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The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care

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Abstract

There is increasing recognition that parents play a critical role in promoting the health outcomes of low birthweight and preterm infants. Despite a large body of literature on interventions and models to support family engagement in infant care, parent involvement in the delivery of care for such infants is still restricted in many neonatal intensive care units (NICUs). In this article, we propose a taxonomy for classifying parent-focused NICU interventions and parent-partnered care models to aid researchers, clinical teams, and health systems to evaluate existing and future approaches to care. The proposed framework has three levels: interventions to support parents, parent-delivered interventions, and multidimensional models of NICU care that explicitly incorporate parents and partners in the care of their preterm or low birthweight infant. We briefly review the available evidence for interventions at each level and highlight the strong level of research evidence to support the parent-delivered intervention of skin-to-skin contact (also known as the Kangaroo Care position) and for the Kangaroo mother care and family integrated care models of NICU care. We suggest directions for future research and model implementation to improve and scale-up parent partnership in the care of NICU infants.

KEYWORDS

family centered care, family integrated care, Kangaroo mother care, neonatal intensive care unit, parents, preterm infants, skin-to-skin care, skin-to-skin contact

1 | INTRODUCTION

Before the development of hospital-based perinatal care, infants were born at home and cared for by their parents and midwives and the survival of preterm infants was unpredictable. Over the last half of the 20th century, the location of most births began to shift from home to hospital setting. With advances in technology that enabled the survival of sicker and smaller infants, the care became more medicalized and was provided in an even more specialized neonatal intensive care unit (NICU). The ability of parents to engage in the care of their infant was dramatically restricted, with almost all caregiving and decision-making being the responsibility of the professional healthcare team (Gooding et al., 2011).

Over time, there has been a reengagement with parents in newborn care, with increasing recognition of the critical role that parents play in promoting the health outcomes of ill preterm infants both in hospital and beyond. The first evidence of the effectiveness of alternate models of care for preterm and low birthweight infants which engaged parents as partners in care was published over 40 years ago. In 1978, Kangaroo mother care (KMC) was presented as a revolutionary new model of care for preterm infants in Bogota, Colombia,

where infants were dying at high rates from infection and hypothermia due to shortages of staff and equipment (Whitelaw & Sleath, 1985). In 1979, in Tallinn Estonia, born out of a shortage of nursing staff, a model of "Humane Care" was developed (Levin, 1994). The principle components of the KMC and Humane care models are close to 24-hr care by the mother (with the mother's chest as the primary place of care for the KMC model), with assistance from nurses, promoting exclusive breast feeding whenever possible, minimal use of technology, and little contact between the baby and medical and nursing staff. Strong research evidence has also been produced regarding the benefits of specific parent delivered interventions for infants in the NICU setting. For example, provision of breast milk feedings, skin-to-skin contact between parent and baby, or both as part of KMC model of care, confer significant physiological benefits during the neonatal period and promote long-term neurodevelopment (e.g., Bera et al., 2014; Charpak et al., 2017; Hickson et al., 2006; Patra et al., 2017; Renfrew et al., 2009).

Despite the evidence and ongoing interest, parent involvement in the delivery of care for preterm and low birthweight infants has not been fully realized in most NICU settings. Hospital systems and neonatal care units have been designed primarily with the healthcare professional or system in mind, and less often are designed to include or support parents and family as part of the infant's healthcare ecosystem. While the accommodation of parents at their infant's bedside is now being considered in the physical design of contemporary NICUs (White, Smith, Shepley, & Committee to Establish Recommended Standards for Newborn ICU Design, 2013), the redesign of NICU care delivery processes to fully include parents has lagged behind.

In this article, we aim to assist researchers, clinical teams, and health systems in evaluating existing, emerging, and future approaches to care of NICU infants that purport to be "family centered" or "family integrated." We begin with a brief review of the philosophy and principles of family-centered care. Then, we present a taxonomy to enable clearer definition and classification of parent-focused NICU interventions and parent-partnered care models. We then briefly describe interventions designed to support the well-being of NICU families, review the current evidence for specific parent-delivered caregiving interventions, and finally describe and compare the models of NICU care that explicitly incorporate parents as partners in the care of their preterm or low birthweight infants. We close by suggesting directions for future research and model implementation to improve and scale-up parent partnership in the care of NICU infants so that NICUs and families may realize the full potential of family involvement through more effective clinical care and optimal infant and family outcomes.

2 | FAMILY-CENTERED CARE: PHILOSOPHY AND PRINCIPLES

Family-centered care is a philosophical approach and set of principles to guide the delivery of healthcare. Family-centered care emphasizes that healthcare should be provided in the context of the strengths and needs of a patient, their family, and community (Johnson et al., 2008). Family-centered care promotes the involvement of the patient and his/her family members—in partnership with the healthcare team—to make informed decisions about the medical care and support services the patient and family receive. Family-centered care promotes orientating care to support and involve the family with the goal of improving quality, psychological well-being, clinical outcomes, and the overall patient and family experience. Today, general consensus on the importance of family involvement in high quality care for hospitalized children has been reached (Committee on Hospital Care & Institute for Patient and Family Centered Care, 2012; Johnson et al., 2008), but consensus has not always existed, and the degree to which family-centered care is implemented in hospitals and health systems varies across institutions, countries and regions (Gooding et al., 2011). The core concepts and principles of family-centered care as applied to the NICU setting are shown in Table 1.

The NICU was an early setting for the adoption of family-centered care principles (Gooding et al., 2011; Jolley & Shields, 2009; McGrath, Samra, & Kenner, 2011) and promotion of relationship-based, family-focused models of care. However, most NICU care is still fundamentally organized and delivered based on the needs of the healthcare professionals to deliver care to individual infants and is not truly family centered at the level of the organization (Harrison, 2010). Thus, there are relatively few models of care that formalize the implementation of the principles of family-centered care in the NICU setting and for which research evidence exists regarding their effectiveness in successfully creating partnership with parents and improving infant and family outcomes. The few models are KMC, care by parent, primary nursing, and family integrated care (FICare).

The lack of clarity with respect to the similarities and differences between the many different parent-focused interventions or among the care models creates confusion and inaction. Although the models of care and relevant research literature have focused on the preterm or low birthweight infant, we believe that the framework and review of the supporting evidence presented below are equally applicable to NICUs caring for infants with birth defects and their families. There are similarities in the challenges faced by families and healthcare providers in caring for NICU infants, regardless of the infant's medical condition (Fonseca, Nazaré, &

TABLE 1 Principles of family-centered care in the NICU setting[a]

Core concept	Principle
Respect	Respecting each infant and his or her family (self-defined)
Diversity	Honoring racial, ethnic, cultural, and socioeconomic diversity of families and their different experiences and perceptions of care
Strengths based	Recognizing and building on the strengths of each infant and family, even in difficult and challenging situations
Choice	Supporting and facilitating choice for the infant and family
Flexibility	Ensuring flexibility in organizational policies, procedures, and practices so services are tailored to the needs, beliefs, and cultural values of each family
Information sharing	Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
Support	Providing formal and informal support for families to support their full partnership in infant caregiving prior to (where possible), during and after the infant's NICU hospitalization
Collaboration	Collaborating with families at all levels of healthcare, in the care of their infants and in professional education, policy making, and program development at the institutional level
Empowerment	Empowering each family to discover their own strengths, build confidence, and make choices and decisions about their own and their infant's health

Abbreviation: NICU, neonatal intensive care unit.
[a]Adapted from Gooding et al. (2011).

Canavarro, 2012; Werner, Latal, Buechel, Beck, & Landolt, 2014).

2.1 | A taxonomy of parent-focused NICU interventions and parent-partnered care models

The taxonomy presented in Figure 1 has three levels, based on the primary group targeted in the work. The first level is labeled "interventions to support parents" and the interventions within this category are defined as psychoeducational, communication, or environmental interventions that support parents to cope with the NICU experience and to ultimately be emotionally, cognitively, and physically able to parent their infant. The primary target populations for interventions are parents of NICU infants and the interventions are delivered by the healthcare system, providers, and specialty consultants. Although interventions to support parents may also promote parent partnership in the care of their infant, for the purposes of classification, we have narrowly defined interventions that support parents as those interventions which are performed with parents alone and not with parents and infants together.

The second level is labeled "parent-delivered interventions," defined as interventions that can be delivered by parents in the care of their newborn infant in hospital settings. The target populations are parents and their infants, and the intervention involves both the parent and the infant. Although parent-delivered interventions require education by and communication with the clinical team and usually have psychological and physical benefits for parents, for the purposes of classification, we have narrowly defined parent-delivered interventions as those performed by parents for or with their infants aimed at improving infant outcomes.

The third level includes models of parent-partnered neonatal care, defined as approaches that center or integrate parents as full partners in the delivery of hospital care to their ill or small newborns. The target populations for parent-partnered

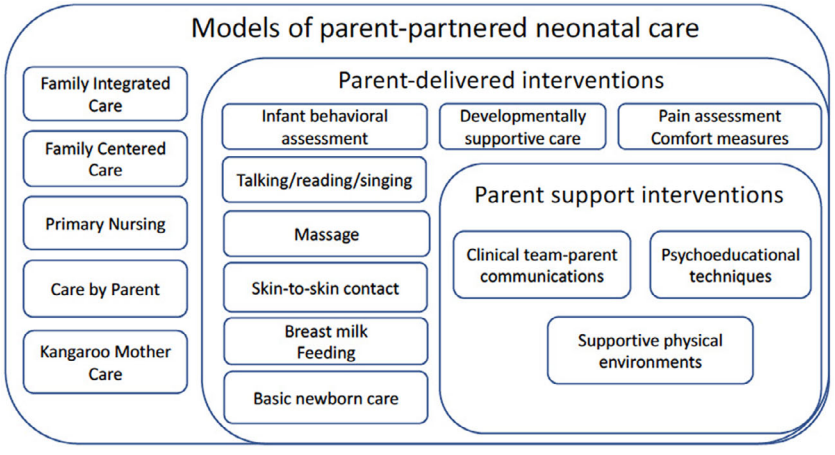

FIGURE 1 Taxonomy of parent-focused NICU interventions and parent-partnered care models

models of care include all levels of the infant's healthcare ecosystem including parents, health system and hospital leaders, NICU leadership, and direct care providers. Such models must encompass at least some of the parent support and parent-delivered interventions mentioned above and successful implementation requires engagement and training of each target group. In addition to meeting the definitions for each level of the taxonomy, we prespecified a further criterion that the interventions or models included in this review must have had one or more experimental or quasi-experimental study suggesting promising efficacy or effectiveness. Figure 1 shows the models and interventions that met the definitions and evidence criteria and each is described in more detail below.

3 | INTERVENTIONS TO SUPPORT NICU PARENTS

Many interventions have been designed to support parents in coping with the NICU experience so that they can ultimately be emotionally, cognitively, and physically able to parent their infant. Interventions that support parents in the NICU can be categorized into three types based on their main approaches and objectives: (a) psychoeducational supports to reduce parent stress and other mental health symptoms, (b) techniques to improve communication and relationships between parents and the clinical team, and (c) interventions to create a more supportive physical environment for parents. The interventions are distinct from parent-delivered interventions in that they do not involve the infant directly. The interventions are distinct from models of NICU care in that the interventions do not necessarily affect the operation of the NICU as a whole, and can be implemented with subgroups of parents who meet specific criteria and by specially trained healthcare team members, without the interventions needing to be applied to the NICU as a whole. Examples of each type of parent support intervention are shown in Table 2.

The evidence for the effectiveness of parent psychoeducational interventions on psychological symptoms such as anxiety, depression, and stress, during and after NICU hospitalization for parents of preterm infants has been critically reviewed (Davidson et al., 2017; Puthussery, Chutiyami, Tseng, Kilby, & Kapadia, 2018). Interventions that included components of parent education (e.g., Melnyk, Crean, Feinstein, & Fairbanks, 2008) were effective in reducing parent stress, anxiety, and depressive symptoms, during and after hospitalization (Melnyk et al., 2008, 2006). Parent stress was also reduced by reflective interventions such as journaling (Carley, 2012; Kadivar et al., 2017). Interventions that provide psychological treatment such as cognitive behavioral therapy to address preterm-birth related psychological trauma and post-traumatic stress (e.g., Shaw et al., 2013, 2014) have also been shown to be effective in reducing parent psychological symptoms that may interfere with their ability to parent (Furuta et al., 2018).

Peer-to-peer support from parents of children who previously were cared for in an NICU setting is an effective psychoeducational intervention, providing parents with support from a nonprofessional peer who has "walked in their shoes." Peer parents receive training in how to listen and share lessons from their own experience without offering medical advice or serving in a therapist role. Peer support can be effective when provided in person, one-to-one or in groups, or remotely using e-mail, text, video conferencing, or telephone modalities (Bourque et al., 2018; Bracht et al., 2013; Hall, Ryan, Beatty, & Grubbs, 2015; Rossman, Greene, & Meier, 2015).

Based on research findings, psychoeducational support interventions for families are now considered an important part NICU care (Hynan & Hall, 2015), but are implemented to a variable level. For true family-centered care to be delivered, parents must be mentally and physically available to engage with their infant and with the healthcare team. Interventions to support NICU parents therefore are a necessary first step toward parent-delivered interventions and must be a core component of any parent-partnered model of care. However, parent support interventions are not sufficient ensure optimal parent–infant interaction nor the full partnership between parents and the healthcare team.

Interventions that focus on the parent–NICU team communication and relationship are relatively new and include parent participation on daily clinical rounds, family meetings, and specific education programs to facilitate the communication between staff and parents (Benzies, 2016; Davidson et al., 2017). Evidence is growing regarding the benefits of parent participation on rounds, including improved parent satisfaction regarding communication and knowledge gained (Voos et al., 2011), reduced anxiety, and increased confidence in the healthcare team, high level of participation by parents and almost unanimous support by parents (Grzyb, Coo, Rühland, & Dow, 2014). In one study, parent education and use of a structured infant progress chart by both the clinical team and parents was effective in improving communication, collaboration, and shared decision-making for low-income ethnically diverse mothers (Penticuff & Arheart, 2005). Further program development and research are being conducted to facilitate communication between parents and the clinical team using multimodal techniques such as relational communication (Benzies, 2016) or structured education programs such as provided in "close collaboration with parents" training (Ahlqvist-Björkroth et al., 2017; Ahlqvist-Björkroth, Axelin, Korja, & Lehtonen, 2019).

TABLE 2 Examples of interventions to support parents in the NICU

Type	Target population	Goal	Examples
Psychoeducational	Parents of preterm and low birthweight infants in NICU settings	To strength knowledge, skills, confidence, and competence in parenting To reduce psychological distress, including anxiety, depression, and post-traumatic stress	Creating opportunities for parent empowerment[a]
		To promote positive coping; enhance feelings of engagement, bonding, and caring for infant	Cognitive behavioral therapy[b]
			Journaling[c]
			Peer-to-peer support[d]
Parent–clinical team communications	Parents of preterm and low birthweight infants in NICU settings	To improve communication and trust between parents and the NICU healthcare professionals	Parent participation in clinical rounds[e]
	NICU clinical team	To improve shared decision-making	Structured team and parent verbal and written communication[f,g]
Environmental	Parents of preterm and low birthweight infants in NICU settings	To create an environment that is supportive of parent involvement in their infant's care	Single family room NICUs[h]
			KMC wards[i]
			Parent overnight accommodation[j]
			Dedicated in-hospital parent spaces[k]

Abbreviations: KMC, Kangaroo mother care; NICU, neonatal intensive care unit.
[a]Melnyk et al. (2006).
[b]Shaw et al. (2013).
[c]Kadivar, Seyedfatemi, Akbari, Haghani, and Fayaz (2017).
[d]Bracht, O'Leary, Lee, and O'Brien (2013).
[e]Abdel-Latif, Boswell, Broom, Smith, and Davis (2015).
[f]Penticuff and Arheart (2005).
[g]Ahlqvist-Björkroth, Boukydis, Axelin, and Lehtonen (2017).
[h]Vohr et al. (2017).
[i]Sharma, Murki, and Oleti (2018).
[j]Franck, Ferguson, Fryda, and Rubin (2015).
[k]White et al. (2013).

The physical environment of the hospital and NICU has also been shown to impact parent involvement in their infant's care. Families who are provided with purposely built overnight accommodations near their ill infant or child report a better hospital experience and feel more involved in their child's care (Franck et al., 2015). In a recent comparison of two similar NICUs, one with single-family rooms, and one with open bays, mothers in the single-family room NICU were present for almost three times as many hours per day and had more skin-to-skin contact with their infant than mothers in the open-bay NICU (Tandberg et al., 2018). Fathers in the single family room NICU were present for twice as many hours and also had more skin-to-skin contact with their infant. Participation in clinical rounds and perceived support from the healthcare team were also higher for parents in the single family room NICU compared with the open bay NICU. Others have also found improvements in parent involvement with a supportive physical environment (Lester et al., 2014, 2016; Vohr et al., 2017). A recent meta-analysis of 13 studies ($n = 4{,}793$ infants) comparing single family rooms to open bay units found that the incidence of sepsis was reduced and exclusive breastfeeding was higher. No difference in neurodevelopment up to 24 months corrected age was detected (van Veenendaal et al., 2019).

There is currently great interest in designing NICU environments that can provide couplet care, where the postpartum mother (and family) as well as the NICU infant are cared for together in a single family room (White, 2016). However, if parents are not able to be present and participate in the infant's care, infants in single family rooms may

receive insufficient stimulation for optimal development (Pineda et al., 2014). Although single family rooms may facilitate families spending better quality time with their infant when present in the NICU, they are clearly not effective at promoting parent engagement in care if the families do not understand that they have a role to play or feel invited to be part of the team.

4 | PARENT-DELIVERED INTERVENTIONS

Facilitating parent-delivered interventions is a key part of any approach to NICU care that purports to be family centered (Craig et al., 2015; Roué et al., 2017). There are a number of important assessments and treatments for NICU infants that parents can safely and effectively perform if parents receive training and support from skilled healthcare providers (Table 3). Parents are encouraged to provide basic newborn care, such as bathing, diapering, and clothing as soon as infants are stable (Gooding et al., 2011). Parents are also encouraged to learn their infant's developmental cues (e.g., assessment of feeding readiness, signs of stress, or readiness for social interaction), and assist the NICU team in providing a developmentally supportive care environment for the infant (e.g., modulating light, sound, and touch) and they can provide the infant with positive stimuli through smell, positioning or holding, skin-to-skin contact, feeding, or other sensitive and appropriate developmental stimulation (Craig et al., 2015). Some NICU-based parent-delivered interventions include training protocols for parents, such as the auditory, tactile, visual, and vestibular (ATVV) intervention developed by White-Traut, Schwertz, McFarlin, and Kogan (2009), which teaches parents how to provide moderate stroking, eye contact, talking, and rocking for the infant in a developmentally sensitive manner.

TABLE 3 Examples of parent-delivered interventions for NICU infants

Parent-delivered intervention
Basic newborn care (diapering, bathing, clothing)
Providing breast milk and or infant feeding
Skin-to-skin contact (kangaroo care position) or KMC
Massage
Pain assessment, prevention, and nonpharmacologic treatment
Talking/reading/singing
Modulation of environmental stimulation
Assessment of infant behavioral cues and readiness for interaction
Developmentally supportive caregiving and provision of appropriate positive stimulation
Oral medication administration
Care of medical devises needed for infant home care, for example, feed tubes, tracheostomy care, oxygen, and monitoring

Abbreviations: KMC, Kangaroo mother care; NICU, neonatal intensive care unit.

Parents can also effectively promote their infant's growth and development by performing massage (Niemi, 2017) and regularly reading or singing to their infant (Caskey, Stephens, Tucker, & Vohr, 2014; Palazzi, Nunes, & Piccinini, 2018; Scala et al., 2018). With training and support, parents can successfully perform infant pain assessment and provide interventions to prevent or lessen pain (e.g., touch, voice, skin-to-skin contact, and other nonpharmacological comfort measures) from common NICU procedures (Campbell-Yeo, Fernandes, & Johnston, 2011; Franck, Oulton, & Bruce, 2012; Hatfield, Murphy, Karp, & Polomano, 2019). Parents can also assist in monitoring infant apnea and bradycardia, administering feeds and oral medicines, and participate in other caregiving tasks (Bracht et al., 2013).

The Family Nurture Intervention (FNI) is a relatively new intervention aimed at establishing emotional closeness between the parent and their infant and thereby reducing parental NICU-related psychological trauma and improving parents' sensitivity and developmentally supportive care to their infant. The FNI has shown strong effects in reduction of maternal anxiety and depression and positive developmental outcomes for infants well beyond the NICU stay (Porges et al., 2019; Welch & Ludwig, 2017; Welch & Myers, 2016).

Of all the parent-delivered interventions, the two most thoroughly studied and powerful interventions that can only be provided by parents are breast milk/breast feeding (Belfort et al., 2016) and skin-to-skin contact, which is also known as the Kangaroo care position. Breast milk and breastfeeding are considered to provide the optimal nutrition for all infants, and to confer immune protection, more appropriate growth, and neurodevelopmental advantage for preterm infants (Patra et al., 2017). Skin-to-skin contact has a multitude of positive effects including supporting infant physiological stability, preventing pain, strongly promoting infant growth and neurobehavioral development, and improving breast feeding (quantity and duration) (Boundy et al., 2016; Holditch-Davis et al., 2014; Johnston et al., 2017; Karimi, Sadeghi, Maleki-Saghooni, & Khadivzadeh, 2019; Lumbanraja, 2016; Nyqvist et al., 2010; Sweeney, Rothstein, Visintainer, Rothstein, & Singh, 2017). Economic benefits from reduction in neonatal morbidities have also been demonstrated with skin-to-skin contact (Lowson, Offer, Watson, McGuire, & Renfrew, 2015).

Parent engagement in the interventions listed above has benefits not just for the infant but also for the parent, specifically with respect to parent-infant bonding and mental health. Parents who perform parent-delivered interventions, such as ATVV and skin-to-skin contact experience less

stress, worry and depression in the first year of life (Athanasopoulou & Fox, 2014; Bera et al., 2014; Holditch-Davis et al., 2014; Sweeney et al., 2017). Parents who learn their infant's cues, how to deliver developmentally appropriate stimulation and are involved in their infant's caregiving, are more likely to feel more positive about their parenting role, become more competent as parents, form stronger attachments to their infants, and have fewer mental health symptoms such as anxiety, depression, or post-traumatic stress (Benzies, Magill-Evans, Hayden, & Ballantyne, 2013; Evans, Whittingham, Sanders, Colditz, & Boyd, 2014). A meta-synthesis of 11 systematic reviews evaluating the effectiveness of parent-involved interventions (excluding FNI), found that skin-to-skin contact/Kangaroo care had the most consistent positive findings across infant and parental outcomes (Puthussery et al., 2018).

Healthcare providers (most often nurses) must train, assist, and supervise parents in the delivery of infant caregiving and other interventions in the NICU setting. Parents of infants with complex medical conditions may be further trained to manage medical technology their infant will require after discharge, such as indwelling feeding devices, oxygen, tracheostomy, or other respiratory support or monitoring. Despite moderate-to-strong evidence that parents can achieve competency in caring for their infant and positive outcomes for their infants and for themselves through delivery of these interventions, parent-delivered interventions remain underutilized in most NICU settings (Puthussery et al., 2018). Interventions at the NICU, hospital, health system levels are needed to increase uptake and sustainment of these essential parent-delivered interventions (Seidman et al., 2015; Umberger, Canvasser, & Hall, 2018).

5 | MODELS OF NICU CARE

The main models of NICU care that explicitly involve parents are KMC, care-by-parent units, primary nursing, family-centered care, and FICare. The main features and evidence base for each of these models are described in Table 4.

5.1 | Kangaroo mother care

KMC is a model of care that was developed to address both the needs of preterm and low birthweight infants (lack of incubators, high nosocomial infection rate) and the needs of mothers (psychological distress, poor breast milk production, and infant abandonment). The mothers are the "place of care" instead of incubators, providing skin-to-skin contact as continuously as possible, ideally more than 18 hr/day. The aim is to gradually transfer the skills and responsibility for taking care of the infant, meeting all the infant's physical and emotional needs, to the mother. The KMC model also includes a practice of early discharge from hospital, as soon as the infant is feeding well, maintaining stable body temperature in KMC position and gaining weight. At home, infants receive ongoing monitoring and mothers receive ongoing support. Frequent and exclusive or nearly exclusive breastfeeding is an essential component of KMC (Charpak, Ruiz-Peláez, & Charpak, 1994; Whitelaw & Sleath, 1985). KMC has been adapted around the world and has been shown to reduce the mortality of low birthweight infants, nosocomial infection/sepsis, hypothermia, and length of hospital stay (Conde-Agudelo & Díaz-Rossello, 2016). KMC was also found to increase infant growth (Bera et al., 2014; Lumbanraja, 2016), breast feeding (Conde-Agudelo & Díaz-Rossello, 2016; Luong, Nguyen, Thi, Carrara, & Bergman, 2016), mother–infant attachment (Boundy et al., 2016; Cho et al., 2016; Conde-Agudelo & Díaz-Rossello, 2016; Feldman, Rosenthal, & Eidelman, 2014), and infant neurodevelopment (Akbari et al., 2018; Charpak et al., 2017). Despite the strong evidence and establishment of KMC Centers of Excellence in many countries (Sarfo, 2018), significant barriers to implementation persist at all levels: organizations, clinical teams and families (Chan, Bergelson, Smith, Skotnes, & Wall, 2017).

5.2 | Care-by-parent model

The care-by-parent model of care is a model of "rooming-in" style care, where mothers are admitted to hospital with their infant and expected to provide most of their infant's care. The first reported observational study comparing infants who received this "humane care" compared with infants who received standard care revealed that the infants cared for by their mothers gained considerably more weight than preterm infants cared for by nurses (Levin, 1994). Studies of this model of care have since come from units in low resource as well as high resource settings from Karachi, Pakistan to Stockholm Sweden (Chabaud et al., 2012; Committee on Hospital Care & Institute for Patient and Family Centered Care, 2012; Nyqvist & Engvall, 2009; Ortenstrand et al., 2010). In low resource settings, care-by-parent units are also known as KMC wards (Sharma et al., 2018). In all studies of care-by-parent models, the neonatal outcomes were reported to be better when mothers remained in the hospital and provided care for their infant. Most of these programs are aimed at preterm infants who are medically stable and not receiving any type of respiratory support and for the most part receiving Level 2 neonatal care, although some care-by-parent model sites initiate the model at the time of birth.

5.3 | Primary care nursing

The primary care nursing model was first described in the 1970s (Manthey, Ciske, Robertson, & Harris, 1970) and

TABLE 4 Comparison of models of NICU care that explicitly involves families

Model	Overall goal	Target population	Key components
FICare (see also: neonatal intensive parenting unit; infant delivered family care)	To achieve parent competence and confidence, family well-being, and improved infant outcomes at NICU discharge through partnership in infant care during NICU hospitalization	Parents; infants NICU clinical team; NICU and hospital leadership	NICU environment focuses on family (physical/operational) NICU team training and support (emphasis on nursing) Parent psychoeducational support (parent classes, peer mentorship, mentorship at bedside) Frequent transparent facilitated communication with parents (parent participation in daily rounds, parent engagement in developing care plan) Parents delivering as much infant care as able with nursing supervision/support (recommended 6–8 hr/day) Design and implementation of all key components in partnership with families
Family-centered care	To improve infant and family outcomes through partnership with families in delivery of NICU care	Parents; infants NICU clinical team; NICU and hospital leadership	Principle-based partnership in all caregiving: —Dignity and respect —Information sharing —Participation —Collaboration No specific components mandated
Primary care nursing	To improve infant and family outcomes through relationship-based, individualized NICU nursing care	Parents; infants NICU nurses; NICU leadership	Consistency in nursing staffing Parent–nurse relationship Individualized care Individualized teaching Advocacy
Care-by-parent unit	To improve infant and family outcomes by providing "rooming-in" care, where mothers are admitted to hospital with their infant to provide most of their care	Parents; infants; NICU clinical team; NICU leadership	Parents expected to be present for nearly 24 hr/day Parents provide the majority of infant caregiving
KMC	To promote survival and optimal development of preterm infant and family	Parents; infants; NICU clinical team; NICU; and hospital leadership	Nearly continuous (18–24 hr) skin-to-skin contact starting as soon as possible after birth Exclusive breastfeeding NICU support for parents Early discharge with KMC continuing at home Community support for parents

Abbreviations: FICare, family integrated care; KMC, Kangaroo mother care; NICU, neonatal intensive care unit.

subsequently proposed as a model of care for NICUs (Bethea, 1985). The main goal of primary care nursing is to promote consistency in nursing care, leading to greater knowledge of individual patients and their families, development of therapeutic relationships, delivery of optimal nursing care, and ultimately to improve health and wellbeing of the patient and family. Parents strongly desire to have consistency in the clinical team members caring for their infants, and to feel they have a trusted individual relationship with nurses (Franck & Axelin, 2013; Franck, McNulty, & Alderdice, 2017). Primary care nursing has been evaluated in one study in the NICU setting. The study was a single site, retrospective comparison of consistency of nursing staffing for 237 preterm infants (Mefford, 2004). Using structural equation modeling, consistency in nursing was found to be a significant mediator of infant length of stay

and the duration of mechanical ventilation, supplemental oxygen therapy, and parenteral nutrition. Primary care nursing has not been widely adopted by NICUs due to significant operational obstacles such as difficulties in matching nursing skill mix with patient acuity mix, staffing patterns, census fluctuations, and inconsistent support from nurse leaders and nurses. Nevertheless, primary care nursing has persisted as an aspirational model of NICU care based on its consistency with family-centered care principles, albeit with limited evidence of effectiveness, and strong parental desire for consistency in NICU clinical team caregivers (McCarley, Dowling, Dolansky, & Bieda, 2018; Mefford, 2004).

5.4 | Family-centered care

Beyond the philosophy and principles, the term family-centered care has also been used to represent models of care that are family focused and partnered. The key components of a neonatal family-centered care model are not precisely defined, presenting a challenge when evaluating the research on family-centered care (Harrison, 2010). The most robust programs include at a minimum family centered NICU design (e.g., family spaces), policies and protocols (e.g., open visitation; family involvement in patient care), family support services (e.g., educational and psychological), and clinical team education and support (Gooding et al., 2011). Several assessment tools have been developed to assist NICUs in self-assessment to aid in quality improvement of family-centered care (Hall, Hynan, & Phillips, 2016; Institute for Patient and Family Centered Care, 2004). Research on the effectiveness of family-centered care models of care compared to traditional care (healthcare professional centered) is limited but promising. Three clinical trials of family-centered care compared with usual care found positive outcomes for infants, including earlier full feeding and discharge, greater weight gain, lower opioid, and vasopressor requirements, fewer signs of stress, better performance on neurobehavioral exam and fewer readmissions (Bastani, 2015; Byers et al., 2006; Yu et al., 2017). Parents were also more satisfied with the family-centered care model and more engaged in two of the trials (Bastani, 2015; Yu et al., 2017), but there was no difference in parent satisfaction between the care models in the third trial (Byers et al., 2006). Interpretation of findings of studies of family-centered care models remains challenging because of the lack of clear definition of the model components and lack of attention to model fidelity in implementation.

5.5 | Family integrated care

The aim of FICare is to integrate families into their infant's neonatal care while in the NICU. Parents are provided with support and education to become their infant's caregiver and to become a central part of the NICU care team, instead of passive observers of their infant's care. A combination of education, physical support, and psychological support are provided to ensure that parents become confident to provide the majority of their infant's daily care, including monitoring, measuring abdominal circumference, preparing and administering feeds, bathing their infant; contributing to medical charts; and providing reports during ward rounds (Bracht et al., 2013; Macdonell, 2013). As the parents' confidence grows, they become the primary caregiver for their infant and nurses provide the more technical aspects of care and act as coaches to support parents. The intent of FICare is to partner with families in the care of their infant, promoting infant growth through increased breast feeding (breast milk supply), providing developmentally responsive care with parents acting as a buffer to the adverse effects of the NICU environment, encouraging and supporting skin-to-skin contact and engaging parents as collaborators in decision-making. FICare focuses on strengthening the partnerships between parents and the clinical team and supporting parental role development so that parents grow to become competent primary caregivers for their infants and can act as advocates for their infants (O'Brien et al., 2013).

The FICare model has been tested in an international cluster randomized controlled trial involving 25 Level III NICUs and has been shown to be of benefit both to parents (e.g., decreased stress and anxiety) and infants (e.g., improved weight gain and breast feeding) (O'Brien et al., 2018). FICare has also been implemented across many different settings both as part of the cluster randomized trial and beyond (Deierl, Williams, Aloysius, Hurlston, & Banerjee, 2018; He et al., 2018; Patel, Ballantyne, Bowker, Weightman, & Weightman, 2018). Preliminary evidence suggests that a long-term benefit to infants of the FICare model exists, with improvements seen in neurodevelopmental outcomes at 18 months postterm (Li et al., 2016). Research on the effectiveness of FICare in Level II NICUs and in the U.S. healthcare context is currently underway (Benzies et al., 2017; Franck et al., 2019).

Common to all of the NICU models of care described above is the belief that the wellbeing of infants and parents (mothers in particular) are inextricably linked and biologically coregulated (Kommers, Oei, Chen, Feijs, & Bambang Oetomo, 2016) and therefore optimal care of the infant must include care for the parent and engagement of the parent in their infant's care. All of the models require a reimagining of the policies, processes, and roles in the NICU environment, and can be further enhanced or enabled by physical alterations that support prolonged parent presence and engagement. All of the models also require ongoing commitment from leadership, resources for initiation, and support to sustain the model of care until the model accepted as the new normal. Although further evidence of the long-term effects

on infants, families, and health systems is important, other factors such as political endorsement and demand from families and communities will likely be required to support the scale-up care delivery models.

5.6 | Other models of NICU care

Neuroprotective Care, Neonatal Integrative Developmental Care, and Close Collaboration in Care are other approaches to care of the preterm and low birthweight infant that include and support the family as an important part of the infant's care. However, these approaches have not yet been evaluated in comparative studies against other NICU models of care.

The pioneering work of Brazelton, Parker, and Zuckerman (1976) and Als (1986) found that assessing the individual infant's ability to cope with stimulation provides the caregiver with information that can be used to provide developmentally supportive individualized care. Extensive studies of the Newborn Individualized Developmental Care and Assessment Program on infant development have been conducted (Ohlsson & Jacobs, 2013), but no comparative studies of the effects on parents or the infant-parent relationship could be found.

Another related developmentally focused approach to NICU care is Developmental Neuroprotective Care, also known as Neonatal Integrative Developmental Care (NIDC) (Altimier & Phillips, 2018). The NIDC model has as its foundation the practice of SSC, surrounded by seven core domains of care: a healing environment, partnership with families, positioning and handling, safeguarding sleep, minimizing stress and pain, protecting skin, and optimizing nutrition. Measures for each of these domains have been proposed (Coughlin, Gibbins, & Hoath, 2009). To address issues with inconsistency in the implementation of NIDC and the lack of institutional operational framework, a joint statement from the National Association of Neonatal Nurses of the United States and the Canadian Association of Neonatal Nurses proposed guidelines in 2018 (Milette, Martel, Ribeiro da Silva, & Coughlin McNeil, 2017). The NIDC approach to care has not yet been evaluated in comparative studies with other models of care in respect to infant or parent outcomes. However, preliminary findings of effects of use of the NIDC model suggest improved nursing knowledge of developmental care and improved parental satisfaction after NIDC implementation (Bruton, Meckley, & Nelson, 2018).

Close Collaboration in Care is an intervention that focuses on educating the NICU multiprofessional clinical team to collaborate with parents by: (a) increasing their ability to see and communicate the behaviors and needs of the infants, (b) actively listening to parents and collaboratively planning the care of the infants, (c) understanding the individual features of families, and (d) integrating parents into the care of their infant from admission (Ahlqvist-Björkroth et al., 2017). The main focus of the model is enabling nurses and other members of the healthcare team to redefine their role in relation to parents as active partners in infant care and to transform the traditional professional approach to infant caregiving so that it is more collaborative with parents and process guided, instead of task or procedure oriented (Axelin, Ahlqvist-Björkroth, Kauppila, Boukydis, & Lehtonen, 2014). The Close Collaboration model has been shown to be effective in a single site, pre–post implementation study to decrease the incidence of postpartum depression in parents of preterm infants (Ahlqvist-Björkroth et al., 2019). Future research should focus on multisite implementation feasibility and fidelity, comparative effectiveness with other models and evaluation of the long-term effect on infant outcomes.

6 | DISCUSSION

In this article, we have presented a taxonomy for classifying interventions to support the philosophy and principles of family-centered care in the NICU. We have highlighted that multidimensional models of newborn care are distinct from interventions that solely focus on supporting parents or providing specific interventions delivered directly by parents to their infants because they involve all levels of the NICU health system including hospital leadership and healthcare providers as well as parents, to promote and sustain family partnership in care. As new ideas and research findings emerge, this taxonomy can aid researchers, healthcare system leaders, healthcare providers, and parents in more clearly identifying into which category it fits, the added value of the intervention or program and where there are gaps in evidence about effectiveness.

In developing this classification system, we found overlap in components and outcomes between many of the interventions described in the literature. In addition, many parent-focused interventions do have wider effects beyond their direct intent. For example, an intervention to improve parent mental health often supports more positive parent–infant interaction. However, we appeal to the research community to use common language and, where possible, common metrics in research so that findings from future studies of the parent-focused or parent-delivered interventions and parent-partnered models of care can be compared and the best interventions and models can be identified. Parent coleadership is critical also for ongoing design and evaluation of interventions and models of care, and ultimately in the implementation and scale-up of any model of care. In addition, to sustain any model of care requires the development of standards for practice and competencies.

The published evidence suggests that KMC and FICare are the most robust and rigorously evaluated of the current

models of care. The KMC model of care has been in existence for just over 40 years now and has had greatest impact in low and middle income countries where neonatal mortality is high. Despite robust evidence of effectiveness, scale-up and sustainability remain problematic, primarily due to health system constraints and difficulty in changing the predominant culture of care (Charpak & Ruiz-Peláez, 2006; Seidman et al., 2015; Vesel et al., 2015). In high income countries, the full KMC model has had greater uptake in Nordic countries and intermittent skin-to-skin contact, rather than the full KMC model, has been more often practiced in other high income countries like the United States, but rates remain quite low despite consensus and advocacy by many professional organizations (American Academy of Pediatrics et al., 2016; United States Institute for Kangaroo Care, 2018). Worldwide barriers and enablers to KMC uptake have been well described and actions recommended (Cattaneo et al., 2018; Chan et al., 2017; Chan, Labar, Wall, & Atun, 2016). It remains to be seen if global efforts can achieve worldwide uptake and sustainability.

FICare is the newest model of NICU care to be supported with research evidence, although it was built on foundation of family-centered care principles and adapted practices from the earlier Levin care-by-parent model. FICare incorporates evidence-based practices with strong evidence including parent education and psychosocial support, peer-to-peer support, clinical team education (with special emphasis around communication with families), and environmental supports including physical and procedural supports for prolonged parental presence. A key tenet of the implementation of FICare is that FICare's implementation needs to be co-led by parents and the clinical team, making FICare adaptable to the needs of different environments, while maintaining fidelity to its core pillars (Bracht et al., 2013; O'Brien et al., 2015). Different strategies and tools may need to be used for different environments depending on their structure and the available resources. In addition, FICare is not a static model. As new evidence-based practices and interventions are brought forward, they can be integrated into the model. For example, technology may be implemented to further support parent education, peer support, and the communication and relationships between the clinical team and parents (Franck et al., 2019). Further research is needed to determine if the positive outcomes of FICare seen in countries with national healthcare systems can also be achieved in countries with predominantly private healthcare systems or in low and middle income countries.

There are several major gaps that must be noted in our current understanding of parent support interventions, parent-delivered interventions, and parent-partnered models of NICU care. First, the research on these topics is almost exclusively with preterm and low birthweight infants and their families. These infants may also have other comorbidities, but little research exists specifically addressing parent-focused interventions or parent-partnered models of care for other groups such as infants with birth defects. Second, there is little research examining the comparative effectiveness of the interventions and models, with the majority of studies using usual or traditional care as the comparator. Finally, there are few multisite or multiregion randomized controlled trials of the interventions or models. Addressing these limitations in future studies, along with standardizing the primary infant and parent outcome measures will significantly advance the field and ultimately lead to improved translation of research to practice and policy.

Overall, the landscape for integrating parents into the care of their infant appears very favorable with many different strategies to choose from to improve NICU care delivery and outcomes. What is clear now is that NICU teams are leading the way in innovation in implementation of parent-partnered neonatal healthcare so the ultimate goal of promoting health and wellbeing for infants, families, and healthcare professionals will be met for all hospitalized newborns.

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CONFLICT OF INTEREST

Both the authors declare no potential conflict of interest.

DATA AVAILABILITY

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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