

Systematic Review of Family Engagement Interventions in Neonatal, Pediatric, and Adult ICUs

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Abstract

Aims and objectives: The purpose of this systematic review was to evaluate interventions that have been used to engage families in direct care activities (active family engagement) in adult, pediatric and neonatal intensive care unit (ICU) settings.

Background (what is known on this topic): Family engagement is universally advocated across ICU populations and practice settings; however, appraisal of the active family engagement intervention literature remains limited.

Search strategy: Ovid Medline, PsycArticles & PsycInfo, Scopus and CINAHL were searched for family interventions that involved direct care of the patient to enhance the psychological, physical or emotional well-being of the patient or family in neonatal, pediatric or adult ICUs.

Inclusion/exclusion criteria: Studies were included if an active family engagement intervention was evaluated. Studies were excluded if they were not published in English or reported non-interventional research.

Results: A total of 6,210 abstracts were screened and 19 studies were included. Most studies were of low to moderate quality and conducted in neonatal ICUs within the United States. Intervention dosage and frequency varied widely across studies. The interventions focused on developmental care (neonatal ICU) and involved families in basic patient care. Family member outcomes measured included satisfaction, stress, family-centered care, confidence, anxiety and depression. Most studies found improvements in one or more outcomes.

Conclusions (what this study adds to the topic): There is a paucity of literature about active family engagement interventions, especially in adult and pediatric populations. The optimal dosage and frequency of family engagement interventions remains unknown. Our systematic review found that data is limited on the relationship between family engagement and patient outcomes and provides a timely appraisal to guide future research.

Relevance to Clinical Practice: Further research on the efficacy of family engagement interventions is warranted. The translation of active family engagement interventions into clinical practice should also be supported.

Introduction

Family engagement is an *active* partnership among health professionals, patients, and their families that can improve individual health and well-being and healthcare quality and safety [1–3]. Current family-centered care guidelines [4] stress the importance of family involvement, particularly in decision-making. However, the evidence base for active family engagement, in which family members contribute to aspects of direct patient care [5–7], is limited. Involving family in the delivery of care is advocated across ICU populations and practice settings, but to our knowledge, an appraisal of active family engagement interventions has not been conducted. Thus, we undertook a systematic review of active family engagement interventions in neonatal, pediatric, and adult ICUs.

Background

Family engagement has become an important concept in the critical care literature [2, 5–8], with numerous calls to improve family engagement in the ICU [2, 5, 6, 9]. In a recent scoping review of family involvement interventions in adult ICUs, family engagement is described on a continuum moving from passive (e.g. physical presence at the bedside and receiving and having needs met) to more active activities (e.g. sharing and receiving information, involvement in decision-making, and making contributions to the care of the patient) [3]. Empirical evidence supports the value of family presence, communication with families, and the importance of decision-making support in the ICU [3, 4, 10, 11]. However, the evidence on

interventions that directly involve families in the care of the critically ill patient and the effect of such interventions on patient and family outcomes has not been well described.

Active family engagement is an important element of and vehicle to achieving family-centered care (FCC) [1], and relevant to healthcare delivery across the lifespan [4]. Although pediatrics has embraced a FCC philosophy longer than adults specialties, universal barriers to FCC in neonatal, pediatric and adult ICUs include: inadequate guidance and support for families; lack of guidelines and policies for family engagement; inadequate time to engage with families; and a lack of unit and organizational support for FCC [12–16]. Hence, there is a need for evaluation of the existing evidence to identify effective strategies for promoting active family engagement in ICU environments across the lifespan [3, 5, 13].

As more researchers begin to test active family engagement interventions in pediatric and adult settings, a detailed review of existing interventions and their impact on patient and family outcomes is needed. The purpose of this systematic review is to describe and evaluate interventions that have been used to actively engage families in neonatal, pediatric, and adult ICUs.

Methods

Design

A systematic review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [17] was conducted. The review was registered in the

International Prospective Register of Systematic Reviews (National Institute for Health Research) - (CRD42018109259).

Search Strategy

The literature search strategies were designed by a medical librarian. Ovid Medline, PsycARTICLES, PsycINFO, SCOPUS, and Cumulative Index of Nursing and Allied Health Literature (CINAHL) databases were searched using a combination of standardized terms and keywords including: empower, involve, activate, engage, participate, collaborate, FCC, and patient participation. The full search strategy for Ovid Medline is shown in Figure 1.

Study Inclusion Criteria

To be included for review, articles had to: (a) include family (defined as family member, family caregiver, partner, significant other, relative, parent, spouse, or children) (b) be conducted in an ICU setting (neonatal, pediatric, or adult), and (c) report quantitative or qualitative outcomes of a family-focused intervention that actively engaged family in some aspect of patient care defined as – doing something with/for the patient to enhance their psychological, physical or emotional well-being. We excluded: (a) non-interventional study designs, (b) quality improvement and dissertation studies, and (c) studies not published in English.

Review Process

Literature searches were completed in September 2018 and updated in May 2019. Results were exported into EndNote, and uploaded into an open source software to manage systematic reviews (Rayyan QCRI) [18]. Six reviewers independently screened all of the

abstracts. If at least two reviewers included an abstract, a full text review was completed. Discussions were held among all six reviewers until consensus was reached about study inclusion.

Data Extraction

A comprehensive data extraction form was developed based on the Cochrane data collection for intervention reviews [19] and the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) [20]. Data extraction focused on the population, setting, sample sizes, intervention descriptions, measures, and intervention outcomes. Two team members were assigned to each study and independently extracted data and graded the quality of the study using the GRADE criteria (quality of evidence based on confidence that the true effect is close to the estimate of the effect and rated as very low, low, moderate or high) [20]. The GRADE criteria examines factors such as limitations in study design and other risks of bias. Differences were resolved through collaborative review and discussion until consensus was achieved among the two reviewers. Data extraction results were entered into a table format to synthesize the findings.

Results/Findings

A total of 6,210 records were identified. With automated duplicate finding, 663 duplicates were removed for a total of 5,547 citations. After abstract screening, 147 full text articles were reviewed for inclusion. Nineteen articles met all inclusion criteria and were included in the review (Figure 2). The summative table of the interventions and study

characteristics can be found in Table 1. Given the heterogeneity across the studies a narrative approach was used to describe the study findings [21]. Intervention descriptions are grouped by patient population (neonates, children, or adults).

Study Characteristics

Design. There were eight reports of randomized controlled trials (RCT) [22–29], and seven quasi-experimental studies [30–36]. Four studies were pilots and/or feasibility/acceptability studies [37–40]. All of the RCTs were conducted in the NICU. Two of the RCTs reported on different elements of the same longitudinal study [24, 25]. A quasi-experimental design was the strongest design used in studies conducted in the PICU or adult ICU.

Study Quality. Study quality varied, with only one study rated as high quality [27]. Seven studies were of moderate quality [23–25, 28–30, 34], four were low quality [22, 26, 31, 32], three were very low quality [33, 35, 36] and four studies could not be assigned a quality grade because of design (pilot/feasibility/acceptability) [37–40]. Only one study included any element of blinding [27]; however, given the types of multifaceted interventions blinding was not feasible in most studies.

Family Sample. Sample sizes ranged from 12 (acceptability study) [38] to 414 (RCT) [27] family members. Of the studies that reported family member demographics, there were larger percentages of female than male participants, with female (mother or other family member) participation ranging from 50% to 95% [22, 23, 26–28, 35, 38–40]. Four studies included only mothers [24, 25, 29, 36], and two studies included only fathers [32, 33]. Of the studies reporting

race, samples ranged from 2.5% to 84% White [22, 24, 25, 27–29], with the most diverse sample reported as 77% Black and 16% Hispanic [24].

Study Setting. Seven studies were conducted in the United States [24, 25, 27, 29–31], two in Italy [26, 37], two in the Netherlands [23, 28], and two in Australia [35, 40]. Other locations included India [38], Denmark [33], China [32], Thailand [36], and Ireland [34]. The majority of the studies were conducted in the neonatal ICU (NICU) (n=14) [22–33, 37, 38], followed by the adult ICU (n=4) [34, 35, 39, 40]. Only one study was conducted in a pediatric ICU [36]. More than half were single center studies (n=11), and many were conducted in large academic medical centers (n = 8). Most NICU settings were designated as Level III care centers (**prompt and readily available access to a full range of pediatric medical subspecialties**), with one Level IV NICU (**highest level of neonatal care for complex and critically ill infants**) [29].

Intervention Characteristics

Theoretical Framework. Thirteen studies included a theoretical model/framework that guided the intervention [23, 27–30, 32, 34–37, 39]. NICU frameworks included developmentally supportive care and the Synactive Theory of Infant Development [41], self-regulation and control theories, mediated learning based on social learning theory, and the philosophy of family-centered care [35, 38, 40]. The PICU study utilized helpgiving practices [42]. Adult ICU frameworks included Neuman’s System’s Model, facilitated sense-making [43], and FCC [35, 40].

Types of Interventions. NICU interventions were focused on involving a parent or parents in some aspect of developmental supportive care for the infant. Intervention components included: education (informational packets and conversations with healthcare professionals) about the NICU environment and behaviors and characteristics commonly exhibited by NICU babies, and structured guidance from healthcare professionals on how to care for the baby using techniques such as kangaroo care, auditory-tactile-visual-vestibular stimulation, infant massage, and calming touch. Almost all of the NICU interventions reviewed included an educational component, and many utilized nurses or other staff (family support specialist or physical therapist) to help parents to master the knowledge and skills required for infant care. Two studies used video-recorded sessions of parents interacting with their infant to provide behavior-based feedback to parents about how to bond and engage with the infant in a developmentally appropriate way [23, 27]. Two studies used the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as a component of an intervention or as an intervention [28, 30]. The Family Nurture Intervention (FNI) used in one study involved calming activities for the mother to perform with the infant [29] including the use of scent cloths for both the infant and the mother to encourage bonding. The PICU intervention involved flexible visiting with structured support from nursing staff to encourage the mother to talk to, touch and hug the child, and participate in daily care [36]. These pediatric-based interventions used behavior change strategies such as modeling, feedback, and increasing parent self-efficacy through mastery of

skills [22, 23, 26, 27, 29, 32, 33, 36–38]. Standard care was most commonly used in the control groups with the exception of one study that used an attention control [27].

Similar to NICU interventions, adult ICU interventions often included a mix of education, information packets, and nurse facilitation of family involvement in care [34, 35, 39, 40]. Specific strategies included nurse-facilitated family communication and interaction with the patient [34], personalized nurse instruction and family visitation kits [39], family involvement in basic patient care [35], and family involvement in the assessment and management of the critically ill patient's nutritional status [40]. These interventions included educational components (providing information via written material or with a healthcare professional on the ICU environment and how to deliver patient care activities), as well as behavioral change strategies such as feedback, modeling and reinforcement of skills in patient care, and teaching families what to expect to guide goal setting. There was only one study that took place in the adult ICU that had a control group receiving standard care [34].

Frequency and duration of intervention (dosage). The majority of the studies required multiple sessions for the delivery of all of the intervention components. NICU intervention sessions ranged from 15 to 60 minutes in length [22–26] and occurred from three to four times per week [24, 25, 29] to as frequently as daily [37]. In other NICU studies there was a specified number of sessions ranging from two to eight total sessions [22, 26, 27, 38]. There was an adult ICU study that included both a low and a moderate intensity intervention [40]. In the pediatric and adult ICU studies dosage was difficult to discern.

Effects of Interventions

Infant Outcomes. There were no significant differences in physiologic outcomes of the newborn such as HR, O2 saturations, growth, feeding, complication rates, and time to return to sleep when comparing infants in control and intervention groups [30]. Pain levels were actually perceived to be higher by parents in the intervention group [22] than parents in a control group. Infant weights were significantly higher [37], length of stay in the NICU and hospital were shorter [27] and infants had more alert periods and total waking time in the intervention groups compared to the control groups [24]. Infants whose parents were instructed on developmentally supportive care demonstrated lower behavioral stress cues and lower respiratory rates during activity than infants in the control group who received usual care with restricted visitation [30].

Adult Patient Outcomes. There were lower physical and psychosocial impact of illness scores for patients in the intervention versus the control; however, there were no differences in delirium or length of stay [34].

Parental Psychological Factors. Ten of the NICU studies examined stress as an outcome. Results varied: Six studies demonstrated a significant association between the engagement intervention and decreased parental stress levels related to parental role, NICU environment, or appearance of the infant [24, 26, 27, 31, 32, 37], three studies showed no significant relationship between parental stress level and participation in an engagement intervention [22, 23, 28]. Two studies were conducted with just the fathers of infants hospitalized in a NICU [32, 33], with conflicting outcome results for stress levels. In one study

there was reduction in stress in the intervention group versus the control [32]; in the other study the intervention group experienced more stress than the control [33].

Nine of the NICU studies examined outcomes in both mothers and fathers. In some of the studies, mothers were more likely to experience a decrease in parental role stress and overall stress than fathers [26, 27]. While both parents demonstrated more sensitive interactions with infants (increase in sensitivity and positive regard) and fewer withdrawn behaviors (detachment and flat affect) following video-interactive guidance, fathers demonstrated greater increases in parental bonding [23].

Two studies examined more distal parental psychological outcomes. Melnyk et al. [27] demonstrated a reduction in symptoms of anxiety and depression in mothers after participation in the Creating Opportunities of Parent Empowerment program, whereas there were no differences in fathers' symptoms. The study conducted by Welch et al. [29] demonstrated a decrease in depressive and anxiety symptoms in mothers following participation in the Family Nurture Intervention.

Parental Satisfaction, Knowledge and Adaptation. In studies with parental satisfaction measures, parent satisfaction with the interventions were generally favorable [25, 37, 38]. Outcomes included improved communication, collaboration, information [37], helpfulness of the nursing staff [25], knowledge acquisition [31], adaption to the NICU environment, and increased closeness to the infant [38]. Mothers of children hospitalized in the PICU who were part of the intervention group reported higher self-efficacy levels in participatory involvement and overall

satisfaction with nursing care [36]. Parents who received education about infant pain and comforting infants expressed a stronger preference to be present or involved than parents in the control group [22]. Two studies demonstrated no differences in: parental perceptions of care delivered [30], confidence levels for caring for their infant, or perceived nursing staff support [28].

NICU Staff Perspectives. Nurses, physicians and other interprofessional team members had positive perceptions of the engagement interventions [31, 38]. They reported more informed parents, increased bonding, open and honest communication, more involvement in decision-making [31], and increased parental presence that enhances the well-being of the newborn [38].

Adult ICUs - Family Member Feedback on Feasibility and Acceptability of Interventions. Outcomes assessed from the four adult ICU studies mainly focused on feasibility of the interventions. Family members reported higher FCC (collaboration, support, respect) when they were engaged in fundamental care activities such as hair combing, hand massage, or bathing than those who did not [35]. Educating families how to use nutrition diaries prompted them to ask other relevant questions about the care and health of their loved ones [40]. Family members found personalized instructions by the nursing staff and family visiting kits to be useful in helping them make sense of the situation and their new role as caregiver [39]. Family members were most engaged in the learning process when given information about what to expect in the ICU environment (monitors, alarms, surroundings etc.) and how to participate in care at the bedside (personal care for the patient such as manicure, lip balm application, or

passive range of motion) [39]. Family maintained journals summarizing patient progress and daily activities were not as helpful as verbal instructions from nurses during interactive care activities [39].

Discussion

All except one study [28] included in the review described one or more benefits of family engagement interventions. Positive outcomes for family members included increased satisfaction, self-efficacy, empowerment and desire to be involved in the care of an infant, as well as reduced stress, anxiety and depression. Positive infant outcomes included shorter length of stay, increased weight [27, 37]. Adult patients had a lower impact of illness in one study [34]. Although the studies were heterogeneous in terms of the intervention studied, measures and outcomes, overall there is evidence that active family engagement results in positive outcomes for patients and families. The evidence base is stronger in NICU studies than adult ICU studies, and research is lacking in PICUs.

The quality of the evidence for the included studies was predominately moderate to low. Three studies were very low quality [33, 35, 36] and three could not be graded due to design [38–40]. Single site study location, lack of intervention fidelity monitoring, inadequate reporting of participant demographics, attrition, lack of statistical control for demographics or unit factors, small sample sizes, lack of randomization, possible intervention contamination, and investigator developed instruments were possible sources of bias in some of the studies. We found that the family samples were predominately female with limited diversity with the exception of two

NICU studies. Additionally, the majority of the studies were conducted in Western countries, an important consideration, as healthcare delivery systems, and family definitions, composition and function may differ in other areas of the world.

There was considerable variability in study design and interventions, making it difficult to compare outcomes. Although more than half the studies included a theoretical framework, few studies made a clear linkage between the theoretical underpinnings and the components of the intervention and expected outcomes. Intervention fidelity was rarely discussed. Family engagement interventions included multiple components, some of which were nurse-led. It was not clear in most studies how nurses enacted intervention delivery. Active family engagement may require more complex interventions to be successful, therefore, clear descriptions of intervention components are needed for replication. Multi-site RCTs of family engagement interventions are a priority for future research to increase the strength of the evidence base for active family engagement interventions, and to support their translation into clinical practice.

Reporting of patient-related outcomes of family engagement interventions was limited [22, 27, 30, 34]. Satisfaction was used as an outcome in many of the reviewed studies, and while important, it may not fully capture the benefits of engaging in care. Studying outcomes beyond stress, anxiety and depression, such as resilience, adaptation, well-being, empowerment, and confidence, could yield important data about other potential benefits of engagement. Only two studies looked at the long term outcomes of interventions [24, 27]. There is a need for more research in this area as psychological symptoms for patients and their family members persist

after hospitalization [44–46]. Understanding the reach of family engagement beyond the ICU may provide important insights.

Exploring the impact of active family engagement based on family role may be important across ICU settings. As parenting roles differ, it is not unexpected that outcomes of family engagement interventions differed for mothers and fathers [23, 26, 27]. Fathers may experience greater stress due to demands outside of the NICU environment such as employment, juggling home demands and caring for other children [33, 47]. Some studies have found that mothers and fathers have different perspectives, with mothers tending to be more detailed oriented and fathers preferring a global picture of their infant’s condition and care [48]. To our knowledge there are no known studies addressing differences among family members in response to active family engagement interventions in the adult ICU. Further, understanding the effects of family engagement beyond individual patients and family members, – the impact on families, remains an important focus for future research [49]. Studying families presents methodological challenges; however, family-based analysis could result in new opportunities to promote active family engagement in more targeted ways.

Family engagement is posited to occur on a continuum [3], with the current review focused on interventions that involve the family in direct care of the patient. A question remains about how to prepare families to be involved in care. Future research should focus on how family members move along the care continuum and specific ways to increase their motivation and confidence to be part of direct care. The interactive care model [50] includes an assessment

of a family member's capacity to be engaged, and may serve as an important framework to guide the development of individualized family engagement interventions and the implementation of active family engagement in the ICU.

The current review offers a lifespan perspective on active family engagement. In the NICU the practice of FCC has long been supported as a philosophy of care that provides optimal support to infants during hospitalization [51]. Beginning in the 1950s, Bowlby's work highlighted the emotional, psychological, and developmental consequences of keeping mothers and infants apart [52]. Additional research has elucidated the importance of including all caregivers in infant bonding, expanding earlier maternal-based models to the entire family [53]. The opportunity to learn about engagement from other developmental stages of life has been described by others [54]. Physical touch is highlighted as an important aspect of developmental care in the NICU [51, 52, 55]; however, less is known about the importance of touch for adults. Similarly, in adult ICUs emphasis is placed on family engagement in terms of communication and decision-making [6, 14, 56] and less is known about communication and decision-making aspects of family engagement in the NICU. A theoretical framework for family engagement requires further development, particularly in the PICU and adult ICU settings. A stronger connection between theory and engagement interventions is needed in future studies. Conceptualizing engagement as a fluid and dynamic phenomenon may lead to the development of family engagement interventions that can be tailored to families in different phases of readiness for involvement in ICU care.

Limitations

Our review was limited to the English language, and thus, we may not have included papers that contributed to this area of science. However, an important strength of this review is the comprehensiveness of the search with assistance of a health librarian and inclusion of a wide range of databases. We included pilot/feasibility and acceptability studies to add a rich description of engagement interventions. However, these studies are only preliminary and cannot provide any evidence of outcomes associated with the interventions. There was also wide variation in the methodology and quality of the intervention studies reviewed. There is the potential risk of reporting bias – negative or non-significant findings may have not been reported in the literature and therefore are not included in this review.

Implications and Recommendations for Practice

In this systematic review, four studies were focused on feasibility indicating that 20% of the literature was early stage intervention work. This suggests that substantial work is needed in the development and evaluation of family engagement interventions, particularly in the PICU and adult ICU settings. Without clear data on the safety and efficacy of involving families in care of the patient it is difficult to develop policies and procedures for practice. More research on who should be engaged, how to engage families, and the outcomes for patients and their families should be the focus of future research.

Conclusion

There remains a limited evidence base for active family engagement in the PICU and adult ICU populations. More high quality family engagement interventional studies are needed. This review highlights important directions for active family engagement in ICUs across the lifespan.

Impacts

Family engagement is theorized to be an important part of high quality critical care but little is known about how to best engage families in direct patient care in the ICU, particularly in the adult and pediatric practice settings. This review summarizes the existing evidence base of active family engagement interventions in the ICU and highlights heterogeneity in interventions and outcomes. There are multiple opportunities to enhance research on active family engagement in the ICU to improve care for patients and their families.

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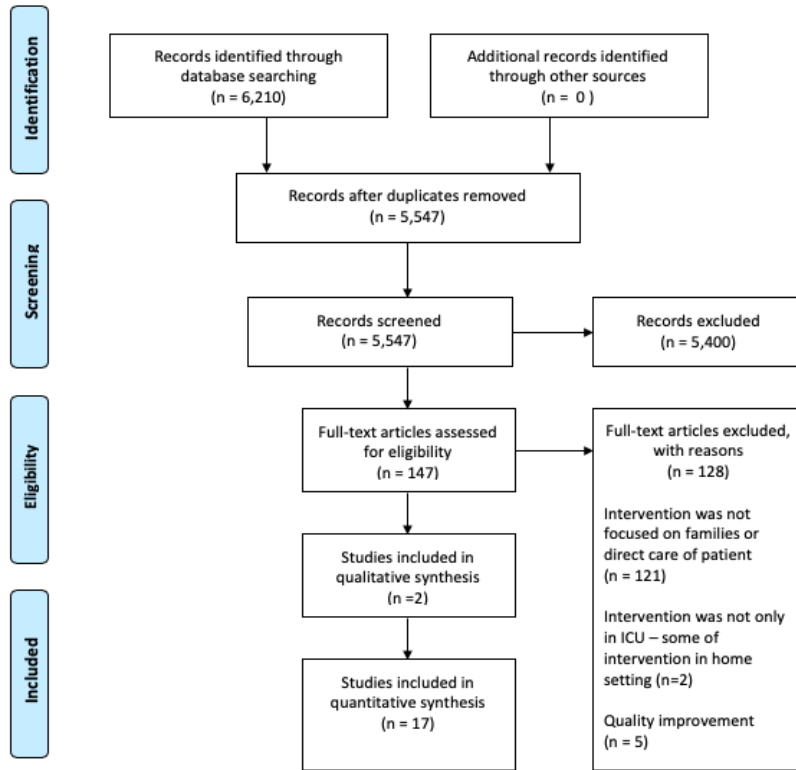
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Figure 1. Ovid Medline Search Strategy.

1. intensive care units.mp. or exp Intensive Care Units/
2. critical care.mp. or exp Critical Care/
3. critical care nursing.mp. or exp Critical Care Nursing/
4. ICU.mp.
5. 1 or 2 or 3 or 4
6. exp FAMILY/ or exp NUCLEAR FAMILY/ or exp FAMILY RELATIONS/ or family.mp.
7. family caregiver.mp. or exp Caregivers/
8. partner*.mp.
9. significant other.mp.
10. relative*.mp.
11. exp Parents/ or exp PARENT-CHILD RELATIONS/ or parent*.mp.
12. family member*.mp.
13. 6 or 7 or 8 or 9 or 10 or 11 or 12
14. patient participation.mp. or exp Patient Participation/
15. professional-family relations.mp. or exp Professional-Family Relations/
16. patient preference.mp. or exp Patient Preference/
17. patient-centered care.mp. or exp Patient-Centered Care/
18. nurse-patient relations.mp. or exp Nurse-Patient Relations/
19. patient satisfaction.mp. or exp Patient Satisfaction/
20. physician-patient relations.mp. or exp Physician-Patient Relations/
21. decision making.mp. or exp Decision Making/
22. personal satisfaction.mp. or exp Personal Satisfaction/
23. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
24. empower*.mp.
25. engage*.mp.
26. participat*.mp.
27. involve*.mp.
28. perception*.mp.
29. collaborate.mp.
30. collaboration.mp.
31. family-centered care.mp.
32. patient activation.mp.
33. family activation.mp.
34. activation.mp.
35. experience.mp.
36. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35
37. 5 and 13 and 23 and 3

Figure 2. PRISMA diagram.



Author Year Location	Setting & Sample	Aims/Research Questions	Theoretical Model	Design/ Sample Size	Study Conditions	Outcome Measures	Results	Quality Appraisal
NICU Studies								
Byers et al. [30] 2006 United States	Setting: neonatal ICU; single center Sample: Parents of premature infants 32 weeks or less	Evaluate the impact of individualized developmental supportive family care on infant and family outcomes	Developmentally Supportive Care (based on Synactive Theory of Development)	Quasi Experimental 114 parent/infant dyads Specific number in control and intervention group not reported	<u>Intervention</u> Individualized, developmentally supportive family-centered care, which included a specialized section of NICU and staff education (1) Specialized Section: open visitation, acoustic panels, privacy curtains (reduce noise and light) (2) Staff Education: developmentally supportive family care course included family centered care, ethics, communication, neonatal developmental NICU experiences; also newborn assessment training (Brazelton, oral/motor; NIDCAP). Full NIDCAP completed within first 7 days of admission. <u>Control</u> Usual care with restricted visitation	Physiologic (vitals) Medical and Development Progress (feeding, growth, behavioral stress cues) Return to sleep Length of stay Complication rates (ventilation days, days to open crib) Parent satisfaction and perceptions Resource utilization	Lower behavioral stress cues intervention group No statistical difference in other measures including cost, physiologic (with exception of lower activity respiratory rate in intervention group), growth, feeding, return to sleep, achievement of infant progress, complication rates, parental perceptions/satisfaction	Moderate Different inclusion/exclusion intervention and control No comparison of parents on demographics Data collection not blinded to study group No intervention fidelity monitoring reported Exclusion criteria was 32 weeks or less, yet demographics indicate infants more than 32 weeks at enrollment
Cooper et al. [31] 2007 United States	Setting: 8 Neonatal ICUs Sample: Hospital administrators, staff, parents/family	Evaluate the impact of March of Dimes NICU Family Support Program on overall care and family centered practices	None	Quasi experimental 3 groups NICU with full (4 NICUs), , partial (3 NICUs), and no implementation of program(1 NICU) Total Sample	<u>Intervention</u> March of Dimes Family Support Program (NFS): national program designed to promote family-centered care in NICUs. Includes: <ul style="list-style-type: none"> Family support specialist Baby photos & scrapbooking Parent to parent support Education for parent and 	Presence of intervention components (yes/no) Parental knowledge, comfort, confidence, connectedness Parental behaviors (asking questions of HCPs, ability to	Parents/family reported: <ul style="list-style-type: none"> increased family receipt education increase parent comfort after education increased parent-parent support NFS specialist helped decrease stress and	Low Measures post implementation only No data given on comparison sites to determine equivalence

				<p>includes: 11 NICU administrators, 502 NICU staff members, 216 NICU families</p>	<p>siblings</p> <ul style="list-style-type: none"> • Staff education <p><u>Control</u> Usual care</p>	<p>describe infant condition, level of involvement in care)</p> <p>Parent self-efficacy</p> <p>Parent report of programs & policies that endorsed intervention components</p> <p>Staff perception of family-centered principles (one time measure of perceived importance of items post intervention)</p>	<p>increase confidence for parents</p> <p>At partially and fully implemented sites, parents were more comfortable knowing what to expect for baby's medical condition and baby's growth and development</p> <p>Parents partially and fully implemented sites felt their opinions were taken seriously 'often' or 'a lot'</p> <p>Families in fully implemented groups were more comfortable putting a child safety seat in their car</p> <p>Staff reported:</p> <ul style="list-style-type: none"> • increased quality of care, more informed parents • decreased parental stress • increased parent-infant bonding <p>Staff reported intervention led to more importance in the following areas:</p> <ul style="list-style-type: none"> • open/honest communication with parents • shared information and meaning • involvement of parents in decision making • partnership with parents/family 	<p>No statistical control for unit factors</p> <p>Data self-report from surveys and interviews</p> <p>No intervention fidelity monitoring/reporting</p>
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							• development of policies/programs to support parent skills and involvement	
De Bernardo et al. [37] 2017 Italy	Setting: NICU, single center Sample: Parents of NICU infants at least 30 days post single surgery	Compare satisfaction and stress between parents in a family centered care group versus non-family centered care	Synactive Theory of Development	Non-randomized, prospective cohort pilot 144 96 Parents (48 control; 48 intervention) 48 newborns (24 control; 24 intervention)	<u>Intervention</u> Implementation of the Family Centered Care (FCC) Model <ul style="list-style-type: none"> Physical changes to the NICU: addition of kitchen and family rooms Caregiver education: nurses taught parents about NICU policies and correct procedures to care for infants Parental access to NICU from 10:00-18:00 Parent participation in care (e.g. bathing, diapering, breast feeding, holding during procedures) Parent observation of rounds Parent meeting with physicians offered daily <u>Control</u> Usual care: parents only able to visit infant one hour per day	Infant weight Parent satisfaction (receipt of information, healthcare team communication & collaboration; privacy) Parent stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU]))	Higher infant weight at day 60 day intervention group Parent increased satisfaction with communication/collaboration; information received; privacy) Lower stress for parental roles, baby appearance/treatment; and NICU environment	Low Small sample size One unit; pre/post intervention (different groups control/intervention) No intervention fidelity monitoring No control variables when evaluating parental stress (e.g. socio-economic status, lack of sleep, etc.)
Franck et al. [22] 2011 England	Setting: 4 NICUs Sample: Parents of NICU babies	Feasibility and effect of an intervention to increase parental involvement in pain management for NICU infants in relation to parents' stress and post discharge parenting competence and confidence	None	Randomized controlled trial (RCT) 169 (84 intervention; 85 control)	<u>Intervention</u> Within 3-7 days of admission parents received a booklet that provided evidence-based information about pain and comforting infants including: <ul style="list-style-type: none"> How acute pain occurs and how it may affect infants How pain is assessed and managed in the NICU The important role parents can play 	Parental stress (Parent Stress or Scale: Neonatal Intensive Care [PSS:NICU]) Parent views on infant pain and its treatment (Parent Attitudes about Infant Nociception [PAIN] Survey) Parental confidence in infant care-giving (Self-	Parents in intervention group perceived that their infant experienced slightly higher pain and expressed a stronger preference to be present or involved (90% vs. 75%). No differences in parental stress No group differences satisfaction with infant	Low Randomization by NICU not individual Differences intervention and control group at baseline High attrition

					<ul style="list-style-type: none"> • Specific instructions on how to comfort infants • Advice on how parents can work in partnership with NICU staff. <p>Parents also received 2 visits (approximately 45 minutes each from a research nurse) to show them how to apply the comforting techniques and to answer questions</p> <p><u>Control</u> General information booklet and 2 visits from nurse</p>	<p>Efficacy In Infant Care Scale [SICS])</p> <p>Parental perceptions of role attainment (What Being a Parent of a New Baby is Like [WBPBL-R])</p>	<p>pain care or confidence in ability of staff to manage infant pain and support parents</p>	<p>Outcomes were self-report</p>
<p>Hoffenkamp et al. [23] 2015 Netherlands</p>	<p>Setting: NICU (2) and maternity ward (7); 7 hospitals</p> <p>Sample: Parents with infants born at < 37 weeks</p>	<p>Effect of hospital-based video interactive guidance (VIG) in parents of preterm infants by means of a pragmatic multicenter clinical trial with 2 parallel arms</p>	<p>2 core concepts framed VIG: (1) intersubjectivity (2) mediated learning</p>	<p>RCT</p> <p>150 (75 control; 75 intervention)</p>	<p><u>Intervention</u> 3 sessions. Parents videotaped at 1st, 3rd, and 6th day postpartum. Videos are made during daily moments of caregiving (e.g. bathing, changing, feeding) to capture spontaneous and natural elements of basic parent-infant communication and are about 15 minutes in length. Recordings are edited by a VIG professional for micro-moments of the infant's cues for making contact and parent responses to those cues. The moments are reviewed by parents. During the review, parents are asked to reflect actively on the nature and details of their interactions. Feedback is given back to parents the day after the recordings are made.</p> <p><u>Control</u> Usual care</p>	<p>Parental interactive behavior (videos)</p> <p>Parental bonding (Postpartum Bonding Questionnaire [PBQ])</p> <p>Parent-infant relationship [Worry, Enjoyment, responsiveness, separation anxiety] (My Baby and I Questionnaire)</p> <p>Parental bonding and distress (Yale Inventory of Parental Thoughts and Actions)</p> <p>Parental Stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])</p> <p>Depression (Edinburgh Postnatal Depression Scale)</p>	<p>VIG was effective in enhancing behavior and diminishing withdrawn behavior in mothers and fathers.</p> <p>Positive effects of VIG very strong in those mothers who had traumatic birth experience</p> <p>Intervention did not change intrusive behavior</p> <p>Positive effects on parental bonding, especially for fathers but no sig effects on stress and well-being</p>	<p>Moderate</p> <p>Interrater agreement for observational coding has some limitations</p> <p>Not clear which part of the intervention actually accounted for the effects</p> <p>No direct comparison between outcomes of mothers and fathers</p> <p>Relatively small sample size of moms who met traumatic childbirth criteria</p>

						Psychologic Trauma (Traumatic Event Scale)		No clear definition of traumatic childbirth
Holditch-Davis et al. ^a [25] 2013 United States	Setting: 4 NICUs: 2 academic m medical centers. 2 community-hospitals Sample: Mothers of preterm infants	Examine mothers' satisfaction with auditory-tactile-visual-vestibular (ATVV) intervention and kangaroo care. Explore whether mother and infant characteristics affected maternal satisfaction ratings	None	Longitudinal 3-group experimental 249 (208 mothers completed satisfaction survey reported here) (73 control, 67 ATVV, 68 KC)	<u>Intervention (two groups)</u> (1) ATVV: perform massage that involves moderate stroking, eye contact, talking to, and rocking infant (2) Kangaroo care: skin-to-skin contact and holding Instructed to provide interventions for at least 15 minutes at least once a day, 3 times a week until infant was 2 months corrected age. Were able to provide whichever care they wanted to their infants <u>Control</u> ^b Attention control; parents met with study nurse to discuss how to select and locate safe equipment needed to care for preterm infants at home. Specific topics included diapers, infant clothing and blankets, car seats, breastfeeding supplements, formula, and toys.	Satisfaction with intervention Helpfulness of nurses who taught them intervention	All groups were satisfied with the intervention and helpfulness of the nurses. Lower satisfaction at 2 months associated with being younger, unmarried, African American, receiving public assistance, lower education, and infants with lower Apgar scores.	Moderate Same nurse performed all interventions Investigator-developed instrument
Holditch-Davis et al. ^a [24] 2014 United States	Setting: 4 NICUs: 2 academic medical centers; 2 community hospitals Sample: Mothers of preterm infants	Examine the effects of auditory-tactile-visual-vestibular (ATVV) intervention and kangaroo care (KC)	None	RCT – 3-group longitudinal study 240 (81 in control, 78 ATVV, and 81 KC)	<u>Intervention (two groups)</u> (1) Auditory-tactile-visual-vestibular intervention (ATVV): : stimulation in a gradual progression over 15 minutes beginning with voice only then auditory and tactile, with visual stimulation as infant becomes alert. Horizontal rocking added and tactile	<u>Infant sleep-wake responses to the intervention</u> Arousal was scored for 5 minutes from the videotapes. The predominant sleep-wake state (alertness, drowsiness, active waking, sleep-wake transition, active sleep,	ATVV infants had significantly more alert periods, total waking, and total alertness. No significant differences in infant responsiveness to stimulation. No difference maternal anxiety, depressive	Moderate Limited sample size Crossover between groups (20-30% of KC and ATVV moms and 58% of control moms

				<p>component withdrawn for final 5 minutes.</p> <p>(2) Kangaroo Care (KC): holding infant skin to skin in upright position between mother's breasts. As long as wanted for at least 15 minutes.</p> <p><u>Control</u> Attention control; parents met with study nurse to discuss how to select and locate safe equipment needed to care for preterm infants at home. Specific topics included diapers, infant clothing and blankets, car seats, breastfeeding supplements, formula, and toys..</p>	<p>and quiet sleep was recorded once a minute following ATVV and beginning following the start of KC.</p> <p><u>Maternal Psychological Distress</u> Depressive symptoms (Center for Epidemiologic Studies Depression Scale [CES-D])</p> <p>Anxiety (State-Trait Anxiety Inventory [STAI])</p> <p>Posttraumatic stress (Perinatal PTSD Questionnaire)</p> <p>Parenting stress (Parental Stress Scale: Prematurely Born Child)</p> <p>Degree of maternal worry about infant (The Worry Index)</p> <p>Mothers' perceptions of child vulnerability (Vulnerable Child Scale)</p> <p>Infant responsiveness to stimulation at discharge (Neonatal Behavioral Assessment Scale)</p> <p>Maternal Involvement</p>	<p>symptoms, or Posttraumatic stress symptoms, or parenting stress.</p> <p>KC mothers more rapid decline in worry than the other groups.</p> <p>Maternal positive involvement, developmental stimulation, and HOME total score did not differ.</p> <p>Parenting stress lower for mothers who did some type of intervention when compared to those that did none.</p> <p>HOME scores higher for mothers who performed massage alone or along with KC than those who did not</p>	<p>engaged in a non-assigned intervention)</p> <p>High attrition rate (21%)</p>
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						and Social-emotional and stimulation characteristics of the home environment (HOME Inventory)		
Lee et al. [32] 2013 Taiwan	Setting: NICU, single center Sample: Fathers of infants < 37 weeks gestation with expected LOS of at least 2 weeks	Evaluate the effectiveness of an intervention on fathering ability, perceived nurse's support and parental stress after a preterm infant's admission to a NICU	Four Components of Support (1) information (2) emotional (3) instrumental (4) esteem	Historical comparison 69 (34 control group; 35 intervention group)	<u>Intervention</u> Booklet distributed to fathers providing information about premature babies and NICU (equipment, developmental care, nutrition, infant appearance and behavior, ways to interact with infant, and relaxation tips). A nurse present during visits to answer questions and encourage use what was in booklet, and support father to use relaxation skills. <u>Control</u> Routine care (brief intro to breast milk and ways of delivering from home, numbers on monitors, visiting policy, and answered questions)	Parental stress: (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU]) Fathering ability (FA:NICU; author developed) Father perceived nursing support (Nurse-Parent Support Tool [NPST])	Intervention fathers had significantly higher fathering ability and perceived nursing support Fathers receiving the intervention program had greater reduction in stress than the comparison group Fathers rated booklet as being helpful	Low No randomization Historical control Only 1 NICU Self-developed tools
Matricardi et. al. [26] 2013 Italy	Setting: NICU, single center academic hospital Sample: Mothers and fathers of preterm infants < 32 weeks	Determine the effects of a parental intervention in reducing parental stress levels during hospitalization	None	RCT 42 mother and father dyads (21 dyads control group; 21 dyads intervention group)	<u>Intervention</u> Each couple met with the unit physical therapist for eight sessions lasting 1 hour each (from 31 to 36 weeks post-menstrual age of infant). Goal of sessions were to increase parental ability to recognize signs of infant stress and well-being, help them to soothe their infant, improve physical contact with appropriate stimulation with infant. - Sessions 1 through 3: parents taught about how to interact with infant	Parental stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])	Mothers (not fathers) reported lower role-stress at time 2 in the intervention group compared to the standard care group	Low Unclear how close the sample represented the population Limited description of what occurred with each session of the intervention Mothers spent more time in

					<p>- Starting in session 4 and continuing through session 8 parents progressed from basic massage of their infant to moderate massage with kinesthetic stimulation</p> <p><u>Control</u> Usual care which included daily information from pediatrician, daily support to assist in care by a nurse, daily kangaroo-care for 1.5 hours, weekly parental meetings with psychologist, weekly interview with PT about developmental care</p>			NICU than fathers in both the intervention and control groups
Melnyk et al. [27] 2006 United States	<p>Setting: NICU, multicenter, two academic hospitals</p> <p>Sample: Mothers and fathers of infants with gestational age of 26 to 34 weeks, a birth weight of less than 2500 grams, and anticipated to survive, had no severe deficits</p>	Evaluate the efficacy of Creating Opportunities for Parent Empowerment [COPE] program (educational-behavioral intervention to enhance parent-infant interactions) and determine effects on parental mental health, parental stress, depression, and anxiety	Self-regulation and control theories	RCT 260 (113 mothers and 73 fathers control group; 147 mothers and 81 fathers intervention group)	<p><u>Intervention</u> COPE: provides information (written and audiotape) to parents in 4 phases from time of admission to after discharge.</p> <p>Phase I content: information provided on infant-behavior and parent-role; parents asked to track milestones</p> <p>Phase II content: - recognizing parent stress cue and readiness for interaction</p> <p>Phase III content(prior to discharge) smoothing transition from hospital to home; recognizing cues and helping stressed infant</p> <p>Phase IV content(1 week post discharge): Information preterm infant development, suggestions for positive parent-</p>	<p>Infant length of stay (LOS)</p> <p>Anxiety (State-Trait Anxiety Inventory [STAI])</p> <p>Depression (Becks Depression Inventory [BDI])</p> <p>Parental Stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])</p> <p>Parent-infant interaction ratings (Index of Parental Behavior in the NICU)</p> <p>Parents' beliefs about their infants and their parental role during hospitalization</p>	<p>Shorter infant LOS in NICU and hospital</p> <p>Mothers in COPE had significantly less parental stress</p> <p>Parents in COPE has more positive parenting interactions with their infant</p> <p>Fathers in COPE more involved in infant care and more sensitive to the babies needs</p> <p>At 2 months, mothers in COPE significantly less anxiety and depressive symptoms No Fathers had no difference between groups for in anxiety and depression at 2 months</p>	<p>High</p> <p>Blinded study</p> <p>Active control group</p> <p>Analysis controlled for infant characteristics</p>

					<p>infant relationships and activities to foster cognitive development</p> <p><u>Control</u> Audiotapes and written information on hospital services, discharge, and immunization provided at same timepoint as COPE phases.</p>	(Parental Belief Scale-NICU)		
<p>Noergaard et al. [33]</p> <p>2018</p> <p>Denmark</p>	<p>Setting: NICU, single center regional hospital</p> <p>Sample: Fathers of infants admitted to NICU</p>	<p>Investigate the impact of a more father-friendly NICU on paternal stress and participation in newborn care</p>	None	<p>Quasi experimental</p> <p>109 (55 control group; 54 intervention group)</p>	<p><u>Intervention</u> 8 activities/ principles implemented to create a father-friendly NICU including:</p> <ul style="list-style-type: none"> • encouragement of fathers' participation (skin-to-skin contact and routine care of newborn) • direct communication with fathers about newborns status and development • counseling from a social worker on paternity leave • provision of support groups for fathers • inclusion of other family members in care of newborn • opportunity for older siblings to stay overnight at the hospital <p><u>Control</u> Usual care</p>	<p>Stress (Parental Stressor Scale NICU)</p> <p>Paternal participation in childcare at the time of discharge for fathers</p>	<p>Higher stress for father's in intervention group in all domains with exception of parental roles subscale</p> <p>Fathers in the intervention group had more skin-to-skin contact compared to controls.</p>	<p>Very low</p> <p>Small sample size</p> <p>Low response rate</p> <p>High rate of surveys missing more than 60% of the items.</p> <p>No data reporting extent to which the intervention was implemented</p> <p>Historical control; non randomized</p>
<p>Van der Pal et al. [28]</p> <p>2007</p> <p>Netherlands</p>	<p>Setting: NICU; multicenter, academic hospitals</p> <p>Sample: Parents of infants born prior to 32 weeks</p>	<p>Two studies reported:</p> <p>#1: Compare the effect of basic developmental care (incubator covers and nests)</p>	Synactive Theory of Infant Development	<p>RCT (Two studies)</p> <p>RCT #1: 192 infant/parent dyads (94 control; 98 intervention)</p>	<p><u>RCT#1 Intervention</u> Basic developmental care which included reduction of light and sound using incubator covers and nests to support motor development</p> <p><u>RCT #1 Control</u></p>	<p>Confidence (Two Scales from the Mothers and Baby Scale): (1) Confidence in Caregiving (CC) (2) Global Confidence Scale (GCS)</p>	<p>No difference confidence, perceived nurse support or parental stress between groups in either RCT</p>	<p>Moderate</p> <p>No blinding of intervention</p> <p>No report of intervention fidelity</p>

		to usual care #2: Compare the effect of basic developmental care to Newborn Individualized Developmental Care and Assessment Program (NIDCAP)		RCT#2: 168 infant/parent dyads (84 control; 84 intervention)	Usual care <u>RCT#2 Intervention</u> Newborn Individualized Developmental Care and Assessment Program (NIDCAP): observations of the infant before, during and after caregiving every 7 to 10 days by NIDCAP trained developmental specialist First observation within 48 hours of birth. Only nurses trained in NIDCAP cared for infants <u>RCT #2 Control</u> Basic developmental care (nests and incubator covers)	Parental perception of nurse support (Nurse Parent Support Tool (NPST)) Parental Stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])		
Welch et al. [29] 2016 United States	Setting: NICU, single academic center Sample: Mothers who had delivered a singleton or set of twins between 26 to 34 weeks gestational age	Evaluate the effects of the Family Nurture Intervention (FNI) on mothers and infants	Calming Cycle	RCT 115 (56 control group; 59 intervention group)	<u>Intervention</u> Family Nurture Intervention incorporating calming activities facilitated by a “nurture” specialist. Calming sessions engage the mother and infant in reciprocal physical, sensory and emotional experiences. Sessions were encouraged 4 times per week and included multiple calming activities (e.g. scent of mother and infant on cloth exchanged, calming touch, holding) Mother also encouraged to participate in care of infant <u>Control</u> Standard care: which allows mothers to engage in nurture activities of their choosing such as skin-to-skin and non-skin-to-skin holding	Depression (Center for Epidemiologic Studies Depression Scale [CES-D]) Anxiety (State-Trait Anxiety Inventory [STAI]) Maternal Motivation (Behavioral Inhibition/Behavioral Activation Scales [BISBAS])	No differences in FNI and standard care (SC) groups at baseline or near term age for depression and anxiety At four months for FNI mothers versus SC: <ul style="list-style-type: none"> • Lower depression and anxiety scores • Higher percentage of mothers breastfeeding • More frequent and longer skin to skin sessions for FNI mothers versus mothers receiving standard care. 	Moderate No blinding Not able to discern if the effect is FNI or additional support/attention for mothers

<p>Sarin et al. [38] 2019 India</p>	<p>Setting: NICU, single academic center Sample: Family of neonates and NICU staff</p>	<p>Understand the acceptability of Family Centered Care (FCC) from providers' and parents' perspectives Explore the integration of providers' and clients' activities in NICU Examine the continuing care competencies of parents after discharge</p>	<p>Philosophy of Family Centered Care</p>	<p>Qualitative 12 family members (5 mothers, 5 fathers, 2 grandparents)6 healthcare providers(3 pediatric residents;3 nurses)</p>	<p><u>Intervention</u> At admission, family members received an introduction to FCC in a face to face session with doctor or nurse. Session included information on the training process required to become a parent-attendant and the parental role in care provision Four education sessions were offered. Session 1 and 2 topics included: infection prevention, breastfeeding, breast milk expression, assisted feeding Session 3 for parents of low weight newborns- addressed kangaroo care. Session 4 focused on preparation for discharge and care of newborn at home. <u>Control</u> None</p>	<p>Acceptability and perceived benefits and challenges of the FCC intervention</p>	<p>Family members reported FCC increased knowledge, promoted adaption to NICU, increased access to their infant and increased infant well-being parents/caregivers reported greater capability and more empowerment to care for newborn Healthcare providers had a favorable perception of FCC due to benefit of parental presence for well-being of the newborn</p>	<p>Unable to grade (qualitative data only) Bias: did not include inter-rater coding and interpretation: data were coded and analyzed by the lead researcher only. Site: hospital had FCC in place prior the study and therefore may have had additional support available in other hospital settings. One group design</p>
PICU								
<p>Kuntaros et al. [36] 2007 Thailand</p>	<p>Setting: PICU, single center Sample: Mothers of children admitted to PICU in the last 24 hours</p>	<p>Compare maternal self-efficacy in participatory involvement in child care and satisfaction with nursing care between control group and experimental group that</p>	<p>Effective Helpgiving Practices (1) technical quality (2) helpgiver traits/attribution (3) help receiver participatory involvement</p>	<p>Quasi-experimental 32 (16 control 16 intervention) Mothers in both control and experimental groups were matched with their</p>	<p><u>Intervention</u> Mothers allowed to visit at any time and were more involved in care than control group mothers. Over 4 days, the investigator accompanied mom and family to bedside visit and provided information about unit, assessed perceptions of the child's illness and expectations for nursing</p>	<p>Self-efficacy in participatory involvement in child care (researcher developed) Satisfaction with nursing care (researcher developed)</p>	<p>Higher self-efficacy and satisfaction in intervention group. Higher scores on satisfaction survey also</p>	<p>Very low It is not clear how mothers were placed into groups. Intervention not well described Small sample size; only one site</p>

		received family-centered care approach		years of education.	services, clarified/corrected misperceptions, gave updates about child's condition, encouraged mental and emotional support and sharing of concerns, needs, and ideas, provided a chance for joint decision-making, and allowed them to provide care to the child by themselves. <u>Control</u> Usual care			Investigator developed instruments; not previously tested Because many patients were under sedation some activities in the experimental intervention could not be performed.
ADULT ICU								
Black et al. [34] 2011 Northern Ireland	Setting: adult ICU; single center Sample: Patient/family dyads	Examine the effects of nurse-facilitated family participation in psychological care (operationalized as emotional support and presence) on the extent of patient delirium and psychological recovery following critical illness	Neuman's Systems Model	Time Series (pre/post) 170 (83 control group; 87 intervention group)	<u>Intervention</u> Information booklet provided to family focused on how to provide psychological support through communication with patient; included suggestions on how to interact and topics/type of information to share with patient Nurse facilitation of family interaction with patient included maximizing family time with patient, chairs at the bedside, verbal encouragement of interaction with patient once per visit <u>Control</u> Usual care	Length of Stay Physiologic (labs; vitals) Medications (sedatives, analgesics, muscle relaxants) Delirium (Intensive Care Delirium Screening Checklist) Impact of illness (Sickness Impact Profile [SIP])	Lower impact of illness (SIP scores) with lower total physical and psychosocial subscale scores for all time points Relationship of impact of illness and intervention remained when controlling for severity of illness, length of ICU stay, and delirium No significant difference delirium or length of stay between groups	Moderate Pre/post design; unclear if groups equivalent at baseline Single setting (7 Bed ICU in one hospital) No intervention fidelity monitoring Number of patients completing post ICU measures not reported
Davidson et al. [39] 2010 United	Setting: adult ICU; single center Sample: Family members or significant support	Evaluate the feasibility of implementing interventions from the Facilitated Sensemaking	Facilitated Sensemaking	Pilot/feasibility 30 family members or significant support person	<u>Intervention</u> Two main components: personalized instruction and provision of family visiting kits (1) Personalized instruction: introduction and	Feasibility and family evaluation of the program Family report of needs (importance and if met)	All items offered within the intervention were found useful to some family members. All proposed family	Unable to grade Small sample size No comparison group

States	person of adult mechanically ventilated ICU patients	Theory into the ICU			<p>explanation of the project, decoding of the environment at the bedside (done by the nurse), instructions on helpful visiting activities, coaching on how to ask questions of the doctor and identify unmet needs, review of available hospital services, and debriefing at the end of encounters</p> <p>(2) Family visiting kits: family workbook with introduction, non-denominational prayer, activities that could be performed at bedside, list of family needs obtained from family survey, instructions on how to perform cognitive recovery activities, cognitive recovery tools (word searches, cards, paper, dominoes), personal care items (nail file, hand lotion, lip balm), and information on medical websites/library resources</p> <p><u>Control</u> None</p>		<p>interventions (e.g. bedside and cognitive recovery activities) were used and found helpful.</p> <p>The journal was least useful and personal care supplies were most useful.</p> <p>Observation of families: most engagement when receiving information on how to participate at bedside and how to decode/interpret the environment</p> <p>Staff time spent with intervention was reasonable for inclusion in the practice of the patient's nurse</p>	<p>Several family members chose not to complete the survey</p> <p>Evaluation of program by families only; no outcome data</p> <p>Intervention instituted by investigator not ICU staff</p>
Marshall et al. [40] 2016 Australia	<p>Setting: Adult ICU, multicenter, academic hospitals</p> <p>Sample: Patients on mechanical ventilation for 48 hours and their families.; healthcare</p>	Evaluate the feasibility and acceptability of an intervention that aimed to educate families about the importance of nutrition for recovery from critical illness	Family-Centered Theory	<p>Pilot/feasibility</p> <p>126 (49 patients, 51 family members, 4 physicians, 20 nurses, 2 dietitians)</p> <p>30 family</p>	<p><u>Intervention (2 groups)</u></p> <p>(1) Low intensity: patient nutritional history acquired from family shared with healthcare team; short education session supplemented with a printed resource emphasizing importance of nutrition and explaining</p>	<p>Feasibility and acceptability</p> <p>Recruitment and retention rates</p>	<p>Recruitment/ consent rate of 26% Retention rate of 67%</p> <p>Families found both the low and moderate intensity interventions acceptable</p> <p>The intervention</p>	<p>Unable to grade</p> <p>Small sample</p> <p>Only 2 ICUs</p> <p>No control group</p> <p>Only qualitative data obtained</p>

	professionals			<p>members received low intensity intervention</p> <p>19 family members received moderate intensity intervention</p>	<p>therapies during and after critical illness. Guided prompts given to families to promote discussion with healthcare team</p> <p>(2) Moderate intensity: low intensity components plus a daily nutritional diary that was completed by the family during the two-week period following extubation of the patient. Diary used to promote conversation between the family and the patient about nutrition and to encourage discussion with healthcare team</p> <p><u>Control</u> None</p>		<p>prompted conversations with family, friends, and healthcare professionals, and supported planning nutrition support post ICU</p> <p>Some limitations with food diary, participants unclear about how it should be used</p> <p>This intervention also prompted families to ask questions related to other aspects of care</p>	
<p>Mitchell et al. [35] 2009 Australia</p>	<p>Setting: Medical/Surgical Adult ICU, multicenter two academic hospitals Sample: Families of patients predicted to be in the ICU more than 2 days</p>	<p>Determine the effect of a family-centered nursing intervention on family members perceptions of family-centered care</p>	<p>Family-centered care philosophy/model</p>	<p>Pragmatic clinical trial-nonequivalent control group, pretest-posttest design</p> <p>174 (75 control group; 99 intervention group)</p>	<p><u>Intervention</u> Families participated in fundamental care activities at the discretion of the nurse including: hair combing, hand massage and bathing</p> <p><u>Control</u> Usual care</p>	<p>Family member perception of collaboration, respect, and support from ICU staff (Family Centered Care Survey)</p>	<p>Those in the intervention were more likely to perceive higher FCC (respect, collaboration and support) than those in the control group.</p>	<p>Very low</p> <p>No control for unit culture and other variables in analysis</p> <p>Adapted outcome measure was not validated</p>

^a Holditch-Davis et al. 2013 and 2014 report results from the same study

^b Publication does not report satisfaction for control group, satisfaction only reported for intervention groups

Systematic Review of Family Engagement Interventions in Neonatal, Pediatric, and Adult ICUs

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