Improving Neonatal Intensive Care Unit Quality and Safety with Family-Centered Care

Linda S. Franck, RN, PhD, FRCPCH, FAAN[a],*, Anna Axelin, RN, PhD[b],
Nicole R. Van Veenendaal, MD, MPH[c], Fabiana Bacchini, MSc, BJ[d]

KEY POINTS

- There is now strong evidence for family-centered interventions and models of care.
- The family-centered care (FCC) research-to-practice gap can be addressed with quality improvement (QI) approaches.
- Families are essential partners in QI.
- FCC QI measures and strategies are available, and there is opportunity for future innovation.

"I was only 25 weeks gestation when one of my twins died in utero… My surviving twin was rushed into the NICU, where he stayed for 146 days. The first time I saw him, I did not see a baby. I saw the wires; the monitors and I was very scared. I asked myself, how can he survive, how can an entire life be contained in only 900 grams? The nurse asked me if I would like to hold him. I was still recovering from the C-section, sitting on a wheelchair. I got transferred to another chair, and he was placed on my chest. He was so small, it felt like a worm, I held my breath as I didn't want to hurt him.

[a] Department of Family Health Care Nursing, University of California San Francisco, 2 Koret Way, N411F, Box 0606, San Francisco, CA 94143, USA; [b] Department of Nursing Science, University of Turku, 20014 University of Turku, Finland; [c] Department of Pediatrics, Emma Children's Hospital, Amsterdam UMC Location University of Amsterdam, Meibergdreef 9, Amsterdam, the Netherlands; [d] Canadian Premature Babies Foundation, 4225-B Dundas Street West, Etobicoke, ON M8X 1Y3, Canada
* Corresponding author.
E-mail address: linda.franck@ucsf.edu
Twitter: @AnnaAxelin (A.A.); @nicolevan_vee (N.R.V.V.); @fabianabacchini (F.B.)

We had two primary nurses who taught me how to change his diaper, take his temperature. As I gained physical strength, I stayed more hours by his bedside and once he got off the ventilator, I was invited to participate in the study of Family Integrated Care. It sounded like a great idea to be able to go to education classes every day so I could learn more about prematurity and what it could mean for him. I was invited to present him at rounds, which was intimidating in the beginning. It was a multidisciplinary team with about ten people, but every day I felt more confident to talk about my son and ask questions. As the days went by, the alarms didn't scare me as much and I learn to identify if my son was breathing well without looking at the monitors. Doctors would always come by the bedside to share information and discuss treatments and involved me in the decision-making. I was welcomed as part of my son's care team. I had access to the hospital 24/7 and it felt like my home away from home.

When I look back…, I realize that I was being prepared for the long road ahead as prematurity does not end when the baby gets discharged. My son came home on oxygen and during the first year of his life we had several trips to the emergency room because of respiratory distress. The first month post-discharge, he got very sick and was admitted in our local hospital. He turned blue while I was breastfeeding him and even after screaming for help, no one came. I ended up doing CPR on him and I saved his life. This monumental day made me realize how important being involved in the care in the NICU is. I learned not only life skills but also the confidence to advocate for my son. My preemie is now 10 years old. He has cerebral palsy and the advocacy never ended, but I'm much more prepared to face the challenges and celebrate the victories. Thanks to the amazing team who care for him and taught me how to be a parent of a child born preterm."
(Excerpt adapted from: Bachinni F. From Surviving to Thriving – A Mother's Journey through Infertility, Loss and Miracles, Toronto: Burman Books, Inc, 2017.)

INTRODUCTION

The essential role of parents (or other primary caregivers) to the survival and optimal development of small and sick newborns has been well documented across the world for more than 60 years. There is now strong evidence that outcomes are improved for infants and families when families are involved in their hospitalized infant's care.[1] The neonatal intensive care unit (NICU) team cannot fully meet the infant's physical and developmental needs during hospitalization or adequately prepare families to care for infants after discharge without strong family engagement as described so powerfully by the mother reflecting on her preterm infant's NICU journey [see Sidebar]. Moreover, the rights of children (including newborns) to fully and continuously be supported by their parents/primary caregivers are codified in the UN Rights of the Child.[2] Therefore, separation of infants from their parents in healthcare settings can be considered a violation of their human rights. Building on this, the European Foundation for the Care of Newborn Infants (EFCNI) states in their *Rights of Parents and Newborns*: "all families have the right to be considered as a unit [..], all parents have the right to receive appropriate education and be actively involved in their baby's care giving in an effective and sensitive manner."[3] The EFCNI also states that "all parents and newborns have the right to family-centered care (FCC) and to stay together while the child receives healthcare."[3,4]

The importance of patient-centered and family-centered healthcare services and the contribution of patients and families in the design and delivery of health care that are safe and high-quality are not unique to the NICU and have been recognized for many years, across all healthcare settings, age groups, and conditions. Patient-centered care and FCC lead to better health outcomes, improved patient and family

experience of care, better clinician and staff satisfaction, and wiser allocation of re-sources when families are fully integrated into the care delivery system and treated as essential and irreplaceable partners in all aspects of healthcare delivery, from the bedside to the health system boardroom.[5–7] Nevertheless, healthcare services remain stubbornly professional-centric and institutional-centric, contributing to underper-formance in attainment of quality and safety goals and adverse/suboptimal patient and family outcomes.[8,9]

As illustrated in the mother's personal reflection above, FCC requires intentional and coordinated effort from the healthcare team to overcome emotional, physical, and institutional barriers to achieve the level of parental partnership in care necessary to achieve optimal outcomes for infants and families. The quality improvement (QI) prin-ciple of improving reliability[10] applies equally to family partnership in caregiving as it does to other routine QI activities such as infection control. Greater investment in FCC QI to assure maximal family partnership both in caregiving and work undertaken to improve systems and processes of care is essential to optimizing infant and family outcomes during NICU stay, at NICU discharge and for long-term health, development and well-being.

In this review, we describe the principles and main constructs of family-centered neonatal care; discuss the state of the science and practice of FCC in the neonatal intensive care setting; and provide recommendations for assessment, development of practice standards and evaluation of FCC in the NICU setting. In keeping with the principles of family partnership and family-centeredness, a NICU parent advocacy or-ganization leader served as a key partner in this review from the inception and is a coauthor (FB). Throughout we provide commentary from different parents, recog-nizing the imperfect level of partnership in the current healthcare quality and safety en-terprise. We seek to further strengthen the voices and essential contributions of parents and caregivers of neonatal patients.

FAMILY-CENTERED CARE PRINCIPLES, CONSTRUCTS, AND CONCEPTS

FCC terminology and definitions vary by setting, discipline, and geography. The term person-centered care may be used to denote the holistic focus on the needs and strengths of the person that extend beyond health care to all societal systems.[11] In patient-centered care and FCC, the focus is on patients and families receiving healthcare services. Patients and their primary caregivers define their "family" and determine how they will participate in care and decision-making.[12] For neonates (or any other individuals who are unable to express their personal agency), parents or other primary caregivers act on behalf of the patient; hence, the use of the term FCC rather than patient and FCC.

Most models of FCC share the core principles of respect and dignity, information sharing, negotiation, participation, and collaboration (Fig. 1, Table 1).[12–14] FCC is rooted in the belief that partnerships among healthcare providers, patients, and fam-ilies are mutually beneficial and lead to higher quality and safer health care. For a health system to be patient-centered and family-centered, there must be collaboration among all stakeholders, including healthcare professionals, administrators, funders, patients, family and community at all levels of care, in all healthcare settings and health systems operations, and health professional education.

Underlying the core principles of FCC are the foundational constructs of mutual trust and power-sharing (see Fig. 1). For FCC to occur, the healthcare practitioners must trust in the capabilities, knowledge and worth of the family, and families must trust in the capabilities and intentions of the healthcare team. Healthcare practitioners
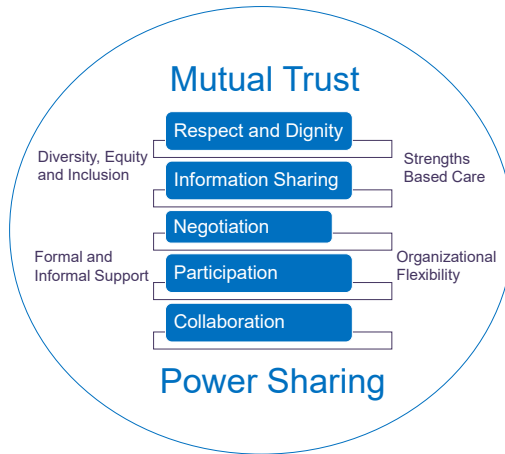
Fig. 1. Family-Centered Care (FCC) ecosystem.[1] The figure depicts the foundational constructs (*large type*), core principles of FCC (*boxes*), and corollary concepts (*regular type*) that comprise the FCC ecosystem. All elements must be addressed for optimal FCC to occur. (*Adapted from* Sigurdson K, Profit J, Dhurjati R, et al. Former NICU Families Describe Gaps in Family-Centered Care. Qual Health Res. 2020;30(12):1861-1875.)

must also be willing to share power and empower families to participate as equal partners in patient care.[15]

Corollary concepts in FCC that are also relevant to quality and safety include the following: strengths-based care; diversity, equity, and inclusion (DEI); formal and informal support; and organizational flexibility. Strengths-based approaches to health care recognize the family as the constant in a child's life and focus first on the positive attributes, capacities, and resources of the infant, family, and community, rather than solely focusing on deficits and needs.[16] DEI are similarly critical concepts, recognizing the preventable yet persistent harmful disparities in health care related to race, ethnicity, gender, and other social identities.[17] Incorporating a DEI focus in delivery of FCC and in FCC QI includes striving for a diverse workforce representative of the population served and training in DEI practices. DEI also pertains to NICU policies that ensure equity in access and delivery of all treatments and services. Formal and informal support refers to the recognition of the importance of providing both formal and structured support to enable FCC as well as encouraging informal peer support among families and with community. Finally, organizational flexibility refers to the concept of adaptable, learning, healthcare systems that can support the tailoring of FCC services to align with the strengths and needs of individual families.[11] FCC approaches that actively incorporate the core principles and corollary concepts create a supportive ecosystem, which then leads to improved quality, safety, and patient/family experience and outcomes of neonatal care (see **Fig. 1**).

FAMILY-CENTERED CARE MODELS AND INTERVENTIONS

Having defined the principles, constructs, and concepts of FCC, the next step in assuring quality and safety is to evaluate the evidence for the various FCC models and intervention bundles. Adoption of evidence-based models of care has the potential to change not only care delivery but also hospital culture.[18] There are several family-centered and parent partnered-care models for the NICU setting supported by research evidence.[19] The models vary in emphasis but all share common elements:

Table 1

Core principles, constructs, and corollary concepts of patient-centered care and family-centered care[11–13]

Foundational Constructs	Mutual trust	Healthcare practitioners need to trust in the capabilities and worth of the family, and families need to trust in the capabilities and intentions of the healthcare practitioners
	Power sharing	Healthcare practitioners must be willing to share power and empower families to participate as equal partners in patient care and decision-making
Core Principles	Respect and dignity	Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care
	Information sharing	Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making
	Negotiation	Healthcare practitioners seek to gain an understanding of the patient and family's perspective, honor the family's right to advocate, explore, rather than explain, differences in perspective so everyone feels heard and validated, promote mutual trust and negotiate differences, which requires flexibility, responsiveness, and compromise
	Participation	Patients and families are encouraged and supported in participating in care and decision-making at the level they choose
	Collaboration	Patients, families, healthcare practitioners, and healthcare leaders collaborate in policy and program development, implementation, and evaluation; in facility design; in professional education; and in research; as well as in the delivery of care
Corollary Concepts	Strengths-based approaches	Healthcare practitioners and health systems recognize the family as the constant in a child's life and focus first on the positive attributes, capacities, and resources of the infant, family and community, rather than solely focusing on deficits and needs
	Diversity, Equity and Inclusion	Healthcare practitioners and health systems recognize the preventable yet persistent harmful disparities in health care related to race, ethnicity, gender, and other social identities
	Formal and informal support	Healthcare providers and health systems provide families with access to formal practical, educational, and emotional support, and encourage informal peer support among families and with community to enable families to participate fully as partners in health care
	Institutional flexibility	The health system works is an adaptable, learning, health systems that can support the tailoring of FCC services to align with the strengths and needs of individual families

providing a supportive environment, clearly defined and collaborative roles and responsibilities for parents, training, and parent-delivered interventions. In addition, there are numerous evidence-based parent-focused and parent-delivered interventions that support or enable FCC. The taxonomy in **Fig. 2** depicts the hierarchy of evidence-based parent support and parent-delivered interventions and the evidence-based parent-partnered care models for NICU FCC.

Family-Centered Models of Care

Many of the models of care, such as Kangaroo Mother Care, Care by Parent and Primary Nursing, have been around for decades and have a solid evidence base, yet have proven difficult to implement sustainably in many settings. Therefore, for the purposes of this review, we will focus on the 2 most recent models, Family Integrated Care (FICare)[20] and Close Collaboration with Parents,[21] which have been designed to address some of the implementation challenges of the prior models while maintaining fidelity to the principles of FCC. These models are briefly described below and in the state of the science and practice in the following section.

Family Integrated Care

In the FICare model (see **Fig. 2**, **Table 2**), parents are welcomed as part of the healthcare team and medical and nursing staff to promote parent involvement toward a level in which parents are supported as primary caregivers. Important to the implementation of FICare is the inclusion and partnership of veteran NICU parents in the core steering group to plan, implement, and sustain the FICare model on the unit. The FICare model has a comprehensive framework of interventions with 4 main pillars: environment; NICU team education and support; parent education/psychological support; and active parent participation/partnership. In this model, the environment is designed or adapted to support 24-hour parental presence/participation. The healthcare team receives training and ongoing support in FCC principles and skills and special needs of NICU families.[22,23] The healthcare team then receives recurring education on the needs of families and provides coaching, education, and mentorship to support parents. Parents are provided group educational sessions as well as individualized bedside teaching. Parents also receive psychosocial support from
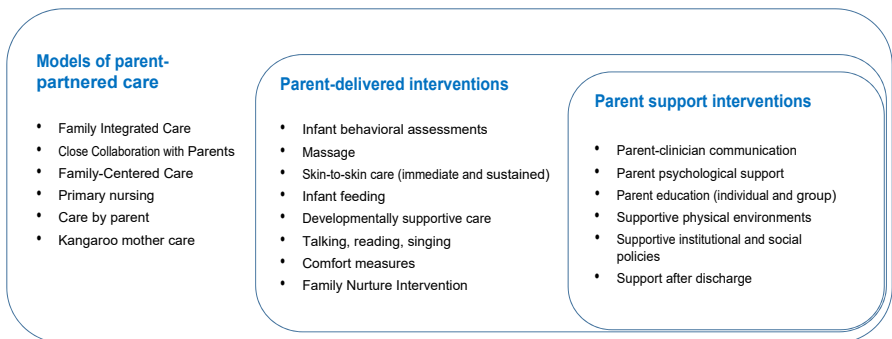

Models of parent-partnered care

- Family Integrated Care
- Close Collaboration with Parents
- Family-Centered Care
- Primary nursing
- Care by parent
- Kangaroo mother care

Parent-delivered interventions

- Infant behavioral assessments
- Massage
- Skin-to-skin care (immediate and sustained)
- Infant feeding
- Developmentally supportive care
- Talking, reading, singing
- Comfort measures
- Family Nurture Intervention

Parent support interventions

- Parent-clinician communication
- Parent psychological support
- Parent education (individual and group)
- Supportive physical environments
- Supportive institutional and social policies
- Support after discharge

Fig. 2. Taxonomy of family-focused or involved NICU interventions and care models. The taxonomy depicts the hierarchy of evidence-based parent support and parent-delivered interventions and the evidence-based parent-partnered care models for NICU FCC. (*Adapted from* Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. Birth Defects Res. 2019;111(15):1044-1059.)

Table 2
Family Integrated Care (FICare) pillars (essential and recommended components)

Environment	NICU Team Education and Support	Parent Education/Psychological Support	Active Parent Participation/ Partnership
Essential			
FICare steering committee comprising parent and multidisciplinary NICU team members			
• Comfortable, semireclining chairs at bedside to support prolonged parent presence and skin-to-skin contact	• NICU leadership support	• Regularly scheduled parent group classes	• Parent participation in baby's direct caregiving
• Dedicated parent room for respite away from but nearby NICU	• FICare nurse champions	• Individual teaching and skills building at bedside	• Parent active involvement in medical rounds and daily care planning
• Food storage and preparation area for parents	• Education on FICare for all team members	• Opportunities for peer-peer support with parent mentors	• Parent tracking progress (baby, their own)
• Place for parents to store coats and personal belongings	• Additional education for nurses emphasizing their role as teacher and coach with parents		
• 24-h NICU open access for parents to be with their babies	• FICare education included in orientation and annual skills updates		
• NICU and hospital policies and services that welcome and support parents			
Suggested			
• Dedicated space for families in patient care area	• Enhanced education on: ○ Developmentally supportive care ○ Trauma-informed care ○ Communication skills	• Parent classes offered evenings and weekends	• Technology support for remote participation in rounds and care planning

Table 2
(*continued*)

Environment	NICU Team Education and Support	Parent Education/Psychological Support	Active Parent Participation/ Partnership
• Single family room NICU	• Parent teaching, coaching, and communication included in NICU team core competencies and performance reviews	• NICU Family Advisory Council	• Technology support for tracking
• Discounted or subsidized food, parking, and transportation between home and hospital		• Stipends or other honoraria for parent mentors	
• Onsite childcare		• Paid parent liaison position	
• Extended paid parental leave for parents of NICU infants		• Technology support for parent education	

Adapted from Franck LS, Waddington C, O'Brien K. Family Integrated Care for Preterm Infants. Crit Care Nurs Clin North Am. 2020;32(2):149-165.

professionals and peer support from former NICU parents. Finally, parents are included on daily rounds and shared decision-making, and they are asked to actively participate in the care for their infant.

Studies have shown that the FICare model in level 2 and level 3 neonatal units across the world is adaptable and associated with improved infant and parent outcomes compared with generic or unstructured FCC implementation.[23] Improved infant outcomes at NICU discharge include higher rates of exclusive breastfeeding; increased weight gain; shorter lengths of stay; and lower infection rates.[24–30] In follow-up studies, preterm infants who were exposed to the FICare model during their NICU stay had more robust self-regulation, fewer challenges with sleep, eating, or communication, and less negative emotionality compared with infants who received NICU FCC.[31–33] Improved parent outcomes for FICare compared with FCC include less stress and improved mental health for mothers and fathers.[34–38] QI and evaluations of FICare indicate that improved infant, parent, and hospital-level outcomes shown in studies are sustained in real-world implementation.[39–42]

Close Collaboration with Parents

The Close Collaboration with Parents model (see **Fig. 2**, **Table 3**) provides education for the whole healthcare team of a neonatal or obstetric unit. By reaching each staff member of the unit, the intervention aims to change the unit's culture to become more family centered. The intervention provides skills for healthcare staff to collaborate with parents and support parenting during the hospital stay. After preparation with the unit leadership, the duration of the training and implementation phase is approximately 1.5 years. The training content includes the following: (1) observations and communication of infant behavior, (2) joint observations of infants with parents, (3) listening to parents' stories about how they become parents for this baby and providing individualized support, and (4) integrating shared decision-making regarding care and discharge planning. The training is integrated into daily practices and supported by reflective discussions. The main implementation strategy is mentoring. The implementation is planned collaboratively with the unit mentors and leaders and adapted to the context.[21]

Close Collaboration with Parents has been shown to improve FCC practices in diverse neonatal units.[43] Nurses reported better mutual trust with parents, better active listening, and shared decision-making skills and emotional support.[44,45] The intervention increased parental presence in the unit and duration of skin-to-skin care.[46] Infant growth was improved in the units that had implemented the Close Collaboration with Parents intervention compared with the units before or without the implementation.[47] Maternal depressive symptoms were decreased at 6 and 24 months after infant's due date.[48,49] The implementation of Close Collaboration with Parents has been more successful in neonatal units that dedicated sufficient time for the training, considered the timing carefully, and had strong support from the leadership and physicians involved.[50]

Family-Centered Care Interventions

Supportive interventions

Within the parent-partnered neonatal care models, or implemented individually, numerous interventions can be provided by NICUs to support FCC. The foundational or most basic of these are the family support interventions (see **Fig. 2**, right panel). These interventions provide the basic and essential services and processes of care to enable FCC to occur. Without these interventions, FCC cannot be implemented with fidelity, and there is risk of bias in access to FCC services, leading to disparities

Table 3
Core elements and implementation process of Close Collaboration with Parents

	Preparation	Training for Unit Leaders and Mentors	Staff Training and Implementation	Sustainability
Target population	Unit leadership	Unit leadership and unit mentors	Whole healthcare team of the unit	Whole healthcare team of the unit
Provider	Training team	Training team	Unit mentors and leadership Support by the training team	Unit staff and leaders Training team
Duration	6–12 mo	18 d per mentor within 3 mo	5 workdays for each staff member within 12–18 mo	Years
Content	Introducing the training program and its outcomes	Education including theory of 4 training phases, bedside practices, and reflective discussions Training about mentoring as facilitation method and reflective practices	E-learning course or manual about the theoretic background, bedside practices related to the content of each phase, and reflections on the practice experiences	E-learning course or manual about the theoretic background, bedside practices related to the content of each phase, and reflections on the practice experiences
Strategies	Negotiating about the commitment to the implementation Visit to the NICU in the training hospital to familiarize with the FCC culture Meetings	Lectures Bedside practices with experienced mentors Reflections with expert mentors	E-learning course or manual including theory, description, and demonstrations of the practices, and reflective questions Bedside practices with unit mentors Reflective discussions with unit mentors about experiences, innovations, and future needs for practice changes	Unit specific strategies for example, planning how to integrate the intervention in staff orientation Yearly seminars for networking organized by the training team

		Reflections with the whole staff of the unit and leadership Monitoring by the leadership
Evaluation	Reviewing unit plan	Following the fidelity by documentation of the realization of practices Following e-learning use by user statistics Reviewing the adherence of practice content The unit reports their implementation process and innovated practice changes

in service access, quality, and outcomes.[51] Without these foundational interventions, the other FCC interventions or models will not be effective or sustained.

Parent-Delivered Interventions

Parent-delivered interventions (see **Fig. 2**, middle panel) are specific techniques for NICU care delivery that can be performed with parents, once they have been trained. In many instances, the training can be brief and performed at the bedside. Most of the interventions, such as developmentally supportive care, require staff training and support for ongoing competency for the interventions to be properly implemented with parents.[52] All of the parent-delivered interventions listed in **Fig. 2** have a strong evidence base and should be practiced within any model of FCC.

CURRENT STATE OF FAMILY-STAFF PARTNERSHIP AND FAMILY-CENTERED CARE PRACTICE

Most NICUs purport to provide FCC. However, consistent implementation, ability to meet minimal requirements, and sustained fidelity have proven to be difficult and practice varies greatly among and within units and regions.[51,53–55] For example, in a large European multicenter qualitative study with NICU healthcare professionals, despite implementation of FICare principles in all the units, mother-infant separation was still very common.[55]

Including parents as primary caregivers requires a profound mind shift from professional-centered care and hierarchical hospital culture to ways of working in partnership with parents in all aspects of care, built on mutual trust and power sharing (see **Fig. 1**). The coronavirus disease 2019 (COVID-19)-pandemic has highlighted the relationship between deimplementation of FCC, increased parent-infant separation and disempowerment in infant care, and associated detrimental outcomes for patients and their families.[56,57]

One necessary condition for optimal FCC is unlimited access for parents to their infant. In another large European study, mothers spent approximately 8 hours and fathers 4 hours per day in the unit. Presence varied across units, with parents in some units staying less than an hour, and in others, they were present almost all the time.[58] Design features of NICUs such as single-family rooms, parent bed next to the infant, showers, and cooking facilities encourage and enable family presence.[58–62] However, the cultural and attitudinal environment of FCC are more important than the physical environment, and FCC can be successfully implemented even in crowded NICUs in older facilities if the clinical teams are committed and willing to invest their efforts in developing creative solutions.[55,63]

Another FCC necessity that is frequently lacking is provision of psychological support to parents.[64,65] Despite consensus that postpartum psychosocial care is essential, routine mental health care of primary caregivers in the NICU remains inadequate. In a US national study, less than half of the NICUs surveyed routinely screened for perinatal mental health problems or provided caregivers with psychoeducation about mental health self-care.[65] Neonatal staff are aware of this shortcoming and wish for comprehensive training on how to support parents.

QUALITY IMPROVEMENT STRATEGIES FOR FAMILY-CENTERED CARE

Evidence-based QI methods currently used to improve a wide range of NICU processes and outcomes are also useful for FCC QI. In fact, FCC QI can be accomplished with existing QI infrastructure (eg, roles and responsibilities, tools, communication strategies).[66] Similar to QI efforts targeting other clinical processes and outcomes,

successful FCC QI requires building a cohesive team which can make decisions, identifying clear goals and achievable intermediate targets, selecting the appropriate assessments (measurement tools), designing, testing, and implementing interventions to improve performance, and explicitly planning for sustainability.[67] Perhaps, even more important for FCC QI than other NICU QI efforts (where it is also important), NICU families *must* be part of the QI core team and active in all aspects of the QI process, rather than being engaged solely for postimplementation consultation. With respect to measurement, FCC-specific assessments must be selected, adapted, or developed to monitor the agreed priority QI goals. Delivery of family support interventions and parent-delivered interventions must be assessed. Communication with families, support of staff and engagement with parent-led organizations are other areas where the QI focus should be tailored. Below, each of the aspects of FCC QI is discussed in more detail.

Building the Family-Centered Care Quality Improvement Team

Former NICU families should be included in the QI team along with representatives from all the main professional groups and decision-makers involved in providing care to neonates. In preparing this review, we spoke with family representatives involved in NICU QI, and they provided practical tips for engaging and preparing families to serve as NICU QI partners (Table 4). There should ideally be more than one parent on the committee so that they are not the "only one" on the committee. It is common to advise parents to reengage in NICU activities once their child has been home for at least a year after discharge. This is because the first year at home with an infant who has spent time in a NICU, with possible subsequent health issues and demands, can be very challenging for families. NICU families need training and ongoing support to prepare and engage in NICU FCC QI.

Useful resources for preparing to engage families in QI work include the Agency for Healthcare Quality evidence-based guidelines toolkit for QI partnership among patients, families, and healthcare professionals.[68] Ultimately, family participation enhances all QI work but for FCC QI, it is essential. The following quotes illustrate the importance of including parents in all NICU QI activities:

"As a parent, I have had the opportunity to collaborate on several QI projects in the NICU where my son was born. I can humbly attest to the value that is brought to the table when the perspective of a parent is shared. In meetings, I have shared my own thoughts and experiences or experiences of other parents on aspects of the project at hand. [I have] come to appreciate that often the ideas, barriers and challenges that I raise, despite best efforts, have not been thought of or realized by the medical team. My participation in QI work is gratifying and rewarding, and I am always thanked by the team for my valued contributions."

Another parent provided a specific example of a practice change resulting from their input:

"We bring a different kind of expertise. I feel valued when I know I've been heard. I've seen my ideas coming to life and this gives me the courage to keep going. For example, my hospital had a check list of practices when the baby was born and the list had a box: 'update the second parent.' I asked about the birthing parent as updating only one parent is not enough. Today, the check list has a box to 'update both parents'."

Assessing Family-Centered Care and Family-Staff Partnership Quality

Measurement and ongoing monitoring are essential components of any QI program. For FCC, (re)assessment must occur at the level of the patient, family, healthcare

Table 4
Tips for engaging and preparing families to serve as neonatal intensive care unit quality improvement partners

Topic	Advice from Parents
Parents' motivation to contribute to QI	*"It's been 7 years since I came back to the same NICU where my baby was born. I came back because I was grateful for the care team, but I soon realized that besides being grateful I could advocate and be a voice of the families."*
	"I like QI because you affect change on a policy level, and they happen.
	The knowledge and connections gained from QI help being an advocate elsewhere."
	"It's hard work and the pandemic made it harder. I am privileged as I have an emotionally and financially supportive partner, but the possibility of the impact I can make in changing the world is more than the tech job my husband does."
Preparing families and staff for collaborating on NICU QI issues	*"Going back to the hospital either as a volunteer or paid position can be very hard for parents who had premature or sick babies admitted in the NICU. Besides the triggers, such as alarms, and the smell of soap, parent-partners learn things that can be emotionally difficult. Helpful framing for this could be: If we knew then what we know now it feels like your story could have changed, but we can't change the past."*
	"The NICU staff need to be aware of the complicated emotions for a parent to have this role. We were not trained for this, parents are allowed to cry, and it doesn't mean that we can't do the job. It just means that we bring out feelings to this professional space. [It helps if] "triggering events" can be announced before they occur (ie, *Picture of deceased baby to be shown)."*
	"I was invited to review a new protocol for the NICU where my son was born. I was given a warning that the material could be hard to read as they were changing protocols from the time of birth (the golden hour) to improve outcomes related to the preterm brain. My task was to make sure the language used to inform new families in the NICU was accessible and in lay language. It was emotionally difficult to review and re-word it, but with enough support I got through the document with the QI nurse to create a one-page document that was given to parents informing minimal handling for 72-hours and how they could still participate in the care of their baby."

Table 4 (continued)	
Topic	**Advice from Parents**
	"I felt overwhelmed for first year due to medical jargon. Committees where quite technical and some family participation was really not necessary. Over time found balance to be able to attend when input is valuable and not attend when not needed."
	"When you get involved with advocacy there is a learning curve, and as you go from project to project you are more able to step away from your personal experience and allow it to inform your involvement as opposed to it being your involvement."
	"Provide background – explain the purpose of the committee. Language/training would be helpful but doesn't exist – most people don't know what a QI project is."
Disparities when parents are volunteers and/or only parent and all other participants are paid staff	*"Being the only unpaid person makes speaking up challenging".*
	"Need more than the experience from one parent – need other views, experience. In order to create policies or trainings. Diversity of opinions is important to be mindful of, but not possible to be 100% inclusive."
	"I felt dissatisfied with the type of family input in some projects, as it did not reflect the wide range of experiences that many families have. You need a great deal of time and to be of a certain economic status to be able to take 4 days out of your life and donate that time when you have a child with complex health needs."
Parents as paid members of staff	*"Being a paid member allowed for more collaboration – necessary unless you hold the meetings at 9pm at night or find other ways for the member to become involved – Presence/Access/Respect all need to be in place."*
Parent impact on FCC and QI	*"There were occasions when my own words were used to create the visual flow of needs and presented on posters at conferences. Also was part of a video that was self-scripted and created and is being used. This is the signal that it's not just lip service –[I] felt listened to."*

team, and healthcare organization. Although there are no universally agreed standards or metrics for FCC, there are several useful assessment tools currently available, and more are undergoing testing. The Donabedian Structure-Process-Outcome framework[69,70] is helpful in organizing a comprehensive FCC QI assessment program (**Fig. 3**). Structural assessment includes measures of NICU and hospital-level resources and leadership necessary for FCC to thrive.[71] Process measures include measures of
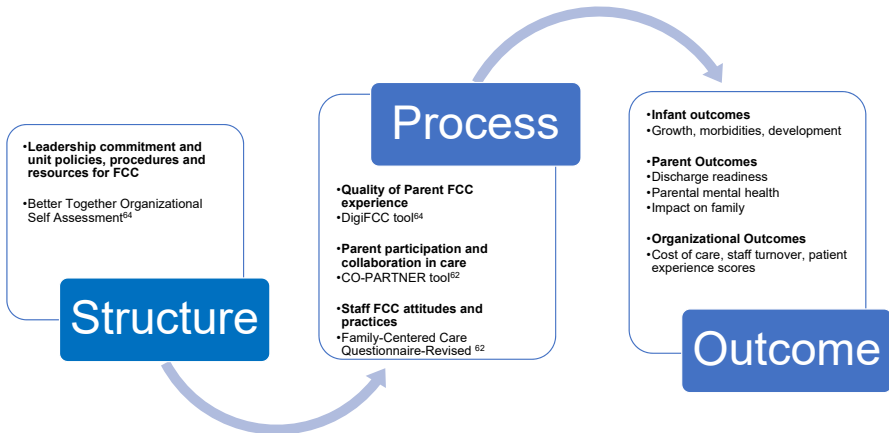
Fig. 3. Potential QI measures for FCC structure, process, and outcomes. This figure shows some potential evidence-informed QI measures for FCC structural elements, processes, and outcomes.

the completion and quality of processes that are essential to FCC implementation, including delivery of family support and parent-delivered interventions; staff knowledge and communication skills competence; interpersonal teamwork and unit culture climate;[72–75] parental presence and participation in caregiving; and shared decision-making, education, and skills.[76] Outcome measures include common infant, family, or organizational outcomes that may be sensitive to FCC interventions. Infant outcomes may include human milk intake, nosocomial infection or other adverse event rates, length of stay, growth, and improved cognitive and motor development or quality of life. Family outcomes may include measures of parental mental health and well-being. Organizational outcomes may include cost of care, adverse event rates, parent experience of care and organizational culture. **Fig. 3** shows some potential QI measures for FCC structural elements, processes, and outcomes. Future study is currently under-way in developing core outcome sets and minimal reporting measures for FCC research, which could also be useful for QI in the NICU.[77] Although common metrics are important, the FCC QI team should establish measures that are locally relevant after consultation with all relevant stakeholders to identify and prioritize areas for improvement.

DEI in FCC QI is of particular importance to ensure NICU care quality. Therefore, FCC assessment should include measurement and analysis of structural, interpersonal and intrapersonal barriers to FCC to that specific context and measures should be stratified based on potential inequities. For example, if audits data reveals that parental participation in NICU rounds varies by demographics (eg, race or ethnicity, language spoken at home, education, or employment status), or if there is a difference in the level of parental participation in caregiving related to the concordance between staff role and demographics, then further analysis is warranted to uncover and address the barriers to improve parental participation. These barriers could for instance include the following: unavailability of interpreters or lack of childcare for siblings (structural); unwelcoming verbal or nonverbal communication by NICU staff to families (interpersonal); and extreme parental distress or lack of knowledge about their important role in clinical rounds (intrapersonal).[51] Only by measuring indicators of FCC DEI, can barriers be identified and addressed.

Creating Culture Change

One of the common themes among units that successfully implement and sustain FCC is a nurturing culture.[42,50,55] Culture is described as jointly held characteristics, values, thinking, and behaviors of people in workplaces and organizations. Units that had a comprehensive and sustained FCC approach, commonly included parents as members of hospital or unit boards, directly influencing management and decisions and regarded them as equal partners.[50,55]

Unfortunately, as the following quote illustrates, some units may have to commit to major culture change to transform their current practices to be more family-centered, as illustrated by this quote from a father:

"One nurse told me that when the babies are very sick, parents cannot hold them. I wish I knew what I know today; that I could have asked, that I could have held her, that I could comfort her when she was in pain. I learned years later that parents should be involved and care for their babies while they are in the NICU. This was not my experience and I still feel angry about this."

Changing hospital culture can be very difficult,[70] and approaches to change have been previously proposed,[18] and success stories have been shared.[39–42,50,78] First, attention must be given to how care is delivered at the bedside, listening to parents and staff. Second, all meaningful improvement should be local and tailored to the setting. Standardization and generic strategies are important starting points but may fail when they do not allow for tailoring to individual circumstances. Third, daily successes in the workplace must also be recognized, appreciating how the clinical team successfully handle dynamic situations, highlighting the factors that promote successful delivery of FCC. Successful cases of culture change usually share 4 common characteristics. They always start with the patient at the center of any proposed change; begin with small-scale initiatives and buildup; convert data and information into intelligence shared with appropriate decision makers; and focus on collaboration as the foundation of productive change rather than the lone hero model.[71] Leaders of successful QI focus on helping the team to create a new mental model of their collective work, appreciating the complexity of care systems and understanding that change is always unpredictable and takes time and sustained effort.[18]

Here is a quote on how one NICU medical leader described the culture change:

"Parents are doing this job for a reason. They are unique. They've been through the NICU journey and now they want to give back. We were pioneers here bringing parents voices in the entire QI process. It was a cultural shift so everyone had to become sensitive to the presence of parents. Parents in QI receive peer-to-peer support. They are all very involved in QI and their voices are quite powerful. We would [now] not consider not having a parent in a QI committee. We see them as colleagues."

Supporting Staff to Deliver High-Quality Family-Centered Care

Staff motivation, competence, and multiprofessional collaboration are essential to deliver high-quality FCC. To sustain and implement high-quality FCC with minimal separation between parents and infants, the overarching core values in successful units in Europe were the shared value to promote closeness between parents and their infants and common shared commitment to *collaboration* (between healthcare professionals, management, and parents), *capacities* (physical space, investment in staffing), and *coaching* (education of staff and parents).[55]

When significant professional staff shortages and high turnover, particularly among nurses, are present, hospital leaders have a nonevidence-based tendency to limit family presence as a means of reducing workload. However, as was poignantly learned

during the COVID-19 pandemic, curtailing or eliminating family presence and FCC was harmful not only to quality and safety of patient care but also further eroded job satisfaction and caused moral distress for healthcare professionals.[79,80]

Addressing these challenges requires leadership and consistent commitment to daily practice in accordance with the principles of FCC. One US study showed that although FCC practices were overall strongly endorsed; there were indications of lack of knowledge or valuing of several key dimensions of FCC, particularly of family partnership at the organizational level and variability across neonatal units and with years of experience.[51,77] Initial and ongoing training and support of the whole healthcare staff is essential and should be treated with the same dedication and recurrence as advanced life support training. Frontline staff and parents should be consulted as to specific areas that need additional QI efforts. Common staff recommendations for the improvement of FCC included language translation and interpreter services for families; improving communication between staff and families; staffing and workflow; team, culture, and leadership; education; and NICU environment. Previous research has shown the need for greater resources for staffing, education, and environmental supports, as well as team culture and staff–parent communications.[51]

Professional and Parent Organization Engagement

FCC QI efforts can be advanced through engagement of parent-led organizations, which can assist with evaluation of the state of the science, building consensus on minimal standards, quality assessment metrics, and benchmarking. These outcomes in turn can be used to negotiate for necessary resources with healthcare administrators. Parent-led organizations can play a critically important role in providing support for families to fully engage in their infant's care and in NICU FCC QI efforts. Some organizations provide practical support to enable parents to stay in hospital, such as access to transportation, food, or support in finding accommodation near the hospital. Others provide education for families and healthcare professionals, deliver mental health programs, and organize peer support groups and training to hospitals to create peer support groups. Representatives from parent-led organizations can support FCC QI by referring potential parent members who have an interest in serving on a QI committee, providing training for parents and staff and facilitating consultations with former NICU families for the assessment of longer term outcomes.

Partnering with policy makers is a final essential component of FCC QI work to address the systemic barriers to FCC identified through as part of FCC QI initiatives. For example, lack of universal paid parental leave and reliable, quality childcare are 2 policy-level barriers to parental partnership in their infant's NICU care. Creating more equity in NICU FCC will require partnership and advocacy on these issues at local, regional, and national levels.

SUMMARY

Evidence abounds that implementation of FCC is beneficial to the health and safety of infants and families in neonatal care settings. Nevertheless, the systematic uptake of interventions required for high-quality and sustainable FCC remains challenging and suboptimal. Two FCC models with strong research evidence are FICare and Close Collaboration with parents. Well-established QI methodology can be applied to FCC QI and must include authentic partnership with neonatal families in FCC QI planning and activities. To further optimize NICU care, families should be included as essential and irreplaceable team members in all NICU QI activities, not only FCC QI activities.

Greater investment in FCC QI is needed to maximize the promise of FCC and ensure all families have equitable access to the necessary support and partnership with healthcare practitioners, and infants can reach their full health and developmental potential.

BEST PRACTICES

- Include former NICU families in the QI team along with representatives from all the main professional groups and decision-makers involved in providing care to neonates.
- Engage with parent-led organizations to expand support for NICU families and as partners in QI.
- Provide training and support for NICU family QI partners, and training for staff on how to engage families in QI.
- Consider evidence-based FCC models, and NICU culture change that might be needed to improve delivery of FCC.
- Support NICU staff to deliver high-quality FCC.
- Incorporate FCC structure, process and outcome metrics into NICU QI.

DECLARATION OF INTERESTS

The authors have nothing to disclose.

REFERENCES

1. North K, Whelan R, Folger LV, et al. Family involvement in the routine care of hospitalized preterm or low birth weight infants: a systematic review and meta-analysis. Pediatrics 2022;150(Suppl 1). e2022057092O.
2. UN general assembly, convention on the rights of the child, 20 November 1989, united Nations, treaty series, vol. 1577, p. 3. Available at: https://www.refworld.org/docid/3ae6b38f0.html. Accessed 29 October 2022.
3. EFCNI, Pallás-Alonso C, Westrup B, Kuhn P, et al. European standards of care for newborn health: parental involvement. 2022. Available at: https://newborn-health-standards.org/standards/standards-english/infant-family-centred-developmental-care/parental-involvement/. Accessed 29 October 2022.
4. EFCNI, Moen A, Hallberg B, et al. European Standards of Care for Newborn Health: core principles of NICU design to promote family-centred care. 2018. Available at: https://newborn-health-standards.org/standards/standards-english/nicu-design/core-principles-of-nicu-design-to-promote-family-centred-care/. Accessed October 29, 2022.
5. Kokorelias KM, Gignac MAM, Naglie G, et al. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res 2019;19(1):564.
6. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med 2017;45(1):103–28.
7. Park M, Giap TT, Lee M, et al. Patient- and family-centered care interventions for improving the quality of health care: a review of systematic reviews. Int J Nurs Stud 2018;87:69–83. Epub 2018 Jul 26. PMID: 30056169.
8. Epstein RM, Fiscella K, Lesser CS, et al. Why the nation needs a policy push on patient-centered health care. Health Aff 2010;29(8):1489–95. PMID: 20679652.

9. Kelleher K, Hardy RY. Coming full circle (to hard questions): patient- and family-centered care in the hospital context. Fam Syst Health 2020;38(2):209–11.

10. The Health Foundation. Quality improvement made simple: what everyone should know about health care quality improvement. 2021. Available at: https://doi.org/10.37829/HF-2021-I05. Accessed 29 October 2022.

11. World Health Organization. WHO global strategy on integrated people-centred health services 2016-2026. Sixty-Ninth World Health Assembly, A69/39 Provisional agenda item 16.1. 2016. Available at: https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1. Accessed 29 October 2022.

12. Committee on hospital care and institute for patient and family-centered care; patient- and family-centered care and the pediatrician's role. An Pediatr 2012;129(2):394–404.

13. Johnson BH, Abraham MR. Partnering with patients, residents, and families: a resource for leaders of hospitals, ambulatory care settings, and long-term care communities. (2012). Bethesda, MD: institute for Patient- and Family-Centered Care. Available at: https://ipfcc.org/about/pfcc.html. Accessed 29 October 2022.

14. Kaslow NJ, Dunn SE, Henry T, et al. Collaborative patient- and family-centered care for hospitalized individuals: best practices for hospitalist care teams. Fam Syst Health 2020;38(2):200–8.

15. Sigurdson K, Profit J, Dhurjati R, et al. Former NICU families describe gaps in family-centered care. Qual Health Res 2020;30(12):1861–75.

16. Peyton C, Sukal Moulton T, Carroll AJ, et al. Starting at birth: an integrative, state-of-the-science framework for optimizing infant Neuromotor health. Front Pediatr 2022;9:787196.

17. Parker MG, Hwang SS. Quality improvement approaches to reduce racial/ethnic disparities in the neonatal intensive care unit. Semin Perinatol 2021;45(4):151412.

18. Braithwaite J. Changing how we think about healthcare improvement. BMJ 2018;361:k2014.

19. Franck LS, O'Brien K. The evolution of family-centered care: from supporting parent-delivered interventions to a model of family integrated care. Birth Defects Res 2019;111(15):1044–59.

20. Franck LS, Waddington C, O'Brien K. Family integrated care for preterm infants. Crit Care Nurs Clin 2020;32(2):149–65.

21. Ahlqvist-Björkroth S, Boukydis Z, Axelin AM, et al. Close Collaboration with Parents™ intervention to improve parents' psychological well-being and child development: description of the intervention and study protocol. Behav Brain Res 2017;325(Pt B):303–10.

22. Family integrated care. Available at: http://familyintegratedcare.com. Accessed 29 October 2022.

23. British perinatal association. Family integrated care: a framework for practice. 2021. Available at: https://www.bapm.org/resources/ficare-framework-for-practice.

24. O'Brien K, Bracht M, Macdonell K, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth 2013;13(Suppl 1):S12.

25. O'Brien K, Robson K, Bracht M, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health 2018;2(4):245–54 [published correction appears in Lancet Child Adolesc Health. 2018;2(8):e20].

26. Murphy M, Shah V, Benzies K. Effectiveness of alberta family-integrated care on neonatal outcomes: a cluster randomized controlled trial. J Clin Med 2021;10(24): 5871.

27. He SW, Xiong YE, Zhu LH, et al. Impact of family integrated care on infants' clinical outcomes in two children's hospitals in China: a pre-post intervention study. Ital J Pediatr 2018;44(1):65.

28. van Veenendaal NR, van der Schoor SRD, Heideman WH, et al. Family integrated care in single family rooms for preterm infants and late-onset sepsis: a retrospective study and mediation analysis. Pediatr Res 2020;88(4):593–600.

29. Chen H, Dong L. The effect of family integrated care on the prognosis of premature infants. BMC Pediatr 2022;22(1):668.

30. Franck LS, Gay CL, Hoffmann TJ, et al. Neonatal outcomes from a quasi-experimental clinical trial of Family Integrated Care versus Family-Centered Care for preterm infants in U.S. NICUs. BMC Pediatr 2022;22(1):674.

31. Synnes AR, Petrie J, Grunau RE, et al. Family integrated care: very preterm neurodevelopmental outcomes at 18 months. Arch Dis Child Fetal Neonatal Ed 2022; 107(1):76–81.

32. Church PT, Grunau RE, Mirea L, et al. Family Integrated Care (FICare): positive impact on behavioural outcomes at 18 months. Early Hum Dev 2020;151:105196.

33. Moe AM, Kurilova J, Afzal AR, et al. Effects of alberta family integrated care (FICare) on preterm infant development: two studies at 2 Months and between 6 and 24 Months corrected age. J Clin Med 2022;11(6):1684.

34. Cheng C, Franck LS, Ye XY, et al. Evaluating the effect of Family Integrated Care on maternal stress and anxiety in neonatal intensive care units. J Reprod Infant Psychol 2021;39(2):166–79.

35. Dien R, Benzies KM, Zanoni P, et al. Alberta family integrated Care™ and standard care: a qualitative study of mothers' experiences of their journeying to home from the neonatal intensive care unit. Glob Qual Nurs Res 2022;9. 23333936221097113.

36. Mclean MA, Scoten OC, Yu W, et al. Lower maternal chronic physiological stress and better child behavior at 18 Months: follow-up of a cluster randomized trial of neonatal intensive care unit family integrated care. J Pediatr 2022;243:107–15.e4.

37. van Veenendaal NR, van der Schoor SRD, Broekman BFP, et al. Association of a family integrated care model with paternal mental health outcomes during neonatal hospitalization. JAMA Netw Open 2022;5(1):e2144720.

38. van Veenendaal NR, van Kempen AAMW, Broekman BFP, et al. Association of a zero-separation neonatal care model with stress in mothers of preterm infants. JAMA Netw Open 2022;5(3):e224514.

39. Banerjee J, Aloysius A, Mitchell K, et al. Improving infant outcomes through implementation of a family integrated care bundle including a parent supporting mobile application. Arch Dis Child Fetal Neonatal Ed 2020;105(2):172–7.

40. Moreno-Sanz B, Montes MT, Antón M, et al. Scaling up the family integrated care model in a level IIIC neonatal intensive care unit: a systematic approach to the methods and effort taken for implementation. Front Pediatr 2021;9:682097.

41. Zanoni P, Scime NV, Benzies K, et al. Alberta FICare in Level II NICU Study Team; Alberta FICare™ in Level II NICU Study Team. Facilitators and barriers to implementation of Alberta family integrated care (FICare) in level II neonatal intensive care units: a qualitative process evaluation substudy of a multicentre cluster-randomised controlled trial using the consolidated framework for implementation research. BMJ Open 2021;11(10):e054938.

42. Patel N, Ballantyne A, Bowker G, et al, Helping Us Grow Group (HUGG). Family Integrated Care: changing the culture in the neonatal unit. Arch Dis Child 2018; 103(5):415–9.

43. Toivonen M, Lehtonen L, Löyttyniemi E, et al. Close Collaboration with Parents intervention improves family-centered care in different neonatal unit contexts: a pre-post study. Pediatr Res 2020;88(3):421–8.

44. Axelin A, Ahlqvist-Björkroth S, Kauppila W, et al. Nurses' perspectives on the close collaboration with parents training program in the NICU. MCN Am J Matern/Child Nurs 2014;39(4):260–8.

45. Toivonen M, Lehtonen L, Ahlqvist-Björkroth S, et al. Effects of the close collaboration with parents intervention on the quality of family-centered care in NICUs [published online ahead of print, 2021 sep 30]. Adv Neonatal Care 2021. https://doi.org/10.1097/ANC.0000000000000953.

46. He FB, Axelin A, Ahlqvist-Björkroth S, et al. Effectiveness of the close collaboration with parents intervention on parent-infant closeness in NICU. BMC Pediatr 2021;21(1):28.

47. Itoshima R, Helenius K, Ahlqvist-Björkroth S, Axelin A, Lehtonen L. Effects of Close Collaboration with Parents intervention on length of stay and growth in preterm infants: a Finnish register study (under review).

48. Ahlqvist-Björkroth S, Axelin A, Korja R, et al. An educational intervention for NICU staff decreased maternal postpartum depression. Pediatr Res 2019;85(7):982–6.

49. Ahlqvist-Björkroth S, Axelin A, Setänen S, et al. Fewer maternal depression symptoms after the Close Collaboration with Parents intervention: two-year follow-up. Acta Paediatr 2022;111(6):1160–6.

50. Toivonen M, Lehtonen L, Ahlqvist-Björkroth S, et al. Key factors supporting implementation of A training program for neonatal family- centered care - a qualitative study. BMC Health Serv Res 2019;19(1):394.

51. Franck LS, Bisgaard R, Cormier DM, et al. Improving family-centered care for infants in neonatal intensive care units: recommendations from frontline healthcare professionals. Adv Neonatal Care 2022;22(1):79–86.

52. Family and infant neurodevelopmental education (FINE). Available at: https://www.finetraininguk.com. Accessed 29 October 2022.

53. Dharmarajah K, Seager E, Deierl A, et al. Mapping family integrated care practices in the neonatal units across the UK. Arch Dis Child Fetal Neonatal Ed 2020;105:F111–2.

54. Reid S, Bredemeyer S, Chiarella M. Perceptions of parents and healthcare professionals on family centred care in Australian neonatal units. J Neonatal Nurs 2022 (in press).

55. van Veenendaal NR, Labrie NHM, Mader S, et al. An international study on implementation and facilitators and barriers for parent-infant closeness in neonatal units. Pediatr Investig 2022;6(3):179–88.

56. van Veenendaal NR, Deierl A, Bacchini F, et al. International Steering Committee for Family Integrated Care. Supporting parents as essential care partners in neonatal units during the SARS-CoV-2 pandemic. Acta Paediatr 2021;110(7): 2008–22.

57. Kostenzer J, Zimmermann LJI, Mader S, EFCNI COVID-19 Zero Separation Collaborative Group. Zero separation: infant and family-centred developmental care in times of COVID-19. Lancet Child Adolesc Health 2022;6(1):7–8.

58. Raiskila S, Axelin A, Toome L, et al. Parents' presence and parent-infant closeness in 11 neonatal intensive care units in six European countries vary between and within the countries. Acta Paediatr 2017;106(6):878–88.

59. van Veenendaal NR, Heideman WH, Limpens J, et al. Hospitalising preterm infants in single family rooms versus open bay units: a systematic review and meta-analysis. Lancet Child Adolesc Health 2019;3(3):147–57.

60. van Veenendaal NR, van Kempen AAMW, Franck LS, et al. Hospitalising preterm infants in single family rooms versus open bay units: a systematic review and meta-analysis of impact on parents. EClinicalMedicine 2020;23:100388.

61. Axelin A, Feeley N, Campbell-Yeo M, et al. Symptoms of depression in parents after discharge from NICU associated with family-centred care. J Adv Nurs 2022;78(6):1676–87.

62. Lehtonen L, Lilliesköld S, De Coen K, et al. Parent-infant closeness after preterm birth and depressive symptoms: a longitudinal study. Front Psychol 2022;13:906531.

63. O'Brien K, Bracht M, Macdonell K, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth 2013;13(Suppl 1):S12.

64. Separation and Closeness Experiences in Neonatal Environment (SCENE) research group. Parent and nurse perceptions on the quality of family-centred care in 11 European NICUs [published correction appears in Aust Crit Care. 2017 Jan;30(1):53-54]. Aust Crit Care 2016;29(4):201–9.

65. Bloyd C, Murthy S, Song C, et al. National cross-sectional study of mental health screening practices for primary caregivers of NICU infants. Children 2022;9(6):793.

66. Profit J, Gould JB, Peña MM, et al. Improving the quality, safety, and equity of neonatal intensive care for infants and families. In Fannaroff A and Martin R Neonatal Perinatal Medicine, 12th (in press).

67. Centers for Disease Control and Prevention. Applying the knowledge to action (K2A) framework: questions to guide planning. Atlanta, GA: Centers for Disease Control and Prevention, US Dept of Health and Human Services; 2014.

68. Agency for Healthcare Quality. Evidence-based guidelines toolkit for QI partnership among patients, families, and health professionals. Available at: https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/index.html. Accessed 29 October 2022.

69. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12): 1743–8.

70. McDonald KM, Sundaram V, Bravata DM, et al. Closing the quality gap: a critical analysis of quality improvement strategies, vol. 7. Rockville (MD): Agency for Healthcare Research and Quality (US); 2007. Care Coordination.

71. Braithwaite J, Herkes J, Ludlow K, et al. Association between organisational and workplace cultures, and patient outcomes: systematic review. BMJ Open 2017; 7(11):e017708.

72. Institute for patient and family centered care. Better together: partnering with families in hospitals. Organizational self assessment. Available at: https://www.ipfcc.org/bestpractices/IPFCC_Better_Together_Self_Assessment_June_2021.pdf. Accessed 29 October 2022.

73. Kainiemi E, Flacking R, Lehtonen L, et al. Psychometric properties of an instrument to measure the quality of family-centered care in NICUs. J Obstet Gynecol Neonatal Nurs 2022;51(4):461–72.

74. Bruce B, Ritchie J. Nurses' practices and perceptions of family-centered care. J Pediatr Nurs 1997;12(4):214–22.

75. van Veenendaal NR, Auxier JN, van der Schoor SRD, et al. Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. PLoS One 2021;16(6):e0252074.

76. Development of a COS for family interventions in the NICU. COMET Initiative. Available at: https://comet-initiative.org/Studies/Details/1925 [Accessed 29 October 2022.

77. Franck LS, Cormier DM, Hutchison J, et al. A multisite survey of NICU healthcare professionals' perceptions about family-centered care. Adv Neonatal Care 2021; 21(3):205–13.

78. Braithwaite J, Mannion R, Matsuyama Y, et al. Accomplishing reform: successful case studies drawn from the health systems of 60 countries. Int J Qual Health Care 2017;29(6):880–6.

79. Semaan A, Audet C, Huysmans E, et al. Voices from the frontline: findings from a thematic analysis of a rapid online global survey of maternal and newborn health professionals facing the COVID-19 pandemic. BMJ global health 2020;5(6): e002967.

80. Bainter J, Fry M, Miller B, et al. Family presence in the NICU: constraints and opportunities in the COVID-19 Era. Pediatr Nurs 2020;46:256.