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Systematic Review of Family Engagement Interventions in Neonatal, Paediatric, 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, paediatric, and neonatal intensive care unit (ICU) settings.

Background

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, paediatric, 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 6210 abstracts were screened and 19 studies were included. Most studies were of low to moderate quality and were 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-centred care, confidence, anxiety, and depression. Most studies found improvements in one or more outcomes.

Conclusions

There is a paucity of literature about active family engagement interventions, especially in adult and paediatric populations. The optimal dosage and frequency of family engagement interventions remains unknown. Our systematic review found that data are 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.

What is known about this topic

- Family engagement is universally advocated across ICU populations and practice settings; however, appraisal of the active family engagement intervention literature remains limited

What this paper adds

- There is a paucity of literature about active family engagement interventions, especially in adult and paediatric populations.
- The optimal dosage and frequency of family engagement interventions remains unknown.
- Our systematic review found that data are limited on the relationship between family engagement and patient outcomes and provides a timely appraisal to guide future research.

1 INTRODUCTION

Family engagement is an *active* partnership among health professionals, patients, and their families that can improve individual health and well-being and health care quality and safety.¹⁻³ Current family-centred care (FCC) guidelines⁴ 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, paediatric, and adult ICUs.

2 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 (eg, physical presence at the bedside and receiving and having needs met) to more active activities (eg, 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 FCC,¹ and relevant to health care delivery across the lifespan.⁴ Although paediatrics has embraced an FCC philosophy longer than adults specialties, universal barriers to FCC in neonatal, paediatric, 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 paediatric 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, paediatric, and adult ICUs.

3 METHODS

3.1 Design

A systematic review following the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines¹⁷ was conducted. The review was registered in the International Prospective Register of Systematic Reviews (National Institute for Health Research)—(CRD42018109259).

3.2 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.

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 RELATIO S/ or family.mp.
7. family caregiver.mp. or exp Caregivers/
8. partner*.mn,
9. significant other.mp.
10. relative*.um,
11. exp Parents/ or exp PARENT-CHILD RELATIO S/ or parent*.um,
12. family member*.um,
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. Participant*.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 1 Ovid Medline search strategy

3.3 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, paediatric, 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.

3.4 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.

3.5 Data extraction

A comprehensive data extraction form was developed based on the Cochrane data collection for intervention reviews¹⁹ 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.

4 RESULTS/FINDINGS

A total of 6210 records were identified. With automated duplicate finding, 663 duplicates were removed for a total of 5547 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.⁴⁰ Intervention descriptions are grouped by patient population (neonates, children, or adults).

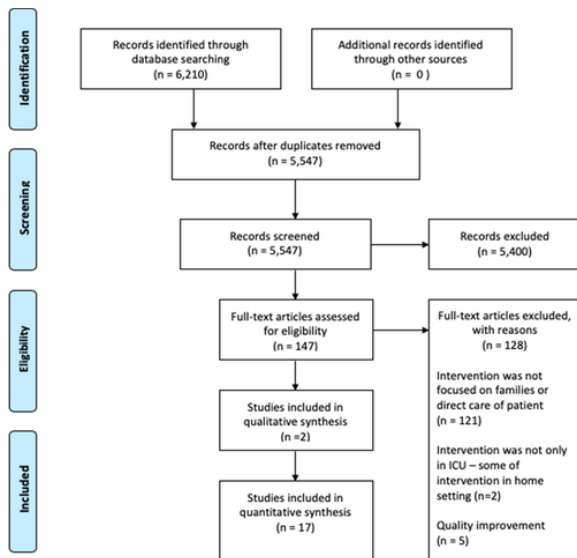


FIGURE 2 Preferred reporting items for systematic reviews and meta-analyses (PRISMA) diagram

TABLE 1. Summative table of interventions and study characteristics

Author Year Location	Setting and sample	Aims/research questions	Theoretical model	Design/sample size	Study conditions	Outcome measures	Results	Quality appraisal
<i>NICU studies</i>								
Byers et al ²¹ 2006 United States	Setting: neonatal ICU; single centre 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- centred 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 centred care, ethics, communication , neonatal developmental NICU experiences; also newborn	Physiologic (vitals) Medical and development progress (feeding, growth, behavioural stress cues) Return to sleep Length of stay Complication rates (ventilation days, days to open crib) Parent satisfaction and perceptions Resource utilization	Lower behavioural 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	<i>Moderate</i> 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 enrolment

					assessment training (Brazelton, oral/motor; NIDCAP). Full NIDCAP completed within first 7 days of admission.			
					<u>Control</u> Usual care with restricted visitation			
Cooper et al ²² 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 centred practices	None	Quasi experimental Three groups NICU with full (four NICUs),, partial (three NICUs), and no implementation of program (one NICU) Total Sample includes: 11 NICU administrators, 502 NICU staff members, 216 NICU families	<u>Intervention</u> March of Dimes Family Support Program (NFS): national program designed to promote family-centred care in NICUs. Includes: <ul style="list-style-type: none"> • Family support specialist • Baby photos and scrapbooking • Parent to parent support • Education for parent and siblings • Staff education <u>Control</u> Usual care	Presence of intervention components (yes/no) Parental knowledge, comfort, confidence, connectedness Parental behaviours (asking questions of HCPs, ability to describe infant condition, level of involvement in care) Parent self-efficacy Parent report of programs and policies that endorsed	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 increase confidence for parents 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 Parents partially and fully implemented sites felt their	<i>Low</i> Measures post implementation only No data given on comparison sites to determine equivalence No statistical control for unit factors Data self-report from surveys and interviews No intervention fidelity monitoring/reporting

						<p>intervention components</p> <p>Staff perception of family-centred principles (one time measure of perceived importance of items post intervention)</p>	<p>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 • development of policies/programs to support parent skills and involvement 	
De Bernardo et al ²³	Setting: NICU, single centre	Compare satisfaction and stress between	Synactive Theory of Development	Non-randomized,	<u>Intervention</u>	Infant weight Parent satisfaction (receipt of	Higher infant weight at day 60 day intervention group	<i>Low</i> Small sample size

<p>2017 Italy</p>	<p>Sample: Parents of NICU infants at least 30 days post single surgery</p>	<p>parents in a family centred care group vs non-family centred care</p>		<p>prospective cohort pilot 144 96 Parents (48 control; 48 intervention) 48 newborns (24 control; 24 intervention)</p>	<p>Implementation of the Family Centred Care (FCC) Model</p> <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 am to 6:00 pm • Parent participation in care (eg, bathing, diapering, breast feeding, holding during procedures) • Parent observation of rounds • Parent meeting with physicians offered daily 	<p>information, health care team communication and collaboration; privacy) Parent stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])</p>	<p>Parent increased satisfaction with communication/collaboration; information received; privacy) Lower stress for parental roles, baby appearance/treatment; and NICU environment</p>	<p>One unit; pre/post intervention (different groups control/intervention) No intervention fidelity monitoring No control variables when evaluating parental stress (eg, socio-economic status, lack of sleep, etc.)</p>
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					<u>Control</u> Usual care: parents only able to visit infant 1 hour per day			
Franck et al ²⁴ 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 to 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 • Specific instructions on how to comfort infants • Advice on how parents can work in partnership with NICU staff. 	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-Efficacy In Infant Care Scale [SICS]) Parental perceptions of role attainment (What Being a Parent of a New Baby is Like [WBPBL-R])	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 pain care or confidence in ability of staff to manage infant pain and support parents	<i>Low</i> Randomization by NICU not individual Differences intervention and control group at baseline High attrition Outcomes were self-report

					<p>Parents also received two visits (~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 two visits from nurse</p>			
<p>Hoffenkamp et al²⁵ 2015 Netherlands</p>	<p>Setting: NICU (2) and maternity ward (7); 7 hospitals 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 multicentre clinical trial with two parallel arms</p>	<p>Two core concepts framed VIG:</p> <ol style="list-style-type: none"> 1. intersubjectivity 2. mediated learning 	<p>RCT 150 (75 control; 75 intervention)</p>	<p><u>Intervention</u> Three sessions. Parents videotaped at first, third, and sixth day postpartum. Videos are made during daily moments of caregiving (eg, 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</p>	<p>Parental interactive behaviour (videos) Parental bonding (Postpartum Bonding Questionnaire [PBQ]) Parent-infant relationship [Worry, Enjoyment, responsiveness, separation anxiety] (My Baby and I Questionnaire) Parental bonding and distress (Yale Inventory of Parental Thoughts and Actions) Parental Stress (Parent Stress Scale:</p>	<p>VIG was effective in enhancing behaviour and diminishing withdrawn behaviour in mothers and fathers. Positive effects of VIG very strong in those mothers who had traumatic birth experience Intervention did not change intrusive behaviour Positive effects on parental bonding, especially for fathers but no sig effects on stress and well-being</p>	<p><i>Moderate</i> Interrater agreement for observational coding has some limitations Not clear which part of the intervention actually accounted for the effects No direct comparison between outcomes of mothers and fathers Relatively small sample size of moms who met traumatic childbirth criteria No clear definition of traumatic childbirth</p>

					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. <u>Control</u> Usual care	Neonatal Intensive Care [PSS:NICU]) Depression (Edinburgh Postnatal Depression Scale) Psychologic Trauma (Traumatic Event Scale)		
Holditch-Davis et al ²⁶ 2013 United States	Setting: 4 NICUs: 2 academic medical centres. 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	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.	<i>Moderate</i> Same nurse performed all interventions Investigator-developed instrument

					<p>2 months corrected age. Were able to provide whichever care they wanted to their infants</p> <p><u>Control^b</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>Holditch-Davis et al^a ²⁷ 2014 United States</p>	<p>Setting: Four NICUs: two academic medical centres; two community hospitals Sample: Mothers of preterm infants</p>	<p>Examine the effects of auditory-tactile-visual-vestibular (ATVV) intervention and kangaroo care (KC)</p>	<p>None</p>	<p>RCT—3-group longitudinal study 240 (81 in control, 78 ATVV, and 81 KC)</p>	<p><u>Intervention (two groups)</u></p> <ol style="list-style-type: none"> 1. Auditory-tactile-visual-vestibular intervention (ATVV):: stimulation in a gradual progression over 15 minutes beginning with voice only then 	<p><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, and quiet sleep) was recorded</p>	<p>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 symptoms, or Posttraumatic stress symptoms, or parenting stress. KC mothers more rapid decline in worry than the other groups.</p>	<p><i>Moderate</i> Limited sample size Crossover between groups (20%-30% of KC and ATVV moms and 58% of control moms engaged in a non-assigned intervention) High attrition rate (21%)</p>

					<p>auditory and tactile, with visual stimulation as infant becomes alert. Horizontal rocking added and tactile 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</p>	<p>once a minute following ATVV and beginning following the start of KC.</p> <p><u>Maternal Psychological Distress</u> Depressive symptoms (Centre for Epidemiologic Studies Depression Scale [CES-D]) Anxiety (State-Trait Anxiety Inventory [STAI]) Posttraumatic stress (Perinatal PTSD Questionnaire) Parenting stress (Parental Stress Scale: Prematurely Born Child) Degree of maternal worry about infant (The Worry Index) Mothers' perceptions of child vulnerability (Vulnerable Child Scale) Infant responsiveness to stimulation at discharge (Neonatal</p>	<p>Maternal positive involvement, developmental stimulation, and HOME total score did not differ. Parenting stress lower for mothers who did some type of intervention when compared with those that did none. HOME scores higher for mothers who performed massage alone or along with KC than those who did not</p>	
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					supplements, formula, and toys.	Behavioral Assessment Scale) Maternal Involvement and Social-emotional and stimulation characteristics of the home environment (HOME Inventory)		
Lee et al ²⁸ 2013 Taiwan	Setting: NICU, single centre 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 <ol style="list-style-type: none"> 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 behaviour, 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	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	<i>Low</i> No randomization Historical control Only one NICU Self-developed tools

					monitors, visiting policy, and answered questions)			
Matricardi et al ²⁹ 2013 Italy	Setting: NICU, single centre 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. <ul style="list-style-type: none"> Sessions 1 through 3: parents taught about how to interact with infant Starting in session 4 and continuing through session 8 parents progressed 	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 with the standard care group	<i>Low</i> Unclear how close the sample represented the population Limited description of what occurred with each session of the intervention Mothers spent more time in NICU than fathers in both the intervention and control groups

					<p>from basic massage of their infant to moderate massage with kinesthetic stimulation</p> <p><u>Control</u> Usual care which included daily information from paediatrician, 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>			
<p>Melnyk et al³⁰ 2006 United States</p>	<p>Setting: NICU, multicentre, two academic hospitals Sample: Mothers and fathers of infants with gestational age of 26 to 34 weeks, a birth weight of less than 2500 g, and</p>	<p>Evaluate the efficacy of Creating Opportunities for Parent Empowerment [COPE] program (educational-behavioural intervention to enhance parent-infant interactions)</p>	<p>Self-regulation and control theories</p>	<p>RCT 260 (113 mothers and 73 fathers control group; 147 mothers and 81 fathers intervention group)</p>	<p><u>Intervention</u> COPE: provides information (written and audiotape) to parents in four phases from time of admission to after discharge. Phase I content: information provided on infant-behaviour and parent-role; parents asked to track milestones</p>	<p>Infant length of stay (LOS) Anxiety (State-Trait Anxiety Inventory [STAI]) Depression (Becks Depression Inventory [BDI]) Parental Stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU]) Parent-infant interaction ratings</p>	<p>Shorter infant LOS in NICU and hospital Mothers in COPE had significantly less parental stress Parents in COPE has more positive parenting interactions with their infant Fathers in COPE more involved in infant care and more sensitive to the babies needs At 2 months, mothers in COPE significantly less</p>	<p><i>High</i> Blinded study Active control group Analysis controlled for infant characteristics</p>

	anticipated to survive, had no severe deficits	and determine effects on parental mental health, parental stress, depression, and anxiety			Phase II content:— recognizing stress cue and readiness for interaction Phase III content(prior to discharge) smoothing transition from hospital to home; recognizing cues and helping stressed infant Phase IV content (1 week post discharge): Information preterm infant development, suggestions for positive parent-infant relationships and activities to foster cognitive development <u>Control</u> Audiotapes and written information on hospital services, discharge, and immunization provided at same timepoint as COPE phases.	(Index of Parental Behavior in the NICU) Parents' beliefs about their infants and their parental role during hospitalization (Parental Belief Scale- NICU)	anxiety and depressive symptoms No Fathers had no difference between groups for in anxiety and depression at 2 months	
Noergaard et al ³¹ 2018 Denmark	Setting: NICU, single centre regional hospital Sample: Fathers of infants	Investigate the impact of a more father-friendly NICU on paternal stress and	None	Quasi experimental 109 (55 control group; 54 intervention group)	<u>Intervention</u> Eight activities/principles implemented to create a father-friendly NICU including:	Stress (Parental Stressor Scale NICU) Paternal participation in childcare at the time of discharge for fathers	Higher stress for father's in intervention group in all domains with exception of parental roles subscale Fathers in the intervention group had more skin-to-skin	<i>Very low</i> Small sample size Low response rate High rate of surveys missing more than 60% of the items.

	admitted to NICU	participation in newborn care			<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 • counselling 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 		contact compared with controls.	No data reporting extent to which the intervention was implemented Historical control; non-randomized
Van der Pal et al ³²	Setting: NICU; multicentre,	Two studies reported:	Synactive Theory of Infant Development	RCT (Two studies)	<u>RCT #1 Intervention</u> <u>Control</u> Usual care	1. Confidence (Two Scales)	No difference confidence, perceived nurse support or	<i>Moderate</i>

2007 Netherlands	academic hospitals Sample: Parents of infants born prior to 32 weeks	#1: Compare the effect of basic developmental care (incubator covers and nests) to usual care #2: Compare the effect of basic developmental care to Newborn Individualized Developmental Care and Assessment Program (NIDCAP)		RCT #1: 192 infant/parent dyads (94 control; 98 intervention) RCT#2: 168 infant/parent dyads (84 control; 84 intervention)	Basic developmental care which included reduction of light and sound using incubator covers and nests to support motor development <u>RCT #1 Control</u> 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)	from the Mothers and Baby Scale): (1) Confidence in Caregiving (CC) (2) Global Confidence Scale (GCS) Parental perception of nurse support (Nurse Parent Support Tool (NPST)) Parental Stress (Parent Stress Scale: Neonatal Intensive Care [PSS:NICU])	parental stress between groups in either RCT	No blinding of intervention No report of intervention fidelity
Welch et al ³³ 2016	Setting: NICU, single academic centre	Evaluate the effects of the Family Nurture Intervention	Calming cycle	RCT 115 (56 control group; 59	<u>Intervention</u> Family Nurture Intervention incorporating calming	Depression (Centre for Epidemiologic Studies Depression Scale [CES-D])	No differences in FNI and standard care (SC) groups at baseline or near term age for depression and anxiety	<i>Moderate</i> No blinding Not able to discern if the effect is FNI or

United States	Sample: Mothers who had delivered a singleton or set of twins between 26 and 34 weeks gestational age	(FNI) on mothers and infants		intervention group)	activities facilitated by a “nurture” specialist. Calming sessions engage the mother and infant in reciprocal physical, sensory and emotional experiences. Sessions were encouraged four times per week and included multiple calming activities (eg, 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	Anxiety (State-Trait Anxiety Inventory [STAI]) Maternal Motivation (Behavioral Inhibition/Behavioral Activation Scales [BISBAS])	At 4 months for FNI mothers vs 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 vs mothers receiving standard care. 	additional support/attention for mothers
Sarin et al ³⁴ 2019 India	Setting: NICU, single academic centre Sample: Family of neonates and NICU staff	Understand the acceptability of Family centred Care (FCC) from providers' and parents' perspectives	Philosophy of Family centred Care	Qualitative 12 family members (5 mothers, 5 fathers, 2 grandparents) ⁶ health care	<u>Intervention</u> At admission, family members received an introduction to FCC in a face to face session with doctor or nurse. Session included	Acceptability and perceived benefits and challenges of the FCC intervention	Family members reported FCC increased knowledge, promoted adaption to NICU, increased access to their infant and increased infant well-being parents/caregivers reported	<i>Unable to grade</i> (qualitative data only) Bias: did not include inter-rater coding and interpretation: data were coded

		Explore the integration of providers' and clients' activities in NICU Examine the continuing care competencies of parents after discharge		providers(3 paediatric residents;3 nurses)	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		greater capability and more empowerment to care for newborn Health care providers had a favourable perception of FCC because of benefit of parental presence for well-being of the newborn	and analysed 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
<i>PICU</i>								
Kuntaros et al ³⁵ 2007 Thailand	Setting: PICU, single centre Sample: Mothers of children admitted to PICU in the last 24 hours	Compare maternal self-efficacy in participatory involvement in child care and satisfaction with nursing care between	Effective Helpgiving Practices 1. technical quality 2. helpgiver traits/attributions 3. help receiver participatory involvement	Quasi-experimental 32 (16 control 16 intervention) Mothers in both control and experimental	<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	Self-efficacy in participatory involvement in child care (researcher developed) Satisfaction with nursing care (researcher developed)	Higher self-efficacy and satisfaction in intervention group. Higher scores on satisfaction survey also	<i>Very low</i> It is not clear how mothers were placed into groups. Intervention not well described Small sample size; only one site

		control group and experimental group that received family-centred care approach		groups were matched with their years of education.	and provided information about unit, assessed perceptions of the child's illness and expectations for nursing 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.
<i>Adult ICU</i>								
Black et al ³⁶ 2011 Northern Ireland	Setting: adult ICU; single centre Sample: Patient/family dyads	Examine the effects of nurse-facilitated family participation in psychological care (operationalized as emotional support and presence) on	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	Length of Stay Physiologic (labs; vitals) Medications (sedatives, analgesics, muscle relaxants) Delirium (Intensive Care Delirium Screening Checklist)	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	<i>Moderate</i> Pre/post design; unclear if groups equivalent at baseline Single setting (Seven Bed ICU in one hospital) No intervention fidelity monitoring Number of patients completing post ICU

		the extent of patient delirium and psychological recovery following critical illness			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	Impact of illness (Sickness Impact Profile [SIP])	No significant difference delirium or length of stay between groups	measures not reported
Davidson et al ³⁷ 2010 United States	Setting: adult ICU; single centre Sample: Family members or significant support person of adult mechanically ventilated ICU patients	Evaluate the feasibility of implementing interventions from the Facilitated Sensemaking Theory into the ICU	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 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	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 interventions (eg, bedside and cognitive recovery activities) were used and found helpful. The journal was least useful and personal care supplies were most useful. Observation of families: most engagement when receiving information on how to participate at bedside and how to decode/interpret the environment Staff time spent with intervention was reasonable for inclusion in the practice of the patient's nurse	<i>Unable to grade</i> Small sample size No comparison group Several family members chose not to complete the survey Evaluation of program by families only; no outcome data Intervention instituted by investigator not ICU staff

					<p>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,</p>			
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					hand lotion, lip balm), and information on medical websites/library resources			
					<u>Control</u> None			
Marshall et al ³⁸ 2016 Australia	Setting: Adult ICU, multicentre, academic hospitals Sample: Patients on mechanical ventilation for 48 hours and their families.; health care professionals	Evaluate the feasibility and acceptability of an intervention that aimed to educate families about the importance of nutrition for recovery from critical illness	Family-centred Theory	Pilot/feasibility 126 (49 patients, 51 family members, 4 physicians, 20 nurses, 2 dieticians) 30 family members received low intensity intervention 19 family members received moderate intensity intervention	<u>Intervention (two groups)</u> 1. Low intensity: patient nutritional history acquired from family shared with health care team; short education session supplemented with a printed resource emphasizing importance of nutrition and explaining therapies during and after critical illness. Guided prompts given to families to promote	Feasibility and acceptability Recruitment and retention rates	Recruitment/ consent rate of 26% Retention rate of 67% Families found both the low and moderate intensity interventions acceptable The intervention prompted conversations with family, friends, and health care professionals, and supported planning nutrition support post ICU Some limitations with food diary, participants unclear about how it should be used This intervention also prompted families to ask questions related to other aspects of care	<i>Unable to grade</i> Small sample Only two ICUs No control group Only qualitative data obtained

					<p>discussion with health care 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 health care team</p> <p><u>Control</u> None</p>			
Mitchell et al ³⁹ 2009 Australia	Setting: Medical/Surgical Adult ICU, multicentre two	Determine the effect of a family-centred nursing	Family-centred care philosophy/model	Pragmatic clinical trial-non-equivalent control group,	<u>Intervention</u> Families participated in fundamental care activities at the	Family member perception of collaboration, respect, and	Those in the intervention were more likely to perceive higher FCC (respect, collaboration and support)	<i>Very low</i> No control for unit culture and other variables in analysis

	academic hospitals Sample: Families of patients predicted to be in the ICU more than 2 days	intervention on family members perceptions of family-centred care		pretest-posttest design 174 (75 control group; 99 intervention group)	discretion of the nurse including: hair combing, hand massage and bathing <u>Control</u> Usual care	support from ICU staff (Family centred Care Survey)	than those in the control group.	Adapted outcome measure was not validated
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^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.

4.1 Study characteristics

4.1.1 Design

There were eight reports of randomized controlled trials (RCT),^{24-27, 29, 30, 32, 33} and seven quasi-experimental studies.^{21, 22, 28, 31, 35, 36, 39} Four studies were pilots and/or feasibility/acceptability studies.^{23, 34, 37, 38} All of the RCTs were conducted in the NICU. Two of the RCTs reported on different elements of the same longitudinal study.^{26, 27} A quasi-experimental design was the strongest design used in studies conducted in the PICU or adult ICU.

4.1.2 Study quality

Study quality varied, with only one study rated as high quality.³⁰ Seven studies were of moderate quality,^{21, 25-27, 32, 33, 36} four were low quality,^{22, 24, 28, 29} three were very low quality,^{31, 35, 39} and four studies could not be assigned a quality grade because of design (pilot/feasibility/acceptability).^{23, 34, 37, 38} Only one study included any element of blinding³⁰; however, given the types of multifaceted interventions blinding was not feasible in most studies.

4.1.3 Family sample

Sample sizes ranged from 12 (acceptability study)³⁴ to 414 (RCT)³⁰ 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%.^{24, 25, 29, 30, 32, 34, 37-39} Four studies included only mothers,^{26, 27, 33, 35} and two studies included only fathers.^{28, 31} Of the studies reporting race, samples ranged from 2.5% to 84% White,^{24, 26, 27, 30, 32, 33} with the most diverse sample reported as 77% Black and 16% Hispanic.²⁷

4.1.4 Study setting

Seven studies were conducted in the United States,^{21, 22, 26, 27, 30, 33} two in Italy,^{23, 29} two in the Netherlands,^{25, 32} and two in Australia.^{38, 39} Other locations included India,³⁴ Denmark,³¹ China,²⁸ Thailand,³⁵ and Ireland.³⁶ The majority of the studies were conducted in the neonatal ICU (NICU) (n = 14),²¹⁻³⁴ followed by the adult ICU (n = 4).³⁶⁻³⁹ Only one study was conducted in a paediatric ICU.³⁵ More than half were single centre studies (n = 11), and many were conducted in large academic medical centres (n = 8). Most NICU settings were designated as Level III care centres (*prompt and readily available access to a full range of paediatric medical subspecialties*), with one Level IV NICU (*highest level of neonatal care for complex and critically ill infants*).³³

4.2 Intervention characteristics

4.2.1 Theoretical framework

Thirteen studies included a theoretical model/framework that guided the intervention.^{21, 23, 25, 28, 30, 32, 33, 35-37, 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 FCC.^{34, 38, 39} The PICU study utilized helping practices.⁴² Adult ICU frameworks included Neuman's System's Model, facilitated sense-making,⁴³ and FCC.^{38, 39}

4.2.2 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 health care professionals) about the NICU environment and behaviours and characteristics commonly exhibited by NICU babies, and structured guidance from health care 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 behaviour-based feedback to parents about how to bond and engage with the infant in a developmentally appropriate way.^{25, 30} Two studies used the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as a component of an intervention or as an intervention.^{21, 32} The Family Nurture Intervention (FNI) used in one study involved calming activities for the mother to perform with the infant³³ 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.³⁵ These paediatric-based interventions used behaviour change strategies such as modelling, feedback, and increasing parent self-efficacy through mastery of skills.^{23-25, 28-31, 33-35} Standard care was most commonly used in the control groups with the exception of one study that used an attention control.³⁰

Similar to NICU interventions, adult ICU interventions often included a mix of education, information packets, and nurse facilitation of family involvement in care.³⁶⁻³⁹ Specific strategies included nurse-facilitated family communication and interaction with the patient,³⁶ personalized nurse instruction and family visitation kits,³⁷ family involvement in basic patient care,³⁹ and family involvement in the assessment and management of the critically ill patient's nutritional status.³⁸ These interventions included educational components (providing information via written material or with a health care professional on the ICU environment and how to deliver patient care activities), as well as behavioural change strategies such as feedback, modelling, 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.³⁶

4.2.3 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^{24-27, 29} and occurred from three to four times per week^{26, 27, 33} to as frequently as daily.²³ In other NICU studies there was a specified number of sessions ranging from two to eight total sessions.^{24, 29, 30, 34} There was an adult ICU study that included both a low and a moderate intensity intervention.³⁸ In the paediatric and adult ICU studies dosage was difficult to discern.

4.3 Effects of interventions

4.3.1 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.²¹ Pain levels were actually perceived to be higher by parents in the intervention group²⁴ than parents in a control group. Infant weights were significantly higher,²³ length

of stay in the NICU and hospital were shorter³⁰ and infants had more alert periods and total waking time in the intervention groups compared with the control groups.²⁷ Infants whose parents were instructed on developmentally supportive care demonstrated lower behavioural stress cues and lower respiratory rates during activity than infants in the control group who received usual care with restricted visitation.²¹

4.3.2 Adult patient outcomes

There were lower physical and psychosocial impact of illness scores for patients in the intervention vs the control; however, there were no differences in delirium or length of stay.³⁶

4.3.3 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,^{22, 23, 27-30} three studies showed no significant relationship between parental stress level and participation in an engagement intervention.^{24, 25, 32} Two studies were conducted with just the fathers of infants hospitalized in a NICU,^{28, 31} with conflicting outcome results for stress levels. In one study there was reduction in stress in the intervention group vs the control²⁸; in the other study the intervention group experienced more stress than the control.³¹

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.^{29, 30} While both parents demonstrated more sensitive interactions with infants (increase in sensitivity and positive regard) and fewer withdrawn behaviours (detachment and flat affect) following video-interactive guidance, fathers demonstrated greater increases in parental bonding.²⁵

Two studies examined more distal parental psychological outcomes. Melnyk et al³⁰ 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 al³³ demonstrated a decrease in depressive and anxiety symptoms in mothers following participation in the FNI.

4.3.4 Parental satisfaction, knowledge and adaptation

In studies with parental satisfaction measures, parent satisfaction with the interventions were generally favourable.^{23, 26, 34} Outcomes included improved communication, collaboration, information,²³ helpfulness of the nursing staff,²⁶ knowledge acquisition,²² adaption to the NICU environment, and increased closeness to the infant.³⁴ 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.³⁵ 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.²⁴ Two studies demonstrated no differences in: parental perceptions of care delivered,²¹ confidence levels for caring for their infant, or perceived nursing staff support.³²

4.3.5 NICU staff perspectives

Nurses, physicians, and other interprofessional team members had positive perceptions of the engagement interventions.^{22, 34} They reported more informed parents, increased bonding, open and

honest communication, more involvement in decision-making,²² and increased parental presence that enhances the well-being of the newborn.³⁴

4.3.6 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.³⁹ Educating families on how to use nutrition diaries prompted them to ask other relevant questions about the care and health of their loved ones.³⁸ 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.³⁷ 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).³⁷ Family maintained journals summarizing patient progress and daily activities were not as helpful as verbal instructions from nurses during interactive care activities.³⁷

5 DISCUSSION

All except one study³² 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.^{23, 30} Adult patients had a lower impact of illness in one study.³⁶ 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^{31, 35, 39} and three could not be graded because of design.^{34, 37, 38} 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. In addition, the majority of the studies were conducted in Western countries, an important consideration, as health care 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.^{21, 24, 30, 36} 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.^{27, 30} 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.^{25, 29, 30} Fathers may experience greater stress because of demands outside of the NICU environment such as employment, juggling home demands, and caring for other children.^{31, 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 model⁵⁰ 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.

6 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 a 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.

7 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.

8 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.

9 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 paediatric 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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