaction tool with 5-point Likert scale (5 = strongly agree). Parent anonymity was not reported.	A panel of experts established content validity. Because of the disparate nature of items, survey reliability was not assessed.
Hurst (2006) (26)	To identify parents' utilization and evaluation of a support program based in a NICU.	1 III level NICU. N. beds not reported. (USA)	48 parents.	Program records and a written survey documented parental use and evaluation of services. A request to complete the survey was sent to families in 3 separate mailings.	Parents' questionnaire: PSS with 13 Likert-type, declarative statements. Parent anonymity was not reported.	Not reported. A pilot test with 5 families was conducted to improve clarity.

Berns et al. (2007) (27)	To assess successes and opportunities for improvement with parents' experiences and involvement in their premature infants' care in NICUs	NICUs. N. of NICUs not reported; (USA)	502 parents of preterm infants.	Questionnaire provided online to parents with a child who had gone through or was currently in a NICU supplemented by telephone interviewing.	A 30 min national survey of 76 questions about FCC topics. A 10-point scale was used to assess parental NICU involvement. A 4-point scale (from 'very much' to 'not at all') was used to measure how comfortable parents felt about asking the nurses and physicians questions. A 5-point scale was used to measure the amount of information. Parent anonymity was not reported	Not reported. Pretesting for comprehension was conducted.
Cooper et al. (2007) (18)	To evaluate the impact of a national program designed to promote FCC in NICUs and to provide information and comfort to families during the hospitalization of their newborns.	8 NICUs. N. beds not reported. (USA)	216 NICU families 502 NICU staff members 11 NICU administrators.	<i>Family survey:</i> self-completion written surveys distributed to NICU families personally by the NFS (NICU Family Support) Specialist and/or NICU staff or mailed. The respondents were families of NICU graduates or with an infant currently admitted to NICU.	Family survey: open-ended, multiple choice and Likert Scale items (n= not reported) from 1 (Strongly Disagree or None at All) to 5 (Strongly Agree or A Lot). Parent participation was anonymous	Not reported
Punthmatharith et al. (2007) (28)	To compare the needs, need responses, and need response satisfaction of mothers.	NICUs of three hospitals. N. of NICUs not reported; (Thailand)	420 mothers of infants admitted into the NICUs divided into three groups.	The mothers who agreed to participate in the study were interviewed through questionnaires for approximately 1 hour by the researchers and well-trained assistant researchers.	Questionnaires on: demographic data, maternal needs, maternal needs responses, maternal need response satisfaction. The 75 responses varied from 0 (no need/no need response/no need response satisfaction) to 3 (the highest need/the highest need response/the highest need response satisfaction). Mothers agreeing to participate in the study were guaranteed protection of confidentiality.	Content validity was examined by three experts in the field of maternal and infant nursing. Reliability was tested with 30 mothers but result was not reported.
Tran et al. (2009) (29)	To identify parents' perception of the type (emotional, informational, appraisal and instrumental) and level of support provided by nurses in NICU. Parents were asked to rate their level of satisfaction with this support.	1 III level NICU N. beds not reported. (Australia)	62 parents of preterm infant.	One self-administered questionnaire distributed to parents of infants prior to discharge. Completed questionnaires were posted back by parents to the university in the envelope provided.	Modified <i>Nurse parent support tool (NPST)</i> previous developed by Miles,(30) with 21 items measuring parents' perception of nursing support and assessing parents' satisfaction. Parents responded on a Likert-type rating scale ranging from 1-5.  Parent anonymity was not reported	The modified instrument was not psychometrically tested as reported by authors.



Domanico et al. (2010) (30)	To compare satisfaction levels of families and health-care staff across different NICU facility designs (open bay, single-family room- SFR)	1 NICU. N. beds not reported. (USA)	161 parents of infants divided into three groups. 161 staff members.	<i>Parent questionnaire:</i> questionnaires distributed around the time of their infant's discharge. Parents of deceased infants were excluded.	Parents' questionnaire: <i>NPST</i> with 21 items, Likert scaled from 1 to 5 (1= almost never, 5= almost always) and 11 similarly styled questions regarding physical facility. Parent participation was anonymous.	Adaptation of a previous validated search (30). Validity and reliability testing of the questionnaire was not reported.
Capdevila et al. (2012) (31)	1. To measure how the severity of the newborn's condition influences parental satisfaction. 2. To compare the results before and after moving to a new building	1 III level neonatal unit. N. beds not reported. (Spain)	Parents of 87 newborns.	A questionnaire survey to check parental satisfaction. The newborns were divided into 2 categories, depending on the severity of their condition. The impact of the move to a new building on satisfaction was also analysed. Statistical descriptive studies and multivariate models were used.	A questionnaire survey divided into two parts: 1. Epidemiological data; 2. Parental satisfaction as regards human and environmental issues. 15 items composed of an analogic scale from 0 to 10. The questionnaire was not anonymous.	Not reported
Bastani et al. (2015) (32)	To determine the effect of FFC, including maternal participation, presence, and information about neonatal care, on maternal satisfaction and neonatal re-admission.	1 NICU of a university maternity hospital. N. beds not reported. (Iran)	110 primiparous mothers of preterm infants with respiratory distress syndrome.	Satisfaction questionnaire was distributed and completed by mothers 24 h after neonatal hospitalization. The questionnaire was again completed by the mothers at the time of discharge. The mean time taken to complete it was 10 min. The neonatal deaths occurring during the study were excluded from the study.	The questionnaire was modified from that of a previous research study. (20) The questionnaire was graded from 0 (very dissatisfied) to 4 (very satisfied). It consisted of 18 items. Mothers' anonymity was not reported	Content validity was determined by 10 faculty members; reliability test was performed through a pilot study with 10 mothers. Result was not reported.

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Table 2 Characteristics of the domains and items of the instruments included

Authors of the study	Name of the instruments	Number of domains	Name of domains	Measure of outcome Experience (E) Perception (P) Satisfaction (S)	Overall satisfaction or assessment	Number of Items	Open ended question/ free space
Latour et al (24)	EMPATHIC-N	5	Information; Care & Treatment; Organization; Parental Participation; Professional Attitude	E+S	Yes	57	Free space for comment
Hagen et al (25)	Neonatal Satisfaction Survey – NSS-13	13	Staff; Admission; nurses; anxiety; siblings (parents' perceptions of caring for the siblings of the new-born); information; timeout; doctors; facilities; nutrition; preparation for discharge; trust and visitors	S		69	Free space for comment.
Byers et al (14)	NICU parental satisfaction tool	3	Parental perceptions of staff caring; education received; preparation for the parental role;	P+S	Yes	11	No
Hurst (26)	Parent Satisfaction Survey (PSS)	No division	Not reported	S	No	13	Free space for comments
Berns et al (27)	USA/DIRECT Inc. national survey	4	Parental NICU involvement, communication, information and transition to home	S	No	76	Open-ended questions. N. not reported.
Cooper et al (18)	Health Systems Research Inc. (HSR) survey	3	Information and comfort; Family-Centered care/parental involvement; Other findings	E	No	Not reported	Open-ended questions. N. not reported.
Punthmatharith et al (28)	modified satisfaction questionnaire	5	Personal; psychological; information; maternal role; treatment; nursing care	S	No	75	No
Tran et al (29)	Modification of NPST	4	Emotional, informational, appraisal and instrumental support	P+S	No	42	2 open-ended questions
Domanico et al (30)	Modified version of Nurse parent support tool (NPST)	2	Staff performance; Physical facility	P	No	31	No
Capdevila et al (31)	Satisfaction survey	2	Human aspect; environmental aspect	S	No	15	1 open-ended question
Bastani et al (32)	Not named	3	Parental presence; participation in neonatal care; information about neonatal care	S	No	18	No



Table 3 FCC principles included in the instruments

Authors	FCC principles					
	Respect	Information and education	Coordination of care	Physical support	Emotional support	Involvement of parents
Byers et al (14)		x	x		x	x
Latour et al (24)	x	x	x	x	x	x
Hagen et al (25)	x	x	x	x	x	x
Hurst (26)		x		x	x	x
Berns et al (27)		x		x	x	x
Cooper et al (18)	x	x	x	x		x
Punthmatharith et al (28)		x	x		x	x
Tran et al (29)		x	x	x	x	x
Domanico et al (30)	x	x		x	x	x
Capdevila et al (31)		x		x	x	x
Bastani et al (32)		x				x