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Engagement of Families in the Care of Hospitalized Pediatric Patients: A Scoping Review

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Abstract

This scoping review was conducted to examine the range, nature, and extent of the published family engagement literature specific to the pediatric acute care setting to highlight future research and practice development opportunities. Included studies ($N = 247$) revealed global relevance. Engagement strategies ranged from more passive such as allowing/encouraging families to be present at the bedside to more active strategies aimed at promoting mutual and reciprocal nurse–patient interactions. Family engagement is distinguished by a mutually beneficial partnership of families with health care team members and care organizations. Future research in the area of family engagement in pediatric nursing should focus on determining the core engaging health professional behaviors and engaged parent outcomes; extending the knowledge base related to mutually beneficial partnerships between families and health care teams; developing effectiveness studies to determine the optimal engaging actions by teams to achieve parent engagement; and measuring the influence of engagement on parent and infant/child outcomes.

Keywords

family, inpatients, nurses, patient participation, pediatric, scoping review

Globally, patient and family engagement has emerged as an important strategy to improve the experience of care and health outcomes; decrease health care cost (Higgins et al., 2017); and enhance the quality and safety of care (Agency for Healthcare Research and Quality, 2017). The term “engagement” is often used interchangeably with patient-centered care and has become a central focus of patient-centered care delivery models (Pelletier & Stichler, 2013). In pediatric care, the patient and family are inseparable; family-centered care has been a core concept of pediatric health care for more than four decades, beginning in the 1970s (Jolley & Shields, 2009). Family-centered care remains a guiding philosophy of care and a multitude of reviews on family-centeredness in pediatric care have been conducted (Hill et al., 2018; Richards et al., 2017; Segers et al., 2019; Shields et al., 2012; Yu & Zhang, 2019). Although family-centered models of care have been operationalized in pediatric practice in many countries (Coombs et al., 2017; Davidson et al., 2017; Kokorelias et al., 2019; Shields et al., 2012), specific attributes and defining characteristics of family engagement in the pediatric acute care setting have not been reported.

The U.S. Agency for Healthcare Research and Quality has provided a broad conceptualization of family engagement to guide movement toward more inclusive care. In their *Guide to Patient and Family Engagement*, family engagement is described as follows:

A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations. (Maurer et al., 2012, p. 10)

The term “family engagement” has been used in pediatric care settings to describe health care professional practices such as “engaging” families in family-centered rounds or as an outcome associated with improved safety (Rosenberg et al., 2016). Disciplinary differences are evident in the translation of this concept into practice (Kleinpell et al., 2018); medical models for engagement have a greater focus on shared decision-making (Cené et al., 2016), whereas nursing models operationalize family-centered care concepts (Franck & O'Brien, 2019; Richards et al., 2017).

Lack of specificity in a definition or conceptualization of the nature of family engagement within the pediatric setting makes it difficult to determine what constitutes a family engagement intervention, the impact on patient and family outcomes, and evidence-based recommendations for care models and practice improvements to increase pediatric family engagement. Our pediatric nursing research consortium planning team, comprised of nurse scientists from a pediatric medical center and two university schools of nursing in the United States, felt that a crucial first step to conceptualize patient/family engagement was to conduct a scoping review and assess the current state of the literature in acute care settings worldwide.

The purpose of this scoping review was to examine the range, nature, and extent of the published family engagement literature specific to the pediatric acute care setting to highlight future research opportunities.

Method

Design

This review was guided by Arksey and O'Malley's (2005) scoping review framework. Conducting a scoping review allowed us to determine the volume of publications on the topic of family engagement, clarify definitions of family engagement, summarize how family engagement research has been represented in research and practice, and identify research gaps (Arksey & O'Malley, 2005; Munn et al., 2018). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist was used to ensure the quality of reporting for this review (Tricco et al., 2018).

The following steps from Arksey and O'Malley (2005) were followed: (a) identifying the research question, (b) identifying relevant studies, (c) study selection, (d) charting the data, and (e) collating, summarizing, and reporting the results (Arksey & O'Malley, 2005).

Step 1: Identifying the research question

The research questions for this review were derived from a brainstorming session conducted with multiple disciplines and members of the Pediatric Nursing Research Consortium in Milwaukee, a collaboration between Children's Wisconsin and the Colleges of Nursing at Marquette University and the University of Wisconsin–Milwaukee, all in the Midwestern United States. Following the session, research questions were formed for the scoping review:

1. How is family engagement defined in the pediatric acute care literature and how does it differ from family-centered care and family empowerment?
2. What interventions and practices are used by clinicians in pediatric acute care settings to engage families in care?
3. What are the key features of family engagement interventions that have been tested in pediatric acute care settings?
4. What are the outcomes of family engagement in pediatric acute care settings?

Step 2: Identifying the relevant studies

Working with a health sciences librarian, the research team searched the following electronic databases: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and Web of Science. The results were limited to English-language articles in peer-reviewed journals; with a date range of 2009–2019. The search strategies were developed in PubMed, using a combination of database-controlled vocabulary—Medical Subject Terms (MeSH)—and keywords. Once the initial search strategy was determined, it was modified to fit the parameters of the other databases.

The parameters included a focus on family engagement between health care professionals and parents/caregivers within the pediatric population in acute care settings. Terms used synonymously with family engagement (patient and family activation, empowerment, involvement, participation, collaboration, preferences, and family-centered care) were included. The complete search strategy was summarized for each database (Supplemental Figure 1).

The searches had a total yield of 1,244 articles. After removing duplicates, the total number of articles was reduced to 782 for the initial review. The Prisma Flow Diagram can be found in Figure 1.

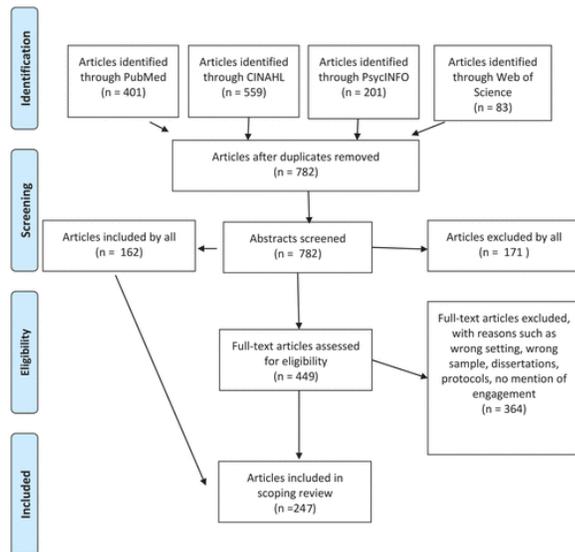


Figure 1. PRISMA flow diagram.

Source. Moher et al. (2009).

Note. For more information, visit www.prisma-statement.org.

Step 3: Study selection

The following inclusion criteria were applied to articles selected in the initial electronic search:

- Right setting: pediatric acute care;
- Right aim: examine family engagement as it relates to family members/caregivers of hospitalized children; can include family-centered care literature if goal is family engagement;
- Right sample: family members/caregivers and/or health care professionals;
- Right article type: research, quality improvement, practice guidelines; and
- English-language.

Abstracts, dissertations, commentaries, editorials, opinions, protocols, and gray literature were excluded.

The abstracts and citations were exported into the Rayyan QCRI systematic review web application ($n = 782$). Six researchers independently screened the abstracts and fully agreed on the inclusion of 162 articles and exclusion of 171, leaving 449 abstracts without full agreement to be reevaluated by the entire study team. After reviewing the full texts, articles were included in the final sample if at least four of six reviewers thought the article should be included in the review and were combined with the initial 162 articles selected for inclusion for a total of 247 articles (Figure 1).

Step 4: Charting the data

Using recommendations from the Joanna Briggs Institute Reviewer's Manual (Peters et al., 2020), the study team developed a structured charting tool in SurveyMonkey™, to guide extraction, narration, and quantification of data from each article. Pilot testing was conducted using the charting tool by having three teams of two researchers independently review and extract data from 10 articles to ensure all relevant results could be extracted using the tool. The entire team subsequently met to discuss discrepancies and interpretation of the charting tool items to ensure transparency of the extraction process. This review process was repeated with an additional five articles to validate the final charting tool and consensus was reached that the tool was ready to implement. Because the reviews by paired researchers were highly consistent and deemed duplicative, article review proceeded with the remaining articles equally assigned to one of the six researchers. The following variables were included in the final tool: (a) author(s); (b) year of publication; (c) country where study was conducted; (d) aims/purpose; (e) sample; (f) setting; (g) design; (h) theoretical framework; (i) definitions of family engagement, empowerment or family-centered care that influenced the design or were stated in findings; (j) family engagement concepts included in purpose, design, or practice descriptions; (k) description of strategies/practices used to engage families; and (l) outcomes of family engagement.

Step 5: Collating, summarizing, and reporting the results

Descriptive data on year of publication, country of sample and setting, and study design were summarized in tables. Thematic analysis (Arksey & O'Malley, 2005) was used to present a narrative account of definitions of family engagement, family-centered care, and empowerment; descriptions of family engagement interventions and practices; and outcomes measured. These data elements were summarized quantitatively with supporting narrative descriptions and exemplars.

Results

Description of Included Studies

The 247 included articles consisted of three syntheses (two meta-syntheses and one meta-analysis), 60 quantitative studies, 78 qualitative studies, 18 mixed-methods studies, 6 instrument development studies, 37 review articles, and 45 quality improvement or practice descriptions (Table 1). The full reference list can be found in the Supplemental Material. The articles presented research and practice descriptions whose participants were either from multiple countries or 34 individual countries. The review team further categorized the samples into regions identified in Table 1; 49.4% of studies were conducted in the North America, followed by 19.8% in Europe. The samples included children of multiple ages ($n = 132$, 53.2%); infants ($n = 106$, 42.7%), children ages 2 to 12 years ($n = 8$, 3.2%), and adolescents ($n = 2$, 0.8%). The care setting reported in the articles (multiple responses permitted) was neonatal intensive care unit (NICU; $n = 111$, 44.8%), general pediatric acute care ($n = 76$, 30.6%), pediatric intensive care unit (PICU; $n = 57$, 23.0%), medical ($n = 15$, 6.0%), surgical ($n = 13$, 5.2%), oncology ($n = 11$, 4.7%), and end of life ($n = 9$, 3.6%).

Table 1. Type of Article by Country/Region of Study Authors.

Type of article	Total	Multicountry	United States	Canada	Mexico	United Kingdom	Europe (other than United Kingdom)	Oceania (Australia & New Zealand)	Asia	Middle East	South America	Africa
	247	15	105	16	1	14	35	18	14	14	8	7
Syntheses												
Meta-synthesis	2	1	0	0	0	1	0	0	0	0	0	0
Meta-analysis	1	0	1	0	0	0	0	0	0	0	0	0
Individual studies												
Quantitative research-intervention RCT study	9	1	2	0	0	0	2	1	2	1	0	0
Quantitative research-quasi-experimental/pretest posttest	12	1	4	1	0	0	1	0	4	1	0	0
Quantitative research	78	3	22	7	1	7	15	7	2	6	5	3
Mixed qualitative quantitative research	18	1	8	1	0	1	2	2	0	0	1	2
Instrument development & testing	6	0	3	0	0	0	1	0	1	1	0	0
Reviews												
Systematic review	4	2	1	0	0	0	0	0	1	0	0	0
Narrative/integrative/scoping review	26	4	11	2	0	2	0	6	0	0	1	0
Concept analysis/conceptual framework	7	1	2	1	0	0	0	0	1	2	0	0
Practice descriptions												
Quality improvement project	16	0	14	1	0	0	0	0	0	0	0	1
Practice innovation/practice description	29	0	21	1	0	2	2	1	1	0	1	0

Note. RTC = randomized controlled trial.

Overall, the articles included in the review represented a range of perspectives related to family engagement. Many reports included results/responses from both families and health care professionals. While the majority of articles presented the parent/family members perspectives ($n = 187, 75.4\%$), there were several that also presented the patient's ($n = 27, 10.9\%$) or siblings' perspective ($n = 1, 0.4\%$). In addition, many of the articles reported the perspectives of the clinical/bedside nurse ($n = 115, 46.4\%$), advanced practice nurse ($n = 7, 2.8\%$), physicians ($n = 56, 22.6\%$), and other health care professionals ($n = 31, 12.5\%$). There were fewer articles reporting program ($n = 15, 6.0\%$) and organizational ($n = 5, 2.0\%$) perspectives.

Definitions of Family Engagement, Family-Centered Care, and Family Empowerment

The actual term “engagement” was found in the aims of only 10 of the articles. Nine definitions of family engagement were abstracted that either guided the study or were derived from the practice descriptions or study results (Table 2). Key concepts within the definitions were highlighted so the definitions could be compared against the three most frequently cited definitions of family-centered care by American Academy of Pediatrics (2012), Institute for Patient and Family-Centered Care (Johnson & Abraham, 2012), and Shields et al. (2006, 2012), and five definitions of family empowerment (Ashcraft et al., 2019; Davies et al., 2017; Franck & O'Brien, 2019; Gibson, 1991; Panicker, 2013). Commonalities of definitions of all three concepts (family engagement, family-centered care, and family empowerment) included a focus on family inclusion, the family as the recipient of care, and the establishment of relationships between the family and health care team. Both family-centered care and family engagement definitions stress the importance of care being driven by families' desires, needs, knowledge, expectations, and values (Agency for Healthcare Research and Quality, 2013; Davidson et al., 2017; Johnson & Abraham, 2012). However, family empowerment and family-centered care appear to be related concepts in the literature. Franck and O'Brien (2019) defined empowerment as a component of family-centered care, whereas Davies et al. (2017) stated that health care professionals empower families through the delivery of family-centered care. Ashcraft et al. (2019) defined empowerment as a vehicle to increase parent engagement and family-centered care as an antecedent to empowerment, conceptualizing family engagement as the end result of family-centered care and empowerment.

Table 2. Family Engagement Definitions.

Family engagement definition	Key concepts within the definition
“Patient engagement is actions individuals must take to obtain the greatest benefit from the health services available to them” (Gruman et al. 2010 . P. 351) Referenced in Jackson et al., 2018.	Actions taken by patients
From health care provider perspective, it is described as a set of behaviors by patients, family members, and health professionals, and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations (Maurer et al., 2012). Referenced in Jackson et al. (2018).	Behaviors of patients, families, and providers Active members of the team work through collaborative partnerships with providers and organizations
From the parent perspective, engagement is active participation in care and decision-making and is driven by parent desires, needs, skills, knowledge, and values (Agency for Healthcare Research and Quality, 2013) Referenced in Samra et al., 2015	Active participation in care and decision-making and driven by desires, needs, skills, knowledge, and values
From the health care professional perspective, authentic engagement is what providers do with parents - building and maintaining trust, focusing on HOW they interacted with parents, empathizing, suspending judgement, adapting own behavior to match what parents needed or wanted, maintaining hope as enabling, motivating, and sustaining for parents, focusing on the positive, showing kindness (Davies et al., 2017)	Health care professional engagement with families - building trust, empathy, suspending judgement, and adapting to parents' needs

Patient engagement can be viewed as an expansion or evolution of patient-centered care (Everhart et al., 2019)	Engagement is an expansion of patient-centered care
Perceptive engagement (pertains to what the nurse does and not the parent): “the nurse perceptively gauges whether a parent is ready and engages him or her in participation of this activity, while teaching the parent. The nurse cautiously guides the parents while still perceptively engaging the parent according to their progress” (Reis et al., 2010, p. 680)	Nurses facilitate family engagement by assessing family readiness and monitoring of progress with skills
“Engagement of patients and families and promotion of self-efficacy in health care are promoted as potential ways to improve safety” (Rosenberg et al., 2016, p. 318)	Engagement as a way to promote self-efficacy and improve safety
“We define engagement as a complex, dynamic, goal-oriented, and guided multifaceted process through which parents participate in the care of their infant to directly influence the outcome within a specific time frame and within a specific context (single encounter, neonatal intensive care unit stay, clinic visit, etc.). As such, engagement is a process aimed at enhancing parent caregiving situational awareness (understanding of health care communication, awareness of cues in the environment, realistic perception of their infant’s condition and cues), ability to problem solve, set goals, make appropriate care decisions, and acquire skills and knowledge to support their infant health needs” (Samra et al., 2015, p. 117).	Engagement is a complex, dynamic, and goal-oriented process - within a specific time frame and context (point-of-care delivery). Engagement is a process of enhancing parent situational awareness, knowledge, problem-solving skills, and decision-making.

Family-centered care was defined as a vision for care delivery through inclusion of core concepts and principles that included dignity and respect, partnerships, listening, and a philosophy that the family is also a recipient of care (Johnson & Abraham, 2012; Shields et al., 2006). Family engagement was distinct from other concepts, as it was defined by actions and behaviors of health care professionals and families. Health care professionals, primarily nurses, engaged families by establishing positive relationships; negotiating roles; collaborating with families; being present with parents to coach and guide them through care; gauging what the family is ready for; enhancing families’ ability to problem-solve, set goals, and make decisions; and preparing families to be situationally aware (Reis et al., 2010). Health care professionals promoted engagement in families through the creation of mutual, authentic partnerships and connecting behaviors (trust, listening, empathizing, suspending judgment; Davies et al., 2017). Family engagement was also defined as an expansion or evolution of family-centered care (Everhart et al., 2019), as engagement is the actionable result of a family-centered care delivery model.

The focus of family engagement can also reach beyond the direct care of the child or collaboration with the health care team. Families may engage at the organizational level through participation in quality improvement initiatives, advisory boards, policy development, or mentorship roles with other parents (Bavare et al., 2018; Bracht et al., 2013; Celenza et al., 2017; Chadwick & Miller, 2019; Maurer et al., 2012; Silver & Traube, 2019).

Practices to Engage Families in Care of Pediatric Patient

Four interdependent themes describing family engaging care practices were identified from the reviewed articles (Figure 2): (a) increasing parental/caregiver involvement in health care and the infant/child’s care (ways to support parent engagement in hospital care); (b) supporting parental decision-making, involvement, and understanding of care through communication (communication-driven engagement); (c) developing a mutual partnership (moving toward equal power in relationships with parents to promote engagement); and (d)

modifying organizational design, infrastructure, and philosophy of care (developing physical and cultural support for engaging families in care). The subthemes are notated in Figure 2 as more passive to active approaches (Olding et al., 2016). More *passive* strategies are unidirectional nurse-to-patient approaches aimed to increase parent/caregiver involvement in care. Examples included allowing the family to be present in the care environment, making families aware of developmentally supportive care, structured communication strategies (providing information to parents), and promoting a family-centered care philosophy. *Active* engagement strategies aimed to promote mutual and reciprocal nurse–patient interactions. Examples included legacy interventions that actively engaged the parent in the infant/child’s death and bereavement process, making parents partners in activation of medical emergency response teams, shared decision-making through use of supportive communication and technology, mutual partnerships that increased parents’ capacity to actively partner as experts in their child’s care, and parent representation on advisory councils and organizational improvement teams. Supplemental Table 1 provides a more detailed description of other practices described in the reviewed literature.



Figure 2. Themes related to family engaging care practices.
Note. Italics denote more active engagement.

Intervention Studies That Aim to Engage Families in the Care of the Pediatric Patient

Twenty-four interventional studies that were reported across 25 articles were examined in detail (Table 3) to explore the state of the science and gaps in research. Of the 24 interventions, 14 (58.3%) were conducted in the NICU. Fifty percent were guided by a specific theory, and of these theoretical-driven interventions, most were developed from family-centered care concepts (75%). The majority of NICU interventions were focused on providing education to families about the NICU and newborn care through pamphlets, videos, or verbally and supporting families to apply the content shared with them by encouraging family presence at the bedside and family participation in newborn care ($n = 9$). The remaining interventions included components of parental presence at rounds ($n = 1$), creating a unit or room environment to encourage parental presence ($n = 2$), using information from the electronic health record to generate personalized progress reports for families ($n = 1$), and workshops with health care professionals to promote neonatal developmental care and family-centered care ($n = 1$). Interventions tested in other pediatric samples and settings focused mainly on improving the communication between families and health care professionals through rounds ($n = 4$), clinical handover between nurses ($n = 1$), family briefings ($n = 1$), and an electronic portal ($n = 1$). Additional interventions included a parenting empowerment module with instructions on meeting children’s nutritional needs and preventing complications from leukemia and the delivery of care based on principles of family-centered care.

Table 3. Descriptions of Interventional Studies.

Author, year, country	Design/theoretical framework	Aim	Participants & setting	Intervention	Outcomes measured	Results
Abdel-Latif et al. (2015) Australia	Cross-over randomized, nonblinded clinical trial (mixed method) FCC concepts	To determine the parents' and health care professionals' perspectives and levels of parental stress with PPCBR versus non-PPCBR	63 parental dyads of infants born at less than 30 weeks gestation (stay in NICUE 4 weeks or longer) or infants greater than 30 weeks with 11 days or longer anticipated LOS 37 dyads in PPCBR 35 dyads in non-PPCBR 24-bed NICU	PPCBR versus no PPCBR (standard care) PPCBR – interprofessional rounds with the opportunity for parents to participate in rounds, ask questions, and clarify information	Parent satisfaction (researcher designed) PSS-NICU Health care professional survey – researcher developed Focus group discussions – parents and health care professionals	PPCBR versus non-PPCBR <ul style="list-style-type: none"> Increased overall parental satisfaction regarding knowledge, understanding, communication, and collaboration No differences in parental stress Providers reported increased knowledge, communication, and collaboration and supported parent presence on rounds
Bastani et al. (2015) Iran	Randomized clinical parallel trail with a prospective posttest two groups design FCC	To determine the effect of FSS, including maternal participation, presence, and information about neonatal care on maternal satisfaction and neonatal readmission	110 mothers of preterm infants (30-37 weeks) with respiratory distress syndrome NICU 55 mothers in FCC 55 mothers in control group (usual care, including visitation restriction)	FCC mothers given pamphlets about infection control, infant positioning, skin-to-skin contact, feeding (gavage and breastfeeding), and visitation. Mothers performed infant skills with researcher	Modified satisfaction (information, participation, and presence) questionnaire Readmissions and LOS	FCC versus non-FCC <ul style="list-style-type: none"> Significant difference for satisfaction Fewer readmissions (p<.001) Lower mean duration of hospitalization was 6.96 versus 12.96 days control groups (p<.001)
Bracht et al. (2013) Canada	Descriptive qualitative pilot study FICare model	To describe the development, implementation, and evaluation of a pilot parent education program (FICare) developed by nurses and	39 mothers from one NICU Group training: for mothers per group	Delivered over 3 weeks and adjusted to family needs – it involved 5 days/week interactive teaching/support sessions	Qualitative evaluation of program/acceptability and feasibility	Mother's responses: <ul style="list-style-type: none"> Program successful; recommended more education on bathing and more visuals for education Most mothers liked having the program

		parents and delivered by trained bedside nurses with support from parents that supports parent participation in care				<p>5 days a week with one mother preferring 7 days a week and two mothers saying 3 days per week</p> <ul style="list-style-type: none"> Appreciated socializing with other mothers
Cox et al. (2017) United States	Cluster randomized trial FCC	To determine the impact of an FCR checklist intervention on performance of checklist items, family engagement, and parent perceptions of the patient safety climate	<p>298 families from four different services in a Children’s Hospital (one pulmonary, two general pediatric, one hematology/oncology) in the Midwest</p> <p>Two services received the FCR intervention</p> <p>Two services delivered usual care</p>	FCR developed from eight best practices for FCRs that were put into a checklist. The checklist was paired with a 1-hr observer interactive training, a brief refresher training, and tools to monitor implementation	<p>Checklist performance measure (coded observations)</p> <p>Family engagement in communication tasks (coded videos)</p> <p>Safety – Children’s Hospital Safety Climate Survey</p>	<ul style="list-style-type: none"> Significant increase in the number of checklist elements performed by health care professionals No intervention effect on family engagement No intervention effect on parental perceptions of safety
De Bernardo et al. (2017) Italy	Nonrandomized prospective cohort pilot study FCC	To compare satisfaction and stress levels between parents in an FCC group and a non-FCC group (NFCC)	<p>126 parents and 63 newborns from one NICU</p> <p>FCC infants (30)</p> <p>FCC parents (60)</p> <p>Control infants (33)</p> <p>Control parents (66)</p>	The FCC model – the NICU was remodeled to be more family friendly; NICU nurses taught and supported parental participation in the cares of infant during visiting hour	<p>Satisfaction survey</p> <p>Parental stress: PSS-NICU</p> <p>Weight of infant at 60 days</p>	<p>The intervention group had:</p> <ul style="list-style-type: none"> Significantly higher scores for satisfaction Lower scores for most items on the stress scale (15/22) Increased infant weights at 60 days
He et al. (2018) China	Pre-postintervention study FCC	To evaluate the impact of an FIC intervention on clinical outcomes of preterm infants born with BPD	<p>249 parents (FIC: n = 115; control: n = 134)</p> <ul style="list-style-type: none"> Born with BPD >1,800 g with respiratory support or >1,500 g with noninvasive oxygen support 	FIC intervention: Parents taught about hand hygiene, neonatal feeding and communication, touching the infant, patting the back of the infant, and providing basic care	<p>Respiratory support time</p> <p>Breastfeeding time</p> <p>Weight gain</p> <p>LOS</p> <p>Oxygen exposure</p> <p>Recovery from BPD – recovery, incomplete, or death</p> <p>Hospital expenses</p>	<p>Infant with parents in FIC</p> <p>Intervention group:</p> <ul style="list-style-type: none"> Decreased time on respiratory support Increased breastfeeding time Increased volume enteral nutrition Greater weight gain

			<ul style="list-style-type: none"> Hospitalized in NICUs at two hospitals in China 	(at least 3-hr per day)		<ul style="list-style-type: none"> No differences between groups for LOS, oxygen exposure, BPD outcomes or expenses
Heo and Oh (2019) South Korea	Intervention development and parallel, two-group RCT prospective, pretest – posttest, experimental design King's theory of goal attainment	To develop a PPIP for NICU parents and evaluate its effects on parent partnership with nurses, attachment to infant, and infant weight	66 infants less than 37 weeks gestational age and no more than high flow nasal cannula oxygen, their parents (control = 33 infant-parent dyads; intervention = 33 infant-parent dyads)	PPIP: 2-week program with three stages: Parents identified factors that affected their participation and developed a plan. Education was provided on those goals; parents then participated in nursing care 6 times	Partnership with nurses: Pediatric Nurse-Parent Partnership Scale Attachment to infant: Maternal Attachment Inventory (translated) Infant body weight	Intervention group had: <ul style="list-style-type: none"> Greater levels of partnership Greater attachment to the infant compared with control No differences between the groups for infant weight
Kelly, Hoonakker, et al. (2017) United States	Cross-sectional pre-postimplementation No framework	To determine the impact of an EMR portal on parent-health care professional communication, health care professional workload and satisfaction, and the quality and safety of care	94 health care professionals (nurses, pediatric intern and resident physicians, pediatric medical and surgical attending physicians, nurse practitioners, and ancillary staff) working in an 81-bed quaternary care children's hospital in the Midwest	Inpatient portal: 296 parents of children less than 12 years old were given access to portal on a hospital-issued tablet. Health care professionals were trained on how to use the portal in regularly scheduled staff meetings.	Researcher developed survey (satisfaction and impact on parent-health care professional communication) Parent use of portal Parent reported medication errors	High provider acceptance of portal: <ul style="list-style-type: none"> Decreased reports that portal use increased workload Positive responses of improved parent and child communication Parent use of portal: <ul style="list-style-type: none"> 85/296 used 16 sent messages to providers through the portal 5% of users notified team of medication error on medication list
Khan et al. (2018) Multicountry:	Prospective, multicenter before and after intervention study	To determine whether medical errors, family experience, and	3,106 admissions (1,574 preintervention and 1,532 postintervention) from	Patient- and family-centered I-PASS: This involved a structured high	Rate of medication errors Family experience (research developed)	<ul style="list-style-type: none"> Overall rate of medical errors was unchanged p = .21

Canada and United States	Framework no described – discuss FCRs	communication processes improved after implementation of an intervention to standardize the structure of healthcare provider-family communication on family centered rounds	seven pediatric hospitals in North America (one in Canada and six in United States) - medical units (nonintensive care)	reliability communication framework for rounds that was based on health literacy, family engagement, and bidirectional communication	Communication processes (observation of rounds and real-time assessment tool)	<ul style="list-style-type: none"> • Preventable adverse events decreased by 37.9% (p = .01) • Nonpreventable adverse events also decreased (p = .003) • FCRs occurred more frequently postintervention • Parent reports of the child's illness severity on rounds increased
Krisana et al. (2019) Indonesia	Quasi-experimental pretest/posttest with control FCC	To determine the effect of an FACE module for mothers of children with leukemia	60 mothers of children with leukemia on inpatient units 30 mothers in FACE (intervention) 30 mothers received usual care (control)	Education to improve cognitive abilities of mothers – instruction on how to meet child's nutritional needs, prevent infection, and bleeding. Two 30-min sessions in 1 week	Mother's physical and psychological response: DASS	<ul style="list-style-type: none"> • Mothers in intervention group had lower DASS scores after the intervention, indicating lower levels of anxiety and depression
Kuo et al. (2012) United States	Prospective cohort study Not described – FCC	To evaluate the effects of FCR versus o FCR	Parents of 140 children admitted to general pediatrics units (infants and toddlers) FCR: n = 70 Non-FCR: n = 70	FCR teams are trained in elements, including family permission, rounding process, and encouraging family questions at the end of rounds; pocket cards provided with reminders of expected behaviors and rolling cart for rounding	Family health care experience Health care service use	<ul style="list-style-type: none"> • 100% of FCR reported that they were able to discuss plan of care with medical team versus 50% of the non-FCR • FCR families more likely to report that doctors listened to concerns, showed respect, spent enough time with child and treat parent like a partner • No differences in clearly explaining things,

						undersatnding discharge pla, remembering appointments, physicians name, discharge hour, medication used or costs
Ladak et al. (2013) Pakistan	A nonrandomized before/after study Not described – FCC	To determine whether FCR improve parents’ and health care professionals’ satisfaction, decreased patient LOS, and improve time utilization compared with standard care	82 parents of children hospitalized at least 48 hr in tow ICUs (pediatric and pediatric cardiac) FCR: n = 41 Non-FCR: n = 41	A protocol was used that informed parents of the presence of rounds, the time they would occur, and responsibilities of team members; parents are invited to ask questions by attending	Parental satisfaction questionnaire (adapted) Health care professional satisfaction questionnaire (adapted) Observation of rounds LOS	<ul style="list-style-type: none"> • No significant difference in satisfaction with care provided to child • Parents in FCR expressed greater inclusion in rounds and decision-making, use of simple language, and teamwork • No difference in satisfaction for health care professionals • Shorter LOS for children in FCR versus non-FCR
Lee et al. (2013) Taiwan	Historical Comparison Study Houses (1981) four Components of Support (information, emotional, instrumental, and esteem)	Evaluate the effectiveness of an intervention on further ability, perceived nurse’s support, and paternal stress after a preterm infant’s admission to an NICU	Sample: Fathers of infants <37 weeks gestation with expected LOS of at least 2 weeks Setting: NICU, single center Intervention fathers: n = 34 Control fathers: n = 35	Booklet given to fathers providing information about premature babies and NICU nurse present during visits to answer questions and encourage use of components of the booklet and support the father using relaxation skills	Parental stress Fathering ability Fathering perceived nursing support	<ul style="list-style-type: none"> • Intervention fathers had significantly higher fathering ability, perceived nursing support, and a greater reduction in stress than the comparison group • A significant moderating effect of perceived nurse support on the relationship

						between furthering ability and paternal stress was found
LeGrow et al. (2014) Canada	Phase 1, single-group posttest study Bourdieu's (1990) The Logic of Practice	To evaluate the feasibility and acceptability of the parent-briefing intervention from the points of view of the clinical and parents	27 parents of children (newborn to 18 years of age) who had a nonelective admission in a large tertiary care center. Nurses: n = 25 Physicians: n = 13	The briefing included the following components to enhance parents' cultural and symbolic capital: (a) update regarding the child's health status; (b) review of the goals and plan of care for the next 12-24 hr; (c) medical terminology, jargon, and acronyms used; and (d) an opportunity to listen to and answer/address parents' questions and concerns	Timing and duration of the intervention, clinical usefulness, preferences for future	<ul style="list-style-type: none"> Parents felt their input important, being present during team meetings was helpful, they were able to ask questions and state concerns, had tests/procedures explained to them Nurses rated all aspects of the parent briefing in a favorable manner, nurses were challenged to be available to participate and having to ensure the briefing was completed per protocol Physician's ratings were mixed, only two of 13 recommended that briefings become part of usual practice and half thought carrying out enhanced communication was easy
Lester et al. (2014) United States	Longitudinal, prospective, quasi-experimental cohort study	To determine whether and SFR NICU, including factors associated	151 infants in an open-bay NICU 252 infants after transition to and SFR NICU.	Being cared for in a single-family room NICU	LOS, age, head circumference, and weight at discharge, rate of weight gain,	SFR associated with <ul style="list-style-type: none"> Increased satisfaction, less stress

	Not described	with the change to and SFR NICU, is associated with improved medical and neurobehavioral outcomes	Infants were born <1500 g.		gestational age at full enteral feedings, rates of common complications, use of supplemental oxygen, continuous positive airway pressure or mechanical ventilation Mother's perception of FCC, satisfaction, stress involvement	<ul style="list-style-type: none"> • Higher perception of FCC • Increased kangaroo care Other outcomes: <ul style="list-style-type: none"> • Increased weight at discharge, quicker weight gain, fewer procedures, full enteral feeds started earlier, less sepsis, better attention span, less physiologic stress, hypertonicity, lethargy, and pain • Developmental support and maternal involvement were mediators in many of the medical and neurobehavioral outcomes
Lv et al. (2019) China	Quasi-experimental study Not described	To evaluate an FCC intervention on clinical outcomes of very-low-birthweight infants	319 very low birthweight infants: Intervention: n = 156 Control: n = 163 Level III NICU	Parental education of basic care knowledge and skills, followed by active participation for at least 4 hr per day	Weight at discharge, LOS, breastfeeding, nasal feeding, total parental nutrition, readmission, hospital expenses, infant complications	FCC Infants had: <ul style="list-style-type: none"> • Higher weight at discharge • Improved nutritional outcomes (including breastfeeding rate and decreased days of TPN and enteral feeds) • Decreased rates of bronchopulmonary dysplasia, retinopathy of prematurity, NEC, and readmissions

Morelius et al. (2012) Sweden (same study as Ortenstrand)	RTC Not described	Evaluate the effect of FCC on salivary cortisol reactivity in mothers and preterm infants and the correlation between their levels	289 infants <37 weeks gestation Intervention: n = 137 Control: n = 137 Two Level II NICUs	FCC ward of single-family rooms, including beds for parents and infant once stable, private bathroom, needed equipment One parent must stay 24 hr.	Cortisol reactivity	<ul style="list-style-type: none"> No difference in cortisol reactivity in infants or mothers between the two groups or between mom and infant cortisol Significant correlation between baseline cortisol mothers' and infants' cortisol level in the FCC group and in the response cortisol levels between mothers and infants
Ortenstrand et al. (2010) Sweden	RCT Not described	Evaluate the effect of a new model of FC in a Level II NICU, where parents stay from admission to discharge	365 infants born <37 weeks gestation FC: n = 183 Control: n = 182 Two Level II NICUs	FC ward: separate room for families, beds for both parents and infant (once stable), a private bathroom, needed equipment; One parent must stay 24 hr	Total length of hospital stay Short-term infant morbidity	<ul style="list-style-type: none"> Total length of hospital stay was reduced by 5.3 days for the FC infants No differences in infant morbidity, except for reduced risk for moderate to severe bronchopulmonary dysplasia
O'Brien et al. (2018) Multicounty: Canada and Australia	Cluster RCT FIC model	To analyze the effect of FIC on infant and parent outcomes, safety, and resource use	Infants born at ≤33 weeks' gestation FICare group: n = 895 Standard care group: n = 891 19 Canadian, six Australian, and one New Zealand tertiary-level NICU	Parents were present at least 6 hr a day, attended educational sessions, and actively cared for their infant	Infants' weight gain at 21 days after enrollment, breastfeeding, clinical outcomes, safety, parental stress and anxiety, and resource use	FIC group significant outcomes <ul style="list-style-type: none"> Greater weight and daily weight gain for infants Higher frequency of exclusive breastmilk feedings at discharge Lowr mean stress scores at Day 21 for parents

						<ul style="list-style-type: none"> No differences in mortality, major morbidity, duration of oxygen therapy, and hospital stay
Palma et al. (2012) United States	Pre-post survey Not described	To evaluate the impact of using EMR data in the form of a daily patient update letter on communication and parent engagement	31 families of babies in the Level II NICU completed the preimplementation survey and 26 families respond to the postimplementation survey	EMR-generated daily patient update letter printed for the parents, YBDU that included baby's status, members of the team, weight, nutritional status, respiratory status, medications, certain results, handwritten update.	Adoption of the daily update Satisfaction Family's knowledge of their infant's care	Families reported using YBDU as an information source, found it "very useful," responded that they "always" liked receiving it and felt more competent to manage information related to the health status of their babies No significant change in rates of receiving info from the attending physician, family's knowledge of specific aspects of their infant's care, families' perceptions about getting the information they needed about their baby's health status
Rosen et al. (2009) United States	Quasi-experimental design Not described	Determine the impact of FCMDR on an inpatient pediatric ward	FCMDR: n = 15 Control: n = 12 14 parent-patient dyads completed the survey after conventional rounds, 22 parent-patient dyads completed the survey post FCMDR 53 staff members completed surveys	Two-week study: FCMDR included all family members. Included overnight events, changes in physical examination, relevant lab or radiographic studies, and an assessment and plan for the day. Patient, parents, and rest of the care team gave input. Discharge and relevant teaching points were discussed.	Patient and family satisfaction with FCMDR Value for staff of FCMDR Difference in time commitment to FCMDR versus conventional rounds	FCMDR vs. Conventional <ul style="list-style-type: none"> No differences in family satisfaction between two groups Staff reported better understanding of the patient's medical plans, better ability to help families, and a greater sense of teamwork 2.7 extra minutes per patient The family affected the medical decision-making discussion in 90% of FCMDR cases.

Rostami et al. (2015) Iran	Quasi-experimental Not described	To determine the effects of FCC on the satisfaction of parents of children hospitalized	Experimental group: Children/parents (n = 35) Control group: Children/parents: (n = 35) Pediatric ward	Care delivered that was based on principles of FCC (details not provided).	Parental satisfaction with care	Mean satisfaction score increased from 20 to 83.2 out of 90.
Zhang et al. (2018) China	Pilot study using an RTC design to inform a main RCT study Not described	To evaluate the effectiveness and safety of an FCC intervention in a Chinese NICU	Premature infants (n = 61) and their parents (n = 110) NICU FCC group infants (n = 31) FCC parents (n = 62) Control infants (n = 30) Control parents (n = 48)	Parent education program, followed by parents' participation in care as primary caregiver until discharge for a minimum of 4 hr per day	Infant weight gain, LOS, readmission Parental stress and anxiety Parental satisfaction and clinical knowledge	FCC group vs. control <ul style="list-style-type: none"> • Infants had a higher weight gain, shorter LOS in NICU, and decreased readmission rate at 1 week • Total mean parental stress and anxiety scores were lower • Mean satisfaction rates were higher • Higher parent education outcome related to neonatal specialized care
Hernandez et al. (2016) South America	Mixed methods and participatory action research FCC NDC	To develop and evaluate strategies to promote NDC and FCC in the neonatal unit	Four focus groups with 40 professionals and one focus group with seven mothers of hospitalized babies in an NICU in Columbia	Seven educational workshops related to NDC and FCC with seven MDs, 25 nursing assistants, five nurses and three RTs Materials for NDC provided (positioners – nests and contention blankets) Video to provide information to families in NICU)	24 observations of care at different timepoints (morning, afternoon, and night) Focus group data	<ul style="list-style-type: none"> • FCC practices improved but were some barriers • Professionals reported wanting more information, evidence, and education about NDC strategies • Challenges of FCC for professionals included interdisciplinary work, increasing awareness of personnel and

						<p>higher time requirements</p> <ul style="list-style-type: none"> • Parents' perception of FCC revealed needs in terms of communication, space for the family, and visiting hours
Mannix et al. (2017) Australia	Mixed methods Not described	To describe how nursing staff in a pediatric ward improved the conduct of clinical handover, using a practice development approach	All nurses were invited to participate in the bedside handovers, surveys, focus groups, and observations. An entire 17-bed pediatric ward in a large public hospital with 30 nurses.	Training session with nurses on use of Identify, Situation, Background, Assessment and Recommendation at bedside report	Satisfaction of nurses Staff performance observations	<ul style="list-style-type: none"> • Improved satisfaction with bedside handover • Significant increases in improved handover practices, including family inclusion and safety checks

Note. FCC = family-centered care; PPCBR = Parental Presence during Clinical Bedside Rounds; NICU = neonatal intensive care unit; PSS = Prenatal Stress Scale; FICare = family integrated care; FCR = family-centered rounds; FIC = family integrated care; BPD = bronchopulmonary dysplasia; PPIP = Parent Participation Improvement Program; FACE = Family-Centered Empowerment; DASS = Depression Anxiety Stress Score; ICU = intensive care unit; LOS = length of stay; SFR = single-family room; TPN = total parenteral nutrition; NEC = necrotizing enterocolitis; FC = family care; EMR = electronic medical record; YBDU = Your Baby's Daily Update; FCMDR = family-centered multidisciplinary rounds; NDC = Neonatal Developmental Care.

Outcomes

In the 65 quantitative studies and systematic reviews, 49 (75%) reported parent outcomes. The most commonly reported parent outcome was satisfaction ($n = 24$, 37%), with being better informed ($n = 11$, 16%), infant outcomes (such as weight gain, breastfeeding, neurologic outcome; $n = 7$, 11%), and parent/health team communication or partnership ($n = 7$, 11%) as the next most frequently measured outcomes. Outcomes reported with less than 10% frequency included morbidity, parent mental health, confidence, better informed, empowered, participation/presence, infant/child care skills, safety issues, health team communication/partnership, quality of care, length of stay, and readmissions. In the 124 qualitative (including mixed qualitative/quantitative) studies and narrative/integrative reviews, half of studies ($n = 67$, 54%) reported an outcome of engagement. Parents being better informed was the most common parent outcome reported in qualitative analyses ($n = 25$, 20%). Satisfaction ($n = 21$, 17%), communication/partnership with the health team ($n = 16$, 13%), parent confidence ($n = 15$, 12%), and parent mental health ($n = 14$, 11%) were also reported in qualitative analyses. The remaining outcomes in these analyses were similar to those reported in quantitative analyses.

Nurse outcomes were reported in 23 (35%) of the quantitative studies and reviews. The most frequently cited outcome related to the nurse–patient relationship, including nurse–parent communication and partnership ($n = 5$, 8%); other reported outcomes included measures or descriptions of satisfaction, effectiveness, engagement, safety, communication with health team, improved care processes, and nurse well-being. Nurse outcomes were included in 43 (35%) qualitative studies and reviews and were similar to those noted in quantitative studies. The most frequent outcomes related to the nurse–patient relationship, communication, and partnership ($n = 10$, 8%), followed by satisfaction ($n = 8$, 7%), effectiveness ($n = 6$, 5%), and workload ($n = 6$, 5%). Other outcomes reported related to improved care processes, family/patient outcomes, nurse well-being, safety, efficiency, communication between nurses, and costs.

Provider/physician outcomes were only reported in 19 (29%) of the quantitative studies and reviews, and 22 (18%) of qualitative studies and reviews. The most commonly measured quantitative outcome was communication/collaboration with the family; the most common qualitative outcome was the provider was better informed.

Of the 25 studies that tested an intervention, the most common outcome measured was satisfaction: 12 (48%) measured family satisfaction and four measured health care professional satisfaction (three of the studies measured both). Nine studies (36%) demonstrated a link between family engagement practices and improved family satisfaction scores. The majority of those studies (78%) were conducted in NICUs. Of the five studies (20%) that were not conducted in NICUs, three did not demonstrate an effect on parent satisfaction scores (Khan et al., 2018; Ladak et al., 2013; Rosen et al., 2009). Five of the six studies that examined health care professional satisfaction found an association between family engagement and professional satisfaction (Abdel-Latif et al., 2015; Kelly, Dean, et al., 2017; Lester et al., 2014; Mannix et al., 2017; Rosen et al., 2009). Several studies also demonstrated an association between family engagement and decreased stress, anxiety, or depression in family members (Abdel-Latif et al., 2015; De Bernardo et al., 2017; Lee et al., 2013; Lester et al., 2014; O'Brien et al., 2018; Zhang et al., 2018).

Interventions in the NICU were associated with various physiological outcomes in newborns: quicker weight gain, fewer procedures, less sepsis, better attention span, less physiologic stress, and less pain (Lester et al., 2014). There were no significant differences in infant morbidity in two studies that looked at the effects of family-integrated care and 24-hr rooming in of parents (O'Brien et al., 2018; Ortenstrand et al., 2010). Outcomes of improved fathering ability, more bedside involvement of family members, increased kangaroo care, breastfeeding rates, and clinical knowledge were also demonstrated in numerous NICU studies.

Discussion

In this scoping review, our goal was to discover how family engagement was conceptualized within the context of pediatric acute care. The major contribution of this review is a more precise family engagement definition in pediatric settings and clearer direction for future family pediatric engagement research based on the identified gaps in a large body of literature.

Defining Family Engagement in Pediatric Acute Care

Given the vast scope of literature in the overlapping areas of family engagement, family empowerment, and family-centered care, we found a limited number of definitions of family engagement. Early definitions of the concept of family-centered care have been omnipresent in pediatric care in the United States for more than four decades, but emerged later in research and practice in other countries. Family-centered care definitions included concepts related to family engagement, such as family involvement in care and family as part of the care team. Nevertheless, newer reframings of family engagement within the broader philosophic and care delivery models for family-centered care focus on the active roles of both families and the health care team, and the family's relationships and interactions with the health care team and organization (Ashcraft et al., 2019; Gruman et al., 2010; Maurer et al., 2012; Samra et al., 2015; Silver & Traube, 2019). What distinguishes family engagement from family-centered care is a mutually beneficial partnership between parents and health care team members. This mutually beneficial partnership is the result of parent and nurse/health team actions to include the other in care activities and decisions, with the parent as an active participant within the care team, as described in the definition of engagement offered by Agency for Healthcare Research and Quality (Maurer et al., 2012).

Being an equal team member and the feeling of having mutually equitable roles (Ashcraft et al., 2019; Benzies, 2016) is a core component of engagement for families. Developing a mutually beneficial partnership is the highest level of family engagement. Families should not be viewed as visitors, but rather participating members of the team (Craig et al., 2015), and health care professionals should move away from their traditional "doing for" role into a coaching role (Mann, 2016). Role negotiation is an important aspect of engagement interventions (de Oliveira Alves et al., 2017; Mikkelsen & Frederiksen, 2011). Eliminating power differentials allows for more fluid communication between families and the health care team, and comfort with shared decision-making (Mastro et al., 2014). Mutually beneficial partnerships lead to more active engagement because roles and strengths of both health care professionals and families are respected, welcoming shared responsibility and action.

Engagement is an active, socially constructed, and situationally based process (Olding et al., 2016) that depends on both families and health care professionals for success. Not surprisingly, family and health care professionals' perspectives about engagement differed. For example, Ladak et al. (2013) measured satisfaction of health care professionals and families after family-centered rounds. Families reported satisfaction and the perspective that family-centered rounds gave them an opportunity to fill gaps in medical history, correct misinformation, and participate in decisions. In contrast, health care professionals held the perspective that families were intrusive, unable to understand discussions, and their presence delayed rounds. Commitment and valuing of family engagement are necessary among all parties to achieve mutually beneficial engagement.

The international scope of this literature review underscores culture and geographic region as important factors in how engaged care was delivered and received. In some reports, parent engagement in children's care was often done out of necessity in developing countries due to lack of resources and staff (Abdelkader et al., 2016; Phiri et al., 2019), and not driven by a family-centered philosophy. Cultural views about the caregiving role also influenced family engagement in care. For example, in some cultures, caring for the child is seen only as the

mother's role, limiting engagement of fathers in the care of their children (Roa & Ettenberger, 2018; Valizadeh et al., 2018).

Practices and Interventions

Although there is a large body of research and practice descriptions for family-centered care, there is much less about family engagement; specifically, 10 of 247 articles had the term “engagement” identified in the aim. However, of the 247 articles reviewed, all, in some way, described engaging or engaged care. Engaging is described from the perspective of the nurse or health care team, while parents' perspectives reflect whether they were engaged and their relative satisfaction with *engaging with* the health team. These perspectives are included primarily in findings of qualitative studies. Engagement strategies abstracted from articles listed in Figure 2 follow a continuum of engagement and are presented in order from more passive (opening the door to communication) to more active (shared decision-making and participation in all aspects of care delivery) actions, consistent with Olding et al.'s (2016) conceptualization of family engagement. The four themes of family engagement practices found in this study are consistent with the four foundational principles of engagement described by Higgins et al., 2017: (a) personalization, (b) access, (c) commitment, and (d) therapeutic alliance. Increasing parental/caregiver involvement in health care and supporting decision-making and involvement are ways to ensure access and commitment. Developing a mutual partnership and modifying organization design, infrastructure, and philosophy of care are ways to ensure personalization of care and the establishment of a therapeutic alliance.

Family engagement practice descriptions focused on unit-level approaches to improve care delivery, with little focus or lack of details regarding the individual actions each nurse and health care professional utilized to engage each unique family-patient unit in care. The trajectory of influence at the individual nurse-family interface is important because the nurse can impact the degree of engagement through role negotiation and establishment of mutual partnership, and families can experience nurses who engage them at varying degrees. The existing body of literature also tends to focus on the perspectives of parent and health team separately, even when both are included in studies. The interaction of parent/team perspectives and actions is missing, as is the interaction of nurses, physicians, and other health care professionals. Team science/interprofessional science is not part of the existing body of literature on family engagement in pediatrics.

Many of the reviewed interventions focused on delivering universal written or verbal education to families about bedside care, followed by the encouragement of families to be present to practice the bedside care. Family preferences for how they would like to engage in their children's care were not assessed. Engagement preferences will vary across families (Aein et al., 2011; Foster et al., 2018) and respect for the individuality of families is a core principle in definitions of family-centered care and engagement (Agency for Healthcare Research and Quality, 2017; American Academy of Pediatrics, 2012; Johnson & Abraham, 2012). There was little evidence that family preferences were being assessed in the studies we reviewed. Discordant goals or parent expectations can lead to feelings of frustration or disengagement (Ashcraft et al., 2019). Tension may arise when families are assigned tasks without first discussing them (Aein et al., 2011). It is crucial for parent preferences for engagement to be assessed, as family engagement is situational and the establishment of a mutual partnership is difficult without considering the needs and values of both parties (Mikkelsen & Frederiksen, 2011).

It is important to note that interventional studies were a very small portion of the included articles and that of these interventions, more than half were focused on the NICU parent population. The NICU situation is different from other pediatric acute care contexts in that developmental needs of the newborn and newborn care are often integrated into interventions and the length of stay is often longer, giving parents more time and foundation to become engaged in the care of their infant. The majority of the interventions in other pediatric samples focused on improving communication with the assumption that better informed parents could lead to

more engagement; however, these interventions did not move beyond a more passive information giving and receiving approach to engaging families in the care of their child.

Interventions focused on parent participation in care (Bastani et al., 2015; Hernandez et al., 2016; Zhang et al., 2018) were predominately based on the Family Integrated Care (FiCare) model (Bracht et al., 2013; He et al., 2018; O'Brien et al., 2018) in which parents were educated on caring for their infant and then actively delivering care to the infant. Family-centered care interventions also modified the physical environment to promote more parental involvement in care (e.g., single rooms and increasing space for families in the unit; De Bernardo et al., 2017; Heo & Oh, 2019; Lester et al., 2014). A unique approach to family engagement was the use of Experience-based Co-design (EBCD) to qualitatively capture the experiences of all involved in care interactions (staff, parents/caregivers, and children) to enhance the understanding of perspectives and, subsequently, mutually develop solutions to improve care (Brosseau et al., 2017).

Outcomes

Parent satisfaction with care was the most commonly cited outcome in quantitative studies and parents being better informed was the most commonly cited outcome in qualitative studies. Although improving the care experience for families is crucial to the establishment of mutually beneficial relationships, the absence of reported clinical outcomes of patients is concerning. If family engagement strategies do indeed improve the quality of care delivered, one would expect that to translate to improved clinical outcomes in patients. The few studies that did report improved clinical outcomes in infants were conducted in the NICU and were specific to developmental needs of the neonate. Furthermore, the notion that families are better informed when engaged by the health care team is largely supported with qualitative data, which speaks to the point that it is difficult to quantitatively measure engagement-based outcomes within individualized care experiences (engagement is situational and families have different needs). The development and testing of standardized engagement outcome measurement tools would enable more comparison of outcomes across studies.

While family engagement is often defined as a mechanism to improve safety, only three interventional studies looked at safety as an outcome and the results were mixed (Cox et al., 2017; Kelly, Hoonakker, & Dean, 2017; Khan et al., 2018). Family engagement has also been advocated as a mechanism to decrease the cost of care through improvements in health care utilization. Again, there was a minimal focus on the impact of family engagement on cost of care, examining outcomes of length of stay, readmissions, and results were conflicting (Bastani et al., 2015; He et al., 2018; Lv et al., 2019; O'Brien et al., 2018; Zhang et al., 2018).

Strengths and Limitations

Strengths of this scoping review were the use of rigorous methodology with the guidance of a health librarian to ensure a thorough review of the literature and the review of a large body of literature to understand the breadth and depth of the existing literature. This review also had some limitations. We included only English-language articles, limiting our ability to understand engagement across cultures/languages. Almost half of the included literature was from the United States and Canada, limiting generalizability. The majority of the interventional studies focused on meeting developmental needs of the neonate in the NICU setting, again limiting generalizability. We did not conduct a quality appraisal of the included articles, although this is not typically an aim of a scoping review (Arksey & O'Malley, 2005). We found it difficult to separate the concepts of family-centered care, family empowerment, and family engagement, leading us to review articles from all three concepts for attributes describing engaging and engaged pediatric care. This approach allowed us to compare and contrast these concepts, but the conceptual overlap challenged our ability to define the unique domains of engagement. We explored both practice-based and research interventions to understand the range of engagement strategies in use. This approach broadened our understanding of the field but also allowed us to

drill into the state of the science. To that end, we did a separate examination of quantitative, qualitative, and intervention studies.

Recommendations

Based on the Agency for Healthcare Research and Quality's definition (Maurer et al., 2012), as well as definitions provided by Carman et al. (2013), Samra et al. (2015) and the conceptualizations of engagement by Olding et al. (2016) and Higgins et al. (2017), we recommend that family engagement in pediatric acute care is defined as follows:

Behaviors and actions of parents/caregivers and health care professionals that support active parent/caregiver participation in care of the infant/child and address individual parent/caregiver preferences to positively influence specific infant/child outcomes. Engagement is time and context specific and intended to build mutually-beneficial partnerships for healthcare delivery at the direct care and organizational levels.

Further work to understand the conceptual components of engagement and how it differs and relates to empowerment and family-centered care will move engagement science forward. Given the nuances of the overlapping concepts of family engagement, empowerment, and family-centered care in the diverse sources reviewed for our analysis, we believe that consolidating the language and meaning of concepts within a framework for family engagement will support global efforts to move family engagement research forward.

There are important directions for future research. There is a gap in our understanding of the core actions/behaviors of health care professionals that promote actively engaged parents and positively influence infant/child/family outcomes. Mutual active participation of the health care team and families is recommended but not well understood. There is a need for inquiry that defines the domains of mutual active participation from stakeholders' perspectives, and their expected outcomes both during and after hospitalization. Effectiveness studies are also needed to determine the optimal engaging actions to achieve active parent/caregiver engagement.

A focus on collaborative family/health care team engagement should be prioritized rather than examining the engaging behaviors of the health care team or family engagement in isolation from the other. Examining the interaction of family/nurse/health care professional perspectives and mutual active engaging interventions within the family/nurse/health care professional dynamic could be facilitated through an approach such as experience-based co-design, in which families and health care professionals work collaboratively to determine what is important and co-create meaningful change (Brosseau et al., 2017). In addition, a team science approach in family engagement research will enhance our efforts to understand unique and effective engaging behaviors of interprofessional team members.

The contribution of assessing parent/caregiver preferences for engagement on the impact of engaging interventions needs to be examined (Jerofke-Owen et al., 2020), as individualized care is a necessary component to family engagement. Preferences for engagement are situation and context specific, making it crucial that family preferences are assessed often. Care should be taken to ensure that interventions are tailored to family preferences. More attention should be placed on the impact of family engagement interventions on patient and family clinical outcomes after the hospital care experience.

Research methods for family engagement in acute care settings are largely qualitative in nature. There is an insufficient body of research on any one approach or specific family and/or nurse/health care team engaging behaviors to conduct meta-analyses. Many of the practices and interventions abstracted from the articles were more passive examples of engagement. Future research should focus on the design and delivery of more active engagement interventions such as inviting families to have two-way discussions about care, involving families in

the development of engagement interventions, welcoming families to be active participants in safety initiatives, and valuing family input within advisory roles. In addition, research findings from NICU studies must be thoroughly examined for clinical significance for other pediatric populations.

Family experience and satisfaction has been the primary engagement outcome measured in studies. Outcomes such as health care utilization and patient health status outcomes should be examined to further evaluate the value of family and patient engagement. Once additional outcomes are recorded, meta-analyses can be performed.

Conclusion

This scoping review examined the range, nature, and extent of the published family engagement literature specific to the pediatric acute care setting. Family engagement concepts have evolved from family-centered care delivery models. What distinguishes family engagement is the mutually beneficial partnership of families with health care team members and care organizations. This review has highlighted that the majority of family engagement research has been conducted in the United States and Europe, focuses on family satisfaction outcomes, uses a qualitative methodology, takes place within an NICU setting, and is not interventional in design. To move engagement science in pediatric acute care forward, research is needed that examines which engaging interventions are most impactful to families, patients, health care teams, and organizations.

To improve family engagement in nursing practice, there is a critical need to enhance the depth and breadth of family nursing education in undergraduate and graduate nursing programs, as well as for practicing nurses and advance practice nurses who work with pediatric populations in acute and critical care. The International Family Nursing Association (2015, 2017) Position Statements on generalist and advanced family nursing practice are foundational documents to guide this effort.

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Supplemental Material

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