

Family Participation in the Care of the Inpatient Newborn

DO NO HARM TECHNICAL BRIEF

Every year 15 million newborns are born preterm¹ and many others have life-threatening conditions that require hospitalization. Family engagement in inpatient care of small and sick newborns leads to better health and developmental outcomes, improved patient and family experience of care, enhanced clinician and staff satisfaction, and wiser allocation of resources. Conversely, a lack of systemic support for parental participation may result in unintentional harm to both newborns and their families. Engaging families as active caregivers during inpatient newborn care requires context-specific adaptation and flexibility.

A global focus to ensure that newborns not only survive but thrive into adulthood has led to an increased appreciation for the value of family participation in inpatient care. Building reciprocal partnerships between families and providers is fast becoming a standard for healthcare planning and delivery across the lifecycle. The core principles of family-centered care are: 1) dignity and respect; 2) information sharing; 3) participation; and 4) collaboration.² While there are many models of family participation for the inpatient newborn (see note on terminology below), all share a common view that the baby, the parents/primary caregivers, and healthcare providers are a unit of care. Integrating parents as caregivers during the inpatient period can enhance the newborn's short- and long-term wellbeing. Moreover, providing emotional, educational and practical support to families of newborns is an important responsibility of providers and health systems, requiring training and resources.^{3,4}



Why is family engagement in inpatient newborn care important?

The newborn period is a sensitive time when parents and their children form healthy attachments to one another. Establishing a lifelong bond between parent and child is critical for a child's healthy development as well as the emotional health of all family members. When a baby is born small or sick, however, separation of the newborn from the parents during hospitalization can disrupt this bonding process. Integrating parents into their newborn's care during hospitalization can maintain infant-parent unity, promote developmental care, and facilitate the formation of a stable and secure attachment.

Parents can make unique contributions to the care of their small and sick newborn by being able to monitor and provide basic caregiving under the supervision and mentorship of healthcare staff. (Please see Table 1 for specific examples.) With lactation support, most mothers can offer breastmilk to boost a newborn's survival, growth, and cognition. By engaging with families as part of the healthcare team, providers can bolster parents' confidence and competence as they transition into their role as primary caregivers. This empowerment can foster greater maternal and paternal emotional coping while improving parenting abilities for these fragile newborns.

Through their partnership with the healthcare team, family members gain health literacy and learn to read their baby's cues which improves parent-provider communications and decision-making.⁵ This collaboration can lead to better post-discharge compliance with the newborn's follow-up plan and higher utilization of preventative care.

How can a lack of family engagement cause harm?

When newborns require inpatient care, the resulting interruption of the attachment process can have devastating, long-lasting consequences for both parents and children. For example, mothers and fathers of sick infants experience more anxiety, depression, and acute or post-traumatic stress disorders when compared to parents of healthy babies.⁶ Parents may struggle with a variety of stressors such as difficulty managing rising out-of-pocket expenditures (related to the care of their newborn) with reduced wages due to missed work.⁷

When left unaddressed, a parent's psychological distress can negatively influence his or her child's cognitive, social, and health outcomes into adolescence.⁸ For example, parental mental health issues might contribute to the neglect or abuse of newborns which can have long-lasting detrimental effects on their cognition, development, and socialization.⁶

Separation of parents from their newborn during inpatient care also makes it more difficult to provide critical developmental support to the newborn such as safeguarding sleep, promoting appropriate sensory interaction (i.e., smell, touch, sound), monitoring and managing pain and stress, and creating a healing environment.⁹ Additionally, a lack of closeness between parents and infants can inhibit breastmilk expression.¹⁰

Together, these stressors and separation can make it more difficult for parents to assume the role of primary caregiver once their newborn is home due to a lack of confidence and self-efficacy.¹¹ When parents are not adequately prepared for discharge, their infant is more likely to be re-hospitalized.¹²

A Note on Terminology

This brief uses the phrases "family participation" and "family engagement" interchangeably to describe the involvement of parents and other family caregivers in the inpatient care of their newborns. Examples of specific models of family participation include Family Participatory Care, Family Centered Care, Family-Led Care, Family Integrated Care, Care by Parent, Continuous Baby Parent Unit, and Partnership in Care.

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What are the current evidence-based best practices?

There is mounting evidence from high- and middle-income countries that family participation in inpatient newborn care leads to enhanced wellbeing for family members, newborns, and healthcare providers.¹³ For example, a multi-center cluster randomized trial in Canada, Australia, and New Zealand reported that integrating family members into care led to improved infant weight gain, increased frequency of exclusive breastmilk feeding at discharge, and better parental mental health indicators.¹⁴ Family participation may also benefit healthcare providers through increasing staff satisfaction, improving decision making, employing resources more efficiently, reducing litigation, and promoting a higher quality of care.⁵

The movement towards greater family engagement in inpatient care can be viewed as a continuum that requires flexible implementation. There may be real or perceived barriers to implementing this approach such as a lack of space, staff shortages, the risk of infection, inadequate infrastructure, security considerations, interference with workflow, concerns about task-shifting, and inability to participate or lack of interest on the part of family members. Therefore, the execution of these practices necessitates context-specific adaptations to suit different environments.

Promising approaches along with a brief synopsis of their potential benefits are detailed in Table 1.

Case Study: Family-Centered Care in India

The Ram Manohar Lohia (RML) Hospital in New Delhi and the Norway-India Partnership Initiative partnered to test the impact of an adapted model of family participation in five special newborn care units (SNCUs). The results of the randomized control trial showed a statistically significant increase in pre-discharge breastfeeding rates without a change in nosocomial infection rates.¹⁵ Based on the impact, feasibility and acceptability of the program,^{15,16} the Government of India elected to expand this model to all SNCUs in the country.

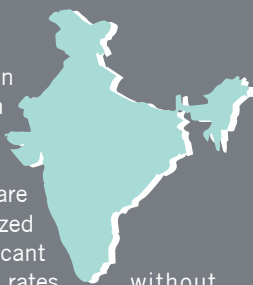


Table 1: Evidence-based clinical approaches to promote family engagement

Approach	Potential Benefits
Infant/family-friendly visitation policies	Early physical closeness and parent-infant interaction is crucial for the emotional health of the newborn and can improve an infant's brain development. ¹⁷
Skin-to-skin contact/Kangaroo mother care (KMC)	KMC can reduce neonatal mortality and risk of infection. ¹⁸ There is evidence that practicing KMC may reduce pain, improve oxygen saturation, help thermal regulation, increase head circumference, and boost breastmilk supply. Skin-to-skin contact between newborn and caregiver is foundational to KMC and is the most fundamental form of neuroprotective care.
Maternal involvement in basic care	Involving mothers in routine caregiving activities (e.g., diaper changes, taking temperatures, breastfeeding or providing breastmilk) reduces anxiety and boosts maternal problem-solving. ¹⁹ Maternal participation is also associated with improved rates of newborn human milk consumption. ¹⁴
Engaging males in care	Engaging fathers and other male family members may improve appropriate care seeking behaviors, bolster relationship communication and mutual decision-making, and foster better care within the home environment. ²⁰
Developmentally supportive care	Developmental care may result in a reduced incidence of necrotizing enterocolitis and moderate to severe lung disease while minimizing parental stress. ²¹
Parent education and discharge planning	Education programs that focus on both maternal and infant outcomes can reduce parental depression and stress while improving parental knowledge, attitudes, and caregiving. ²² Preparing parents for discharge by educating them on the best ways to provide care for their newborns can lead to better infant-parent interactions and increased parent self-efficacy and caregiving competency. ²²
Lactation support	Timely and practical guidance on milk expression can support human milk feeding which can have a range of cognitive and health-promoting benefits. ²³
Psychosocial support	A variety of psychosocial support activities including journaling, psychotherapy, and mindfulness practices have shown to be helpful in improving parent coping and mental health. Health professional-led family support groups have enhanced staff-family communications as well as parental confidence. ^{22,24}
Parent involvement in comfort and stress reduction/pain management	Involving parents in infant comfort and stress/pain management may reduce neonatal distress and improve brain development. ²⁵ Skin-to-skin care may lessen a newborn's pain when practiced during minor procedures such as heel pricks. ^{26,27}
Peer support programs	In addition to boosting caregivers' moods, parent-led support groups can promote a better home environment. ^{14,22}
Home visitation	Home visits providing education and assistance have significantly reduced parental stress and led to improved caretaking at home. ²⁸

What are the current WHO recommendations for family engagement?

Current World Health Organization (WHO) recommendations and clinical guidelines address several aspects of engaging families in the care of inpatient newborns.

The World Health Assembly adopted the Integrated People-Centered Health Services (IPCHS) framework in 2016.²⁹ This framework embraces universal health coverage (UHC) principles to promote a person-centered approach to healthcare delivery. IPCHS proposes five interdependent strategies which include: (1) empowering and engaging people and communities; (2) strengthening governance and accountability; (3) reorienting the model of care; (4) coordinating services within and across sectors; and (5) creating an enabling environment. The IPCHS framework acknowledges that family members play a critical role in healthcare delivery across all patient age groups, and affirms the need to empower and engage them as partners. This is particularly relevant for newborn babies who require intensive caregiving to fulfill their basic needs and protect their rights.

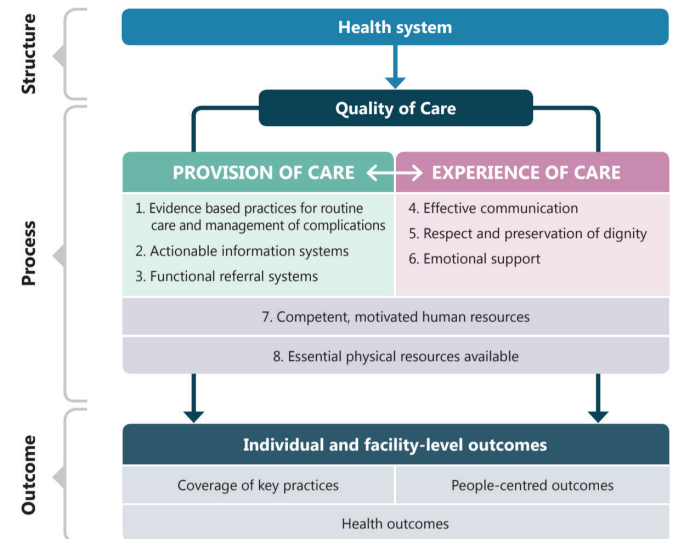
A Framework for Nurturing Care, published by WHO and its partners in 2018, embraces the role of caregivers and family members in the early childhood development of children under the age of three.³⁰ (Figure 1) The framework proposes that the health system is uniquely positioned to initiate the multi-sectoral partnerships required to ensure that all at-risk children receive the support they need to thrive.

Figure 1: A Framework for Nurturing Care



Quality, Equity, Dignity: A Network for Improving Quality of Care for Maternal, Newborn, and Child Health also offers a conceptual framework that upholds the importance of family engagement during healthcare delivery.³¹ (Figure 2) This framework supports the idea that equitable and people-centered health services are essential parts of quality care. It acknowledges that families and communities need to be engaged in the process to build trust, access, and demand for quality maternal, newborn, and child

Figure 2: Conceptual framework for quality maternal and newborn care



health (MNCH) services and places equal emphasis on the provision of care, the experience of care, human capital, and availability of physical resources.

Lastly, KMC/skin-to-skin contact for thermal care (which requires family engagement) is one of ten guidelines in the *WHO recommendations on interventions to improve preterm birth outcomes*.³²

System requirements for positive family engagement

A shift towards a healthcare model that embraces family participation in newborn care requires reasonable investments in health systems and will vary across settings. Policymakers and program planners can first assess the status of family engagement. This knowledge can inform the establishment of necessary pathways and related investments based on existing provider-family partnerships, available resources, policies, and legislation. Needed improvements may include:

- A robust and formal commitment from policymakers and health facility leadership;
- Educated healthcare workers who understand the evidence for integrating family members into inpatient newborn care;
- Open newborn care facilities that support family caregiver visitation 24 hours a day, 7 days a week;
- Parental access to food, water, bathrooms, and sleeping quarters inside or near the healthcare facility;
- Space and support at the infant's bedside for direct care by parents;
- Lactation support and a private place for pumping or breastfeeding;
- Infrastructure and policies that promote, protect and support breastmilk feeding;
- Healthcare worker and family training on principles and actions of developmental care for newborns;
- Availability of psychosocial services to provide emotional support for families; and
- Stakeholder and community input on the delivery of high-quality inpatient newborn care and post-discharge follow-up care services.

What actions can be taken to improve family engagement and related health outcomes?

Core actions needed by key stakeholders to ensure family participation are presented below.

Policy Makers

- Champion policies, legislation, and regulations that affirm appropriate family engagement in the health system, particularly in the inpatient care of the newborn
- Recognize and engage with parent-led advocacy groups
- Develop and support laws that support paid parental leave (which should be extended for mothers and fathers with hospitalized newborns)
- Promote the adoption of universal health coverage so that families can obtain the care they require without undue financial burden

Program Planners/Implementers

- Establish a unit-wide training curriculum for staff and educational materials for family members on best practices for care collaboration
- Develop or adapt family participation indicators to monitor and evaluate progress
- Promote partnerships with affected family members to improve program quality

Facility Managers/Administrators/Leaders

- Create policies, procedures, and infrastructure that affirm parent-newborn unity and family participation, including open access to newborns during the inpatient care period
- Make an explicit commitment to support evidence-based family engagement practices
- Facilitate the development of family advisory councils and peer support groups
- Develop feedback loops so that the family experience is regularly monitored, reported, and acted upon
- Provide handwashing stations and space for parents to provide care for their newborn during hospitalization
- Offer lactation/human milk feeding support including amenities (e.g., cups for hand expression) and privacy

Health Care Providers (physicians, nurses, midwives, ancillary staff)

- Embrace core components of family participation and partnership in care
- Infuse evidence-based clinical approaches in routine medical and nursing practice, foster interdisciplinary newborn care teams, and participate in quality improvement initiatives
- Educate family members on the unique contribution that they play in the care of their newborn; train family members on the importance of their involvement in human milk feeding, hand-hygiene, developmentally supportive care, and decision-making
- Safeguard opportunities for parent-infant attachment and family involvement in routine caregiving
- Provide basic psychosocial support, including screening and referring at-risk parents with appropriate mental health services

Families

- Stay engaged and informed in care while the newborn is in an inpatient setting, in follow-up care, or in the home environment
- Build and participate in parent-led advocacy groups (such as family advisory councils) and peer-support networks

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