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Individualized Family-Centered Developmental Care

A Model for High-Quality Care

High-quality care is a process of current practice based on credible evidence that is continuously evaluated to improve short- and long-term health outcomes and is measurable and monitored over time. The process and outcome of quality care are dynamic, evolving, holistic, and resilient. Systems thinking guides the study of quality care, standardized competent practice, and relationship of the interacting parts of the system/process to achieve optimum outcomes.[1,2] Quality care and systems thinking are inextricably linked in the delivery of family-centered care (FCC).

FCC came to the forefront in the United States in 1987 when the US Surgeon to General called for a family-centered coordinated approach to care for families of children with special needs.[3] This model of care promoted partnerships and collaboration with families. Over the course of the next few decades, studies centered on its applicability to many settings, including the intensive care units (ICUs). Neonatal intensive care unit designs incorporated family spaces; yet, there was a gap in the evidence to accurately measure family perceptions and health outcomes.[3] A paucity of evidence existed to support FCC interventions. Increasing evidence and a focus on both babies and their families in intensive care has emerged in the last decade. As a result in 2015, the Interprofessional Consensus Committee of Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care in Intensive Care began work to create an evidence-based framework to guide neonatal care.[4] The framework is grounded in evidence from a review of more than 1000 articles, with levels of evidence identified.[5]

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Infant Family-Centered Developmental Care (IFCDC) stresses neuroprotective aspects that support positive infant growth and development, infant mental health (IMH), and support/empowerment of families in care delivery. The baby/mother/family is the focus of caregiving that anchors the model, so the term "m/other" has been used to define the dyad and signify the baby as an active interactor in the nurturing relationship with the mother (biologic or other), and with the interactive and integrated influence of the father/partner/significant other. Furthermore, family members reinforce and enhance the supportive relationship.

IFCDC is a holistic model of continuing care for babies, parents, and families in the ICU that describes the interaction of principal values and includes 7 interacting principles:

Systems thinking in complex adaptive systems: It describes the interrelationship of each component of a dynamic and evolving system, human or organization. Each part of the system influences or is influenced by the other parts. Without integration into the system of care, each of the evidence-based standards and recommendations may not be implemented. Taking a system's view of practice support and implementation, consideration is given for how the system will address the assurance of interprofessional staff competencies and practice and assurance of positive outcomes.[1,6,7]

Baby as a competent communicator and interactor: The baby is capable of communicating distress, pain, comfort, and the need for interaction through behavior, facial expression, and physiologic changes/indicators. The m/other, father, family, and caregiver can better identify the baby's communication and respond accordingly. Misinterpreting the communication can lead to physiologic disruption and stress.[8–12] Emerging science has identified

behavioral communication as an important way of understanding the experience of the baby. Understanding, interpreting, and responding appropriately to the nonverbal communication of approach and avoidance responses to the environment and caregiving allow for an interactive communication between the baby, professionals, and family and respect the baby's ability to be a significant interactor in caregiving and lead to protective and nurturing opportunities.[11]

Individualized care: It focuses on the strengths, needs, and interactions of each baby and family. Recognizing the approach and avoidance behavior of the baby and the voiced and/or inferred responses of family members to events. Supporting comfort and managing stress are essential to the healing of babies and their families.[12–15] Babies and their families have unique cultural and educational backgrounds, social and medical history, communication style, and preferences. Addressing the needs of individual babies, based on an understanding of their behavioral communication and preferences, will enhance their ability to establish optimal regulation and support development. Families should be valued for their individual preferences in parenting their baby and receive support for their individual physical, psychosocial, cultural, language, and educational needs.

Family integration: It emphasizes the essential nature of the baby as part of the family and the role of the healthcare team to support the family unit.[16–18] Physiological, nutritional, and emotional regulation is provided by the m/other and contributes to the baby's stability.[19–22] The m/other's partner/significant other and close family members provide physical and emotional support to the m/other throughout the hospital stay and transition to home.[23–26] As families are the constant in their baby's lives, support for their full-time involvement in the caregiving and informed decision-making are essential. A supporting, comfortable, and homelike atmosphere with no restrictions on being with their baby will further allow for family integration and decision making.

Environmental protection: It describes the need to mitigate the effects of distal sensory environments such as sound, light, and activity and proximal sensory stimuli in the environment such as bedding and caregiving. Diminishing adverse stimuli from the proximity of the baby increases the opportunity for positive intimate interactions with family.[4,27–31] During the sensitive periods of development, babies are particularly vulnerable to stressful environmental perturbations. Protection provided from overwhelming light, sound, odor, and activity is especially essential to protect sleep and to diminish their being overwhelmed during times of arousal. Considering that the most environmentally protected space for the baby is the mother's body, efforts should be made to ensure intimate contact between parents and their baby.

Neuroprotection of the developing brain: It stresses the importance of optimal brain and body development as an ultimate objective of every baby's care plan. Regardless of the gestational age, the baby's brain develops faster and is most vulnerable during the time of birth than at any other time in life. Furthermore, the baby's brain is vulnerable to stressful and painful procedures, so individualized, sensitive caregiving through the m/other's regulatory influence of holding, feeding, and interacting is essential for optimal brain development.[32–36]

Infant mental health: It identifies intervention strategies that provide baby- and family-driven individualized care and developmentally appropriate regulation of physiology, arousal and sleep, body movement, interaction with others, eating, and soothing. IMH also focuses on enhancing the relationship between babies and their parents and primary caregivers. It is important to practice/consult using a reflective stance to consciously process impactful experiences and promote best practices and optimal mental health for families and professionals.[37–41]

IFCDC is aimed to benefit the provision of holistic care for babies and families to help them not only survive but also thrive. Integrating IFCDC principles into intensive caregiving practices lays a foundation for optimal long-term physical, developmental, and mental health outcomes. The Consensus Committee's application of evidence for this model resulted in the development of Recommended Standards, Competencies, and Best Practices in 6 essential areas: (1) Systems Thinking; (2) Positioning and Touch; (3) Sleep and Arousal; (4) Skin-to-Skin Contact with Intimate Family Members; (5) Reducing and Managing Pain and Stress in Newborns and Families; and (6) Feeding, Eating, and Nutrition Delivery.[4] For more information, please see https://nicudesign.nd.edu/nicu-care-standards.

The need for integration of IFCDC principles in the care of babies and families in intensive care is supported by recent research including epigenetic effects of early caregiving and resulting neurodevelopment. A growing body of epigenetic studies show that stressors and painful experiences cause epigenetic changes to the DNA sequence by altering or blocking the interpretation of the DNA sequence to influence the way DNA works.

The DNA sequence itself is not altered.[42] In the ICU setting, the baby is subjected to multiple forms of biophysical and psychosocial stressors that cause epigenetic change to the baby's DNA expression. They include early birth, separation from the regulatory nurturing of the mother, multiple painful procedures, inconsistent feeding practices, repetitive sleep disturbance, poor body alignment, infrequent touch and skin-to-skin contact, and distress of the sound and activity of the clinical setting. Parents and family members suffer physical, social, and mental health stressors from the experience that can alter expression of their DNA sequence.[42–46]

Epigenetic changes can be reversed, but if they are not, the changes are passed to offspring. Reversing the epigenetic changes, or modulations, to the baby's DNA can be incorporated in the unit culture and the care during hospitalization, transition to home, and continuing care by implementing individualized FCC and developmental practices.

Unfortunately, the care and management of the baby in the ICU are designed more to benefit the time, organization, and practice of the healthcare provider and the caregiver than the baby, parent, and family.[47–50] Oftentimes, ICUs describe the services as family-centered; yet, the policies that limit what care a family can provide or what activities are open to them such as rounds do not coincide with a true FCC.

During COVID-19, mothers and infants were often separated more due to fear than to science. Even the use of technology to keep the families connected with their babies was not always encouraged, often resulting in a lack of co-regulation and subsequent bonding between the parent-infant dyad. Limited face-to-face interactions with the interprofessionals managing the care of their baby reduce the ability for parents/families to develop a trusting and respectful relationship. This depletes the power of the parents to share decision making for their baby with the members of the healthcare providers/team. As a result, parents may not own the healthcare decision and the health outcome. This creates a sense of moral distress for the parents and potentially a fractured relationship with the healthcare providers/team.

When families spend little time with their baby or are not able to interact with the healthcare team, worry and fear increase. Confidence in their parenting skills diminishes, leading to concerns about how to take over caregiving once home. The transition to home and the continuity for continued community-based care are often impacted. The implementation of IFCDC approach will promote high-quality care, ease the transition to home, and facilitate positive long-term outcomes of the family unit.

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