



Individualized Family-Centered Developmental Care

An Essential Model to Address the Unique Needs of Infants With Congenital Heart Disease

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Background: Infants born with critical congenital heart disease (cCHD) who require surgical intervention in the newborn period are often hospitalized in a cardiac intensive care unit (CICU). Cardiac surgery and the CICU environment are traumatic to infants and their families. Infants are exposed to overwhelming stress, which can result in increased pain, physiologic instability, behavioral disorganization, disrupted attachment, and altered brain development. Individualized Family-centered Developmental Care (IFDC) is a model that can address the unique needs and developmental challenges of infants with cCHD. **Purpose:** The purpose of this article is to (1) clearly describe the uniqueness of the infant with cCHD, including the medical, neurological, and parental challenges, and (2) propose methods to apply IFDC to support recovery of infants with cCHD in the CICU. **Conclusions:** The experiences in the CICU shape the developing brain and alter recovery and healing, thus adversely impacting development. Individualized Family-centered Developmental Care is a promising model of care that nurses can integrate into the CICU to promote neuroprotection and development. Nurses can effectively integrate IFDC into the CICU by understanding the unique characteristics of infants with cCHD and applying IFDC interventions that include both maturity and recovery perspectives. **Clinical Implications:** The incorporation of IFDC interventions is essential for the infant with cCHD and should be a standard of care. Applying IFDC with a recovery perspective in all aspects of caregiving will provide opportunities for individualization of care and parent engagement, allowing infants in the CICU to recover from surgery while supporting both short- and long-term neurodevelopment.

KEY WORDS: congenital heart disease, critical care, development, family-centered nursing, infant care

Infants born with critical congenital heart disease (cCHD) are the most fragile subset of patients with CHD because they require open heart surgery in the

newborn period to be able to survive. These infants are at 3 to 4 times the risk for developing learning disabilities, behavioral problems, mental health problems, and other developmental deficits or delays compared with children with structurally normal hearts.^{1–6} Much focus has been given by researchers and clinicians on describing and mitigating these challenges in this at-risk

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population.⁷ Although the causes are clearly multifaceted, little attention has been given to the early care needs during the fragile newborn period. Infants born with cCHD are often hospitalized in a mixed pediatric intensive care unit or a dedicated cardiac intensive care unit (CICU). For the purposes of this article, we will use “CICU” throughout. The developing infant brain needs closeness with its mother and family, including voice and affect regulation with family members to support security and trust, which are greatly reduced in the CICU.⁸ However, necessary care in the CICU exposes infants to overwhelming stress through a myriad of noxious stimuli, including painful procedures, invasive lines and tubes, and intense sensory stimulation. Bonding and attachment between parent and infant are disrupted. Mobility is limited. Neurotoxic medications are required to reduce pain and agitation. The combination of these negative experiences disrupts the infant's synaptogenesis, brain maturation, and neurodevelopment.⁹ The CICU environment creates a misalignment between what the developing brain needs and what the environment provides, impacting both short- and long-term neurodevelopment.

Current research advocates for the integration of Individualized Family-centered Developmental Care (IFDC) into CICU care.^{9,10} It is a model of care that minimizes the mismatch between infant neurobiological needs and the CICU environment, thus diminishing the frequency and/or severity of adverse effects on the high-risk infant. Core components of IFDC include parent engagement, cue-based care, and the provision of a supportive environment. Many positive outcomes of IFDC have been demonstrated.^{11–13} Individualized Family-centered Developmental Care originally evolved from the Neonatal Individualized Developmental Care and Assessment Program, which demonstrated positive outcomes for premature infants including enhanced brain structure and function, along with improved behavioral outcomes into school age.¹⁴ In addition, medical benefits have been reported such as decreased length of ICU and hospital stays, earlier oral feeding, and increased weight gain,^{12–17} along with parental engagement, parent attachment to their infant, and parental confidence in caregiving.^{18–22}

Individualized Family-centered Developmental Care has been integrated into neonatal intensive care units but only recently surfaced for CICUs.^{23–29} Currently, the use of IFDC in CICUs is variable; many centers report difficulty in implementation due to the perceived acuity of patients and lack of staff education.²⁴ One contributing explanation may be that there is sparse literature describing the challenges of infants with cCHD during the neonatal period. Furthermore, most literature on IFDC is focused on the premature infant in the neonatal intensive care units and arises from a maturation perspective, where developmental supports are focused on enhancing development and promoting growth

outside the womb for the infant born early. Most infants with cCHD, however, are born near- or full-term and struggle with recovery after cardiac surgery, along with challenges in growth and development. Although there are some similarities, we believe that the infant with cCHD in the CICU is fundamentally different from the premature infant in the neonatal intensive care units, requiring an approach to care that includes both an understanding of neurodevelopmental maturation and cardiac-specific recovery requirements. We propose that these unique characteristics create barriers and challenges for staff to fully integrate IFDC into CICUs. We believe that a synthesis of the literature regarding the behavioral and developmental profile of infants with cCHD will provide guidance to nurses and healthcare professionals in the CICU to understand the behavioral profile of the infant with cCHD and to successfully apply IFDC into practice. The purpose of this article is to (1) clearly describe the uniqueness of the infant with cCHD, including the medical, neurological, and parental challenges, and (2) propose methods to apply IFDC to support recovery of infants with cCHD in the CICU.

Unique Considerations for the Infant With Critical Congenital Heart Disease

Infants with cCHD show some similarities to other hospitalized newborns; however, they also have their own unique behavioral profile with specific medical, neurological, and parental challenges (see Figure).^{25,30,31}

Medical Challenges

Infants with cCHD require frequent monitoring of physiological parameters including evaluation of heart rate and rhythm, blood pressure, central filling pressures, perfusion, volume status, urine output, and temperature regulation.³² Many are physiologically fragile, with minimal reserve to adapt to stressors in the environment. Routine nursing is a source of stress, impacting both sleep and pain. Sleep, which is essential for synapse formation and memory facilitation, becomes frequently disrupted.^{33,34} Painful experiences during early development shape the overall pain system and determine the final architecture of the adult brain.³⁵ Pain must be monitored and managed, particularly after surgery, often requiring pharmacologic intervention, which places infants at an increased risk for adverse effects of excessive sedation, respiratory depression, withdrawal, and diminished responsiveness to caregivers and parents.³⁶ Furthermore, infants are at risk for a myriad of consequences of open heart surgery, including hemodynamic instability, persistent hypoxemia, infection, dysrhythmias, cardiac arrest, seizures, cardiovascular collapse requiring extracorporeal membrane oxygenation, and a prolonged length of stay.

	Fetal	Before Surgery	After Surgery	Hospital Discharge
CHD-Specific Risk Factors for Abnormal Neurodevelopment and Prolonged Length of Stay	<ul style="list-style-type: none"> • Low Oxygen Delivery • Placental Insufficiency • ↑ Incidence of Prematurity and Small for Gestational Age • ↑ Risk of Genetic Abnormalities • ↑ Family Anxiety and Stress 	<ul style="list-style-type: none"> • Low Cerebral Oxygen Delivery • ↑ Incidence of Necrotizing Enterocolitis • ↑ Risk of Paradoxical Embolus if Right to Left Shunt Present • Continued Family Anxiety and Stress 	<ul style="list-style-type: none"> • Unstable Hemodynamics and Cerebral Oxygen Delivery • ↑ Incidence of Seizures • ↑ Risk of Paradoxical Embolus if Right to Left Shunt Present • ↑ Risk of Extracorporeal Membrane Oxygenation • Prolonged Mechanical Ventilation • Intermittent Hyperventilation During Hand Bagging and Suctioning • Need for Significant Amounts of Sedation and Analgesia • Prolonged Phthalate and Other Toxin Exposure • Bland Environment and Lack of Social Stimulation • Frequent Noxious Stimuli and ↑ Noise Levels • ↑ Time in Supine Position Secondary to Sternotomy • ↑ Tissue Edema Reducing Range of Motion • Feeding Intolerance • Poor Oral Motor Coordination • Continued Family Anxiety and Stress 	<ul style="list-style-type: none"> • Acute Decrease in Nursing Observation and Cardiovascular Monitoring • Continued Family Anxiety and Stress • Multiple Medications • Continued Feeding and Growth Challenges • Incomplete Transmission of Neurodevelopmental Care Plan and/or Medical Plan
Individualized Family-Centered Developmental Care Interventions	<ul style="list-style-type: none"> • Mental Health Screening • Psychological Support • Frequent Communication • Parental Education Regarding Early Expectations After Birth • Lactation Consultation 	<ul style="list-style-type: none"> • Skin-to-Skin (Kangaroo) Care • Feed Based on Oral Feeding Readiness Cues - Consider Pacifier Dips of Breast Milk if Unstable for Enteral Feeds • Breastfeeding Opportunities When Infant is Feeding Orally • Begin to Teach Parents About Infant Behavioral Cues • Non-pharmacologic Methods to Reduce Pain and Stress • Mental Health Screening • Ongoing Parental and Family Support • Lactation Consultation • Thermoregulation 	<ul style="list-style-type: none"> • Skin-to-Skin (Kangaroo) Care • Feed Based on Oral Feeding Readiness Cues – Consider Pacifier Dips of Breast Milk if Unstable for Enteral Feeds – Supplement Oral Feeding with Nasogastric When Needed • Maximize Nutrition by Reviewing Daily Caloric Intake Goals. • Continued Lactation Consultation • Breastfeeding Opportunities When Infant is Feeding Orally • Bundle Invasive Care to Minimize Sedation and Analgesia Use • Non-pharmacologic Methods to Reduce Pain and Stress • Early and Frequent Utilization of Physical, Occupational, and Speech Therapists • Cycled Lighting and Noise Reduction • Continued and Frequent Parental and Family Support • Maximize Parental Engagement and Participation in Care • Thermoregulation 	<ul style="list-style-type: none"> • Neurodevelopmental Follow-up Appointments Scheduled Prior to Hospital Discharge • Specific Instructions on When, How and Who to Contact with Parental Concerns • Continued and Frequent Parental Support After Discharge • Frequent Nutritional and Feeding Assessments, Particularly for Infants Receiving Tube Feedings • Skin-to-Skin (Kangaroo) Care at Home

FIGURE. IFDC with CHD-Specific Risk Factors and Interventions.

Neurological Challenges

Critical CHD is frequently associated with “congenital brain disease,” given the known prenatal and postnatal insults to brain development.^{37,38} Up to 50% of infants with cCHD are at risk for neurodevelopmental impairments.³⁹ Brain injury may occur during intrauterine life and before cardiac surgery.^{22,40} Studies have shown that infants with cCHD present with higher rates of microcephaly, brain immaturity, and white matter injury at birth.³⁷ Prenatal programming of the infant may also occur as a result of maternal stress during pregnancy, which has been shown in other populations to increase the risk for neurodevelopmental sequelae.⁴¹ Later, acquired neurologic injury may arise from the adverse effects of anesthetics, cardiopulmonary bypass, sedation, analgesia, hypoxia, seizures, or stroke.^{1,42}

Delays in neurodevelopment can appear early in infancy and present as atypical autonomic, state, and motor organization, as well as feeding dysfunction.⁴³ Infants with cCHD are easily overwhelmed by social and sensory stimulation, are difficult to console, and have poor visual orienting.^{44–46} Motor challenges can occur related to neurologic injury, including hypotonia/hypertonia, asymmetry of movement, and general gross motor delays.^{5,30,43,47,48} Infants also often demonstrate weak sucking and few feeding readiness cues. Feeding difficulties, coupled with symptoms of congestive heart failure, frequently lead to tube feeding, delayed oral feeding, and

poor weight gain and growth.^{49–51} The etiology of feeding dysfunction is multifactorial and often related to the hemodynamic status of the infant and, in some, injury to the recurrent laryngeal nerve, phrenic nerve, and thoracic duct as a consequence of surgery near the aortic arch or left pulmonary artery. Additional factors influencing feeding dysfunction may include fatigue, increased respiratory rate, sedation levels, neurologic status, vocal cord dysfunction, and dysphasia. Neurologic insult may also contribute to poor feeding organization in this population.⁵²

Parental Challenges

Parents of infants born with cCHD experience high stress from the time of infant diagnosis through the subsequent hospitalization(s) for cardiac surgery and beyond. Infants may be immediately separated from their parents after birth, causing an alteration in the normal attachment process.⁵³ Parents are often unable to feed, hold, care, and, at times, even touch their critically ill infant, creating a sense of altered parental role.^{54,55} Mothers, in particular, experience heightened stress, anxiety, and depression.^{56–61} Parental stress influences the parent's quality of life, mental health, and overall family functioning.⁶² Parental stress impacts the child's overall development, and research is emerging that maternal mental health has more significant influence on child behavioral outcomes than the physiologic impact of the cCHD.⁶³

TABLE 1 Individualized Family-centered Developmental Care With a Recovery Perspective

IFDC Core Components	Benefits of Integrating IFDC Into Care	Vulnerabilities When Not Integrating IFDC Into Care	Examples of IFDC Interventions
Parent engagement	<ul style="list-style-type: none"> -Caregiver attunement to infant's experience -Considerations for emotional development: trust vs mistrust; enhances development of trusting relationships with parents -Parents actively participate in infant care practices -Parents feel confident and competent in providing direct care (eg, diaper change, feeding, wound care) 	<ul style="list-style-type: none"> -Isolation, parental separation for extended periods -Parent anxiety and stress -Missed opportunities for holding, skin-to-skin contact 	<ul style="list-style-type: none"> -Parent presence and participation in daily medical rounds -Parent holding of infant, skin-to-skin contact preferred -Parent provides as much infant care as possible based on the clinical stability of the infant (mouth care, diaper change, feeding, turning, holding, comforting, touching) -Parent provides nonpharmacologic comfort measures (pacifier, facilitated tucking, holding) during routine nursing care -Mother encouraged to breastfeed preoperatively and as soon as infant is able to eat by mouth postoperatively
Cue-based care (eg, infant state and attention)	<ul style="list-style-type: none"> -Individualized plan of care tailored to the unique needs of the infant -Caregivers respond to infant behavioral cues -Infant organization is supported 	<ul style="list-style-type: none"> -Bedside caregivers and/or parents unaware of when infant is most comfortable and available for social interaction -Infant stressed during feeds -Infant requires medication to recover from a disorganized state 	<ul style="list-style-type: none"> -Incorporation of infant behavior into routine assessment -Parents are taught to read and respond to infant behavioral cues -Feeds are provided to infants based on feeding readiness cues instead of a time-based schedule -Nonpharmacologic comfort measures are provided when infant shows stress cues
Supportive environment (eg, thermoregulation, positioning/motor)	<ul style="list-style-type: none"> -Promotion of normothermia -Circadian rhythm is supported -Neutral tucked body alignment and developmental positioning supported 	<ul style="list-style-type: none"> -Often cared for on warming beds, not able to wear clothes -At risk for hypothermia -Fixed extended postures for long periods without opportunities for neutral flexion -Fixed postures with head to one side (particularly for infants with an endotracheal tube or extracorporeal membrane oxygenation via neck cannulation) 	<ul style="list-style-type: none"> -Provision of cycled lighting to facilitate circadian rhythm -Low noise levels in the unit -Skin-to-skin contact offered as the preferred method of holding when infants require an artificial heat source (warming bed or incubator) -Positioning devices provided to maintain midline, neutral postures -Parents encouraged to provide containment and swaddling for the infant

Abbreviation: IFDC, Individualized Family-centered Developmental Care.

Applying Individualized Family-centered Developmental Care to Support Recovery in the Cardiac Intensive Care Unit

The challenge for nurses and other medical professionals in the CICU is to apply IFDC. We propose the application of IFDC in the CICU by including considerations for the infant's postoperative recovery needs (Table 1). Unlike the premature infant who spends weeks and months in the neonatal intensive care units working on feeding and growth (maturation), most infants with cCHD may spend only days to weeks in the CICU yet undergo an overwhelmingly stressful open heart surgery, requiring invasive medical and surgical care and constant attention to their physiology to be able to survive (recovery). It is important to note that approximately 20% of infants with cCHD have hospital lengths of stay of

2 months or greater; therefore, individualizing care based on their changing developmental needs is paramount.^{64,65} Regardless of the length of stay, all fragile infants benefit from the IFDC approach to care. Optimal outcomes will occur when the healthcare team focuses on both physiology and infant behavior, to adjust caregiving practices and the physical and emotional environment to support the developmental needs of the infant. Individualized Family-centered Developmental Care requires a shift in the critical care paradigm to include the evaluation of the infant's behavior and building a relationship between caregiver, infant, and family.

To the developing brain, all experience matters, both positive and negative; thus, each interaction shapes neural connections and long-term brain maturation. Individualized Family-centered Developmental Care provides the essential framework for nurses to support the

vulnerable developing brain while maintaining the medical stability of the recovering infant after cardiac surgery. To provide this care, nurses must add to the medical and task-oriented model of caregiving to include a relationship-based model of care where the infant is recognized as an individual who is communicating and interacting with the environment. All care must be regarded as “engaging with” the infant rather than “doing to” or “doing for.”⁶⁶ An understanding of infant communication should occur to properly individualize caregiving to meet the expectations of the infant's susceptible brain. Caregivers and parents should be engaged in continuous assessment of the infant, responding to the infant's behavioral cues and providing a supportive environment.⁶⁷

Nurses in the CICU are already acutely attuned to assessing the physiological status of the infant, but behavioral assessment should be included into care as well. In current practice, most nurses begin caregiving with a physical assessment of the patient, then creation of a plan of care, implementation of the plan, and re-evaluation of the patient. Behavioral assessment should be integrated as the first step into IFDC implementation to guide the plan of care. Reading infant behavior is key to promote individualization of care and inform nursing interventions at the point of care.

Behavioral Assessment

Infant behavior is composed of 4 subsystems of functioning: autonomic, motor, state, and self-regulation. These systems exist simultaneously and mutually influence each other, occurring in continuous interaction with the environment.⁶⁸ The infant with cCHD is physiologically vulnerable, and this instability is seen in all systems of functioning, such as poor coloring, low motor tone, prolonged metabolism of sedative medications and withdrawal, limited alertness, and poor self-regulation. Reading infant behavior is similar to learning any language, requiring education and practice. Even very fragile infants display reliably observable behaviors in the form of autonomic and visceral responses, movement patterns, level of alertness of state, and self-regulation.^{68,69} Medical providers can assess each subsystem while performing the standard head-to-toe body system assessment (Table 2). Infant behaviors can be categorized as organized when the infant is well regulated and disorganized when the infant has difficulty adapting to internal or external stimuli.^{70,71} Parent engagement is essential because they are the infant's stable, familiar, predictable, and primary caregivers. Therefore, parents must also be educated on how to read and respond to infant behaviors and to discern when the infant is organized versus disorganized.

TABLE 2 Behavioral Assessment

	Assessment Definition	Organized	Disorganized
Autonomic	Respiration patterns, color fluctuations, visceral system, heart rate variability	Smooth respiration, good and stable color, and stable digestion	Respiratory pauses and changes, color changes, tachypnea, cyanotic, gray, flushed, gagging, gasping, spitting up, hiccupping, bowel movement strains/straining, gas, tremors, startling, coughing, sneezing, yawning, and sighing
Motor	Postures; tone of the trunk, extremities, and face; movement patterns; coordinated suck	Smooth well-modulated posture and well-modulated tone, synchronous smooth movements with efficient strategies such as hand-on-face protection, hand clasping, foot clasping, finger folding, hand-to-mouth maneuvers, grasping, suck-searching and sucking, hand holding, tucking	Flaccidity, tuning out, low tone in face/gape face, hypertonicity, hyperextensions, legs and arms (stretching out, stiffening, trying to brace), trunk (arching), tongue thrusting, finger splaying, facial grimacing, protective maneuvers such as high guard arm position and fisting, and frantic and diffuse activity
State	Range, robustness, transitions	Clear, robust sleep states, rhythmic, robust crying, good self-quieting, robust, focused, shiny-eyed alertness with intent and/or animated facial expression, frowning, cooing, smiling, cheek softening, mouth pursing to “ooh” face	State-related signals of disorganization, strained fussing or crying, glassy eyed, strained alertness, irritability, panicked or worried, staring or averting eyes, eye floating, diffuse sleep or awake states with whimpering sounds, facial twitches and discharge smiling, rapid state oscillations
Self-regulation	Behaviors the infant uses to maintain the integrity and balance of other subsystems and to move smoothly between states	Any of the organization signals mentioned previously	Any of the disorganization signals mentioned previously

Supporting Organization by Applying Individualized Family-centered Developmental Care Interventions in the Cardiac Intensive Care Unit

Autonomic. Autonomic assessment in an infant with cCHD may be challenging as skin color is often atypical at baseline and sedative medications, as well as excessive stimulation, can cause abnormal movements. Nurses must consider other sources of autonomic instability, including pain, temperature instability, hemodynamic instability, atypical seizures, or withdrawal from analgesic or sedative medications. The provision of calming techniques during and after caregiving, such as offering a pacifier, swaddling, or gentle touch, has been shown to increase physiologic stability.⁷² Another alternative is offering 2-person care to fragile infants, where the nurse provides a medical intervention and a parent, therapist, or second nurse supports the infant. Parents should be given a key role in the CICU and encouraged to provide these forms of nonpharmacologic comfort measures. It is important to consider thermoregulation and the need for clothing and blankets when the infant is held or in the open environment. Partial swaddling during caregiving is helpful. For example, during a diaper change, the upper extremities and chest can be maintained swaddled in a blanket. A particularly vulnerable time for temperature instability is when the infant is transitioning out of an artificial heat source such as a warmer bed or an incubator.

Motor. Supporting the motor system may be challenging for postsurgical infants who must remain supine given medical risks, including sternotomy and delayed sternal closure, transthoracic intracardiac catheters, and chest tubes. These medically necessary limitations present a challenge to creating a position supportive of the infant's motor system. Postoperative infants often have low tone and need assistance to round their hips and shoulders forward and bring their hands and knees to midline. Small blanket rolls or positioning devices under both sides of the shoulders and hips are necessary, especially for the child who is sedated and paralyzed. Positioning devices should prevent hyperextension of the neck. If hyperextension of the neck is required to maintain an open airway for long periods, reintubation should be considered. Positioning devices should support flexion of the hips and knees toward midline, minimizing outward extension ("frog legs"), as often occurs in the immediate postoperative period. Supportive positions, such as prone in a well-tucked position on the parent's chest, are ideal and should be a goal for the infant with cCHD before and after surgery. In addition to holding, parents should be encouraged to support flexion and containment with their hands, also known as *facilitated tucking*.

State Regulation and Self-regulation. Postsurgical analgesia and sedation, along with a compromised autonomic

system, create challenges for infants to attain a quiet alert state. Caregiving interventions to support state regulation include remaining in-tune with the infant's cues, providing breaks as needed by bundling care with pacing, and maintaining contact with the infant so that stimulation is not continually coming and going. If the infant is overwhelmed or stressed, nurses can modify caregiving to provide support for the infant. Environmental interventions such as minimizing sound, regulating light, and promoting sleep provide additional stress relief to the infant and support self-regulation. Televisions should not be used as a state regulator for infants, rather, supportive holding, swaddling, and a soft voice to promote quiet alertness. Sound machines, lullabies, soft music, and musical crib toys should be used sparingly because these often are overwhelming to the recovering infant and also add to the overall noise level in the room. Preferably, lower the sound level in the CICU rather than cover up the noise with more sound. Parents can read or sing to their infants or provide recordings of their voices if they are unable to be present at the bedside. Nurses can provide cycled lighting to promote infant circadian rhythm development, allowing low, indirect light during the day when awake and darkness at night. Care in the CICU will inevitably require bright light at times; however, infants' eyes should be protected from the light with a dark cloth or a hand, even during periods of sedation. Excessive noise and light also disrupt sleep, which is critical in the newborn period. Sleep disturbances impact cognition, attentional, and psychosocial development.⁷³

Supporting Family-centered Care

The CICU team is uniquely positioned to enhance parental role and support attachment and bonding between infants and parents. Even when the infant is critically ill, parents should be viewed as the infant's primary caregiver and participate in care and decision making. Parents can and should be integrated into care, regardless of the infant's medical fragility. For the most fragile infant, parent engagement might include assisting the nurse in routine care such as mouth care, diaper changing, positioning, touching, or providing facilitated tucking. Evidence is overwhelming in infant literature that holding and touch stabilizes the most fragile infants.⁷⁴⁻⁷⁷ When holding is not possible, alternative types of nurturing touch can be used, such as supporting the parent to cradle the infant in the crib. As infants recover, parental engagement can be expanded to include all aspects of care, including feeding, comforting, and holding the infant to support parent's active participation in the care of their infant. The preferred method of holding for parents is skin-to-skin contact, also known as *kangaroo care*. Skin-to-skin contact protects infants from nosocomial infection, supports growth, and promotes temperature stability for infants requiring

What's New and Important?

- Infants with cCHD are exposed to overwhelming stress in the CICU, which can result in increased pain, physiologic instability, behavioral disorganization, challenges to attachment, and altered brain development.
- The infant with cCHD is unique from the premature infant, requiring an approach to care of IFDC that includes both maturation and cardiac-specific recovery perspectives.
- Reading infant behavioral cues allows nurses, caregivers, and parents to assess infant needs at a specific point in time and respond with IFDC interventions that promote short- and long-term neurodevelopment.

an artificial heat source in the preoperative or postoperative period.^{78–80}

Conclusions and Implications

Infants with cCHD have an increased risk for abnormal neurodevelopment. The experiences in the CICU shape the developing brain and alter recovery and healing, thus adversely impacting development. Individualized Family-centered Developmental Care is a promising model of care that nurses can integrate into the CICU to promote neuroprotection and development. Nurses can effectively integrate IFDC into the CICU by understanding the unique characteristics of infants with cCHD and applying IFDC interventions that include both maturity and recovery perspectives.

We have presented some examples of clinical interventions that can be incorporated into the care of infants with cCHD in the CICU using IFDC; however, many research implications also exist. Specific IFDC interventions should be studied to understand their impact on infants with cCHD, such as cycled lighting, holding and positive touch, or the use of nonpharmacologic comfort interventions. Future research should examine both short- and long-term outcomes of IFDC on infant neurodevelopment. Instrument development for the measurement of developmental care in the CICU, which accounts for the infant's medical fragility, would be beneficial to enable researchers to examine both the individual and unit level variables of IFDC. Finally, studies should examine the impact of parent engagement and participation in care on infant developmental outcomes, as well as family outcomes such as parent stress, parent-infant attachment, or family functioning.

REFERENCES

1. Clouchoux C, Du Plessis AJ, Bouyssi-Kobar M, et al. Delayed cortical development in fetuses with complex congenital heart disease. *Cereb Cortex*. 2013;23(12):2932–2943.
2. Mussatto KA, Hoffmann RG, Hoffman GM, et al. Risk and prevalence of developmental delay in young children with congenital heart disease. *Pediatrics*. 2014;133(3):e570–e577.
3. Newburger JW, Sleeper LA, Bellinger DC, et al. Early developmental outcome in children with hypoplastic left heart syndrome and related anomalies: the single ventricle reconstruction trial. *Circulation*. 2012;125(17):2081–2091.
4. Wernovsky G. Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. *Cardiol Young*. 2006;16(suppl 1):92–104.
5. Snookes SH, Gunn JK, Eldridge BJ, et al. A systematic review of motor and cognitive outcomes after early surgery for congenital heart disease. *Pediatrics*. 2010;125(4):e818–e827.
6. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation*. 2012;126(9):1143–1172.
7. Wernovsky G, Licht DJ. Neurodevelopmental outcomes in children with congenital heart disease—what can we impact? *Pediatr Crit Care Med*. 2016;17(8 Suppl 1):S232–S242.
8. Hofer MA. Early social relationships: a psychobiologist's view. *Child Dev*. 1987;58:633–647.
9. Anand KJS, Scalzo FM. Can adverse neonatal experiences alter brain development and subsequent behavior?. *Biol Neonate*. 2000;77:69–82.
10. Daniels JM, Harrison TM. A case study of the environmental experience of a hospitalized newborn infant with complex congenital heart disease. *J Cardiovasc Nurs*. 2016;31(5):390–398.
11. Als H, Lawhon G, Duffy FH, McAnulty GB, Gibes-Grossman R, Blickman JG. Individualized developmental care for the very low birthweight preterm infant: medical and neurofunctional effects. *J Am Med Assoc*. 1994;272(11):853–858.
12. Als H, Gilkerson L, Duffy FH, et al. A three-center randomized controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting and caregiving effects. *J Dev Behav Pediatr*. 2003;24(6):399–408.
13. Als H, Duffy FH, McAnulty GB, et al. Early experience alters brain function and structure. *Pediatrics*. 2004;113(4):846–857.
14. McAnulty G, Duffy FH, Kosta S, et al. School age effects of the newborn individualized developmental care and assessment program for medically low-risk preterm infants: preliminary findings. *J Clin Neonatol*. 2012;1(4):184–194.
15. Westrup B, Kleberg A, von Eichwald K, Stjernqvist K, Lagercrantz H. A randomized, controlled trial to evaluate the effects of the newborn individualized developmental care and assessment program in a Swedish setting. *Pediatrics*. 2000;105(1 pt 1):66–72.
16. Kleberg A, Westrup B, Stjernqvist K, Lagercrantz H. Indications of improved cognitive development at one year of age among infants born very prematurely who received care based on the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Early Hum Dev*. 2002;68:83–91.
17. Als H, Lawhon G, Gibes R, Duffy FH, McAnulty GB, Blickman JG. *Individualized behavioral and developmental care for the VLBW preterm infant at high risk for bronchopulmonary dysplasia and intraventricular hemorrhage: study II NICU outcome*. Woodstock, VT: Paper presented at: New England Perinatal Association Annual Meeting; 1988.
18. Als H, Duffy FH, McAnulty G, et al. NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction. *J Perinatol*. 2012;32:797–803.
19. Sannino P, Gianni ML, De Bon G, et al. Support to mothers of premature babies using NIDCAP method: a non-randomized controlled trial. *Early Hum Dev*. 2016;95:15–20.

20. Kleberg A, Hellström-Westas L, Widström AM. Mothers' perception of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared to conventional care. *Early Hum Dev.* 2007;83(6):403–411.
21. Nelson AM, Bedford PJ. Mothering a preterm infant receiving NIDCAP care in a level III newborn intensive care unit. *J Pediatr Nurs.* 2016;31(4):e271–e282.
22. Ohlsson A, Jacobs SE. NIDCAP: a systematic review and meta-analyses of randomized controlled trials. *Pediatrics.* 2013.
23. Peterson JK. Supporting optimal neurodevelopmental outcomes in infants and children with congenital heart disease. *Crit Care Nurse.* 2018;38(3):68–74.
24. Sood E, Berends WM, Butcher JL, et al. Developmental care in North American pediatric cardiac intensive care units: survey of current practices. *Adv Neonatal Care.* 2016;16(3):211–219.
25. Torowicz D, Lisanti AJ, Rim JS, Medoff-Cooper B. A developmental care framework for a cardiac intensive care unit: a paradigm shift. *Adv Neonatal Care.* 2012;12(suppl 5):S28–S32.
26. Butler SC, Huyler K, Kaza A, Rachwal C. Filling a significant gap in the cardiac ICU: implementation of individualised developmental care. *Cardiol Young.* 2017;27(9):1797–1806.
27. Lisanti AJ, Cribben J, Connock EM, Lessen R, Medoff-Cooper B. Developmental care rounds: an interdisciplinary approach to support developmentally appropriate care of infants born with complex congenital heart disease. *Clin Perinatol.* 2016;43(1):147–156.
28. Medoff-Cooper B, Irving SY, Hanlon AL, et al. The association among feeding mode, growth, and developmental outcomes in infants with complex congenital heart disease at 6 and 12 months of age. *J of Peds.* 2016;169:154.e1–159.e1.
29. Peterson JK, Evangelista LS. Developmentally supportive care in congenital heart disease: a concept analysis. *J Pediatr Nurs.* 2017;36:241–247.
30. Ricci MF, Andersen JC, Joffe AR, et al. Chronic neuromotor disability after complex cardiac surgery in early life. *Pediatrics.* 2015;136(4):e922–e933.
31. Sables-Baus S, Kaufman J, Cook P, da Cruz EM. Oral feeding outcomes in neonates with congenital cardiac disease undergoing cardiac surgery. *Cardiol Young.* 2012;22(1):42–48.
32. Beke DM. Norwood procedure for palliation of hypoplastic left heart syndrome: right ventricle to pulmonary artery conduit vs modified Blalock-Taussig shunt. *Crit Care Nurse.* 2016;36(6):42–51.
33. Peng NH, Chen CH, Bachman J, et al. To explore relationships between physiological stress signals and stress behaviors in preterm infants during periods of exposure to environmental stress in the hospital. *Biol Res Nurs.* 2011;13(4):357–363.
34. Smith GC, Gutovich J, Smyser C, et al. Neonatal intensive care unit stress is associated with brain development in preterm infants. *Ann Neurol.* 2011;70(4):541–549.
35. Anand KJS, Carr DB. The neuroanatomy, neurophysiology, and neurochemistry of pain, stress, and analgesia in newborns and children. *Pediatr Clin North Am.* 1989;36:795–822.
36. Naguib AN, Dewhirst E, Winch PD, Sinsic J, Galantowicz M, Tobias JD. Pain management after surgery for single-ventricle palliation using the hybrid approach. *Pediatr Cardiol.* 2012;33(7):1104–1108.
37. Wernovsky G, Licht DJ. Neurodevelopmental outcomes in children with congenital heart disease—what can we impact? *Pediatr Crit Care Med.* 2016;17(8 suppl 1):S232–S242.
38. Licht DJ, Shera DM, Clancy RR, et al. Brain maturation is delayed in infants with complex congenital heart defects. *J Thorac Cardiovasc Surg.* 2009;137(3):529–537.
39. Mebius MJ, Kooi EMW, Bilardo CM, Bos AF. Brain injury and neurodevelopmental outcome in congenital heart disease: a systematic review. *Pediatrics.* 2017;140(1):e20164055.
40. Khalil A, Bennet S, Thilaganathan B, Paladini D, Griffiths P, Carvalho JS. Prevalence of prenatal brain abnormalities in fetuses with congenital heart disease: a systematic review. *Ultrasound Obstet Gynecol.* 2016;48(3):296–307.
41. Kim DR, Bale TL, Epperson CN. Prenatal programming of mental illness: current understanding of relationship and mechanisms. *Curr Psychiatry Rep.* 2015;17(2):5.
42. Naguib AN, Winch PD, Tobias JD, et al. Neurodevelopmental outcome after cardiac surgery utilizing cardiopulmonary bypass in children. *Saudi J Anaesth.* 2015;9(1):12–18.
43. Limperopoulos C, Majnemer A, Shevell MI, Rosenblatt B, Rohlicek C, Tchervenkov C. Neurodevelopmental status of newborns and infants with congenital heart defects before and after open heart surgery. *J Pediatr.* 2000;137(5):638–645.
44. Owen M, Shevell M, Donofrio M, et al. Brain volume and neurobehavior in newborns with complex congenital heart defects. *J Pediatr.* 2014;164(5):1121.e1–1127.e1.
45. Massaro AN, Glass P, Brown J, et al. Neurobehavioral abnormalities in newborns with congenital heart disease requiring open-heart surgery. *J Peds.* 2011;158(4):678.e2–681.e2.
46. Butler S, Sadhwani A, Stopp C, et al. *Neurodevelopmental assessment of infants with congenital heart disease in the early postoperative period.* Cincinnati, Ohio: Second Annual Cardiac Neurodevelopmental Symposium; 2016.
47. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation.* 2012;126(9):1143–1172.
48. Miller G, Egli KD, Contant C, Baylen BG, Myers JL. Postoperative neurologic complications after open heart surgery on young infants. *Archives of Pediatrics and Adolescent Medicine.* 1995;149(7):764–768.
49. Davis D, Davis S, Cotman K, et al. Feeding difficulties and growth delay in children with hypoplastic left heart syndrome versus d-transposition of the great arteries. *Pediatr Cardiol.* 2008;29(2):328–333.
50. Imms C. Feeding the infant with congenital heart disease: an occupational performance challenge. *Am J Occup Ther.* 2001;55(3):277–284.
51. Costello CL, Gellatly M, Daniel J, Justo RN, Weir K. Growth restriction in infants and young children with congenital heart disease. *Congenit Heart Dis.* 2015;10(5):447–456.
52. Medoff-Cooper B. Feeding Behaviors as an Index of Developmental Outcomes. International Congress of Infant Studies; Toronto, Canada; 2002.
53. Boztepe H, Ay A, Kerimoğlu Yıldız G, Çınar S. Does the visibility of a congenital anomaly affect maternal–infant attachment levels? *J Spec Pediatr Nurs.* 2016;21(4):200–211.
54. Lisanti AJ, Golfenshtein N, Medoff-Cooper B. The pediatric cardiac intensive care unit parental stress model: refinement using directed content analysis. *Advances in Nursing Science.* 2017;40(4):319–336.
55. Franck LS, Mcquillan A, Wray J, Grocott MP, Goldman A. Parent stress levels during children's hospital recovery after congenital heart surgery. *Pediatr Cardiol.* 2010;31(7):961–968.
56. Vrijmoet-Wiersma CM, Ottenkamp J, van Roozendaal M, Grootenhuis MA, Koopman HM. A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiol Young.* 2009;19(6):608–614.
57. Lawoko S, Soares JJ. Psychosocial morbidity among parents of children with congenital heart disease: a prospective longitudinal study. *Heart Lung.* 2006;35(5):301–314.
58. Bevilacqua F, Palatta S, Mirante N, et al. Birth of a child with congenital heart disease: emotional reactions of mothers and fathers according to time of diagnosis. *J Matern Fetal Neonatal Med.* 2013;26(12):1249–1253.

59. Pinto NM, Weng C, Sheng X, et al. Modifiers of stress related to timing of diagnosis in parents of children with complex congenital heart disease. *J Matern Fetal Neonatal Med.* 2016;29(20):3340–3346.
60. Franich-Ray C, Bright MA, Anderson V, et al. Trauma reactions in mothers and fathers after their infant's cardiac surgery. *J Pediatr Psychol.* 2013;38(5):494–505.
61. Utens E, Versluis-Den Bieman H, Verhulst F, Witsenburg M, Bogers A, Hess J. Psychological distress and styles of coping in parents of children awaiting elective cardiac surgery. *Cardiol Young.* 2000;10(3):239–244.
62. Ernst MM, Marino BS, Cassedy A, et al. Biopsychosocial predictors of quality of life outcomes in pediatric congenital heart disease. *Pediatr Cardiol.* 2018;39(1):79–88.
63. McCusker CG, Doherty NN, Molloy B, et al. Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. *Arch Dis Child.* 2007;92(2):137–141.
64. Tabbutt S, Ghanayem N, Ravishankar C, et al. Risk factors for hospital morbidity and mortality after the Norwood procedure: a report from the Pediatric Heart Network Single Ventricle Reconstruction trial. *J Thorac Cardiovasc Surg.* 2012;144(4):882–895.
65. Brown KL, Ridout DA, Goldman AP, Hoskote A, Penny DJ. Risk factors for long intensive care unit stay after cardiopulmonary bypass in children. *Crit Care Med.* 2003;31(1):28–33.
66. Als H, Gilkerson L. The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Semin Perinatol.* 1997;21(3):178–189.
67. Als H, Butler S. Neurobehavioral development of the preterm infant. In: Martin R. AFMW, ed. *Fanaroff and Martin's Neonatal-Perinatal Medicine: Diseases of the Fetus and Infant.* 9th ed. St Louis, MO: Elsevier Mosby; 2011:1057–1074.
68. Als H. A synactive model of neonatal behavioral organization: framework for the assessment and support of the neurobehavioral development of the premature infant and his parents in the environment of the neonatal intensive care unit. *Phys Occup Ther Pediatr.* 1986;6:3–53.
69. Als H. Reading the premature infant. In: Goldson E, ed. *Developmental Interventions in the Neonatal Intensive Care Nursery.* New York, NY: Oxford University Press; 1999:18–85.
70. Als H, Lester BM, Brazelton TB. Dynamics of the behavioral organization of the premature infant: a theoretical perspective. In: Field TM, Sostek AM, Goldberg S, Shuman HH, eds. *Infants Born at Risk.* New York, NY: Spectrum Publications; 1979:173–193.
71. Als H. *Manual for the Naturalistic Observation of the Newborn (Preterm and Fullterm).* Revision. Boston, MA: The Children's Hospital; 1984.
72. Committee on Fetus and Newborn, Section on Anesthesiology and Pain Medicine. Prevention and management of procedural pain in the neonate: an update. *Pediatrics.* 2016;137(2):e20154271.
73. Kurth S, Olini N, Huber R, LeBourgeois M. Sleep and early cortical development. *Current Sleep Med Rep.* 2015;1(1):64–73.
74. Smith JR. Comforting touch in the very preterm hospitalized infant: an integrative review. *Advances in Neonatal Care.* 2012;12(6):349–365.
75. Domínguez Rosales R, Albar Marín MJ, Tena García B, et al. Effectiveness of the application of therapeutic touch on weight, complications, and length of hospital stay in preterm newborns attended in a neonatal unit. *Enferm Clin.* 2009;19(1):11–15.
76. Harrison LL, Williams AK, Berbaum ML, Stem JT, Leeper J. Physiologic and behavioral effects of gentle human touch on preterm infants. *Res Nurs Health.* 2000;23(6):435–446.
77. Reynolds LC, Duncan MM, Smith GC, et al. Parental presence and holding in the neonatal intensive care unit and associations with early neurobehavior. *J Perinatol.* 2013;33(8):636–641.
78. Conde-Agudelo A, Díaz-Rossello JL. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Cochrane Database Syst Rev.* 2016;8:CD002771.
79. McCall EM, Alderdice F, Halliday HL, Jenkins JG, Vohra S. Interventions to prevent hypothermia at birth in preterm and/or low birthweight infants. *Cochrane Database Syst Rev.* 2010;3:CD004210.
80. Ludington-Hoe SM. Thirty years of Kangaroo Care science and practice. *Neonatal Network.* 2011;30(5):357–362.