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Supporting Optimal Neurodevelopmental Outcomes in Infants and Children With Congenital Heart Disease

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Abstract

Improved survival has led to increased recognition of developmental delays in infants and children with congenital heart disease. Risk factors for developmental delays in congenital heart disease survivors may not be modifiable; therefore, it is important that lifesaving, high-technology critical care interventions be combined with nursing interventions that are also developmentally supportive. Implementing developmental care in a pediatric cardiac intensive care unit requires change implementation strategies and widespread support from all levels of health care professionals. This manuscript reviews developmentally supportive interventions such as massage, developmentally supportive positioning, kangaroo care, cue-based feeding, effective pain/anxiety management, and procedural preparation and identifies strategies to implement developmentally supportive interventions in the care of infants and children with congenital heart disease. Improving developmental support for these infants and children at high risk for developmental delay may improve their outcomes and help promote family-centered care.

Congenital heart disease (CHD) affects approximately 1% of all live births, or about 40 000 births per year in the United States, and approximately one-third of infants with CHD require surgical or catheter-based intervention in the first year of life.¹ Advances

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This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Describe the mechanisms that place infants and children with congenital heart disease at risk for developmental delays
2. Identify 3 nursing interventions that promote optimal development in infants and children with congenital heart disease
3. Discuss how developmental supportive care could be integrated into existing nursing care for patients with congenital heart disease

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in CHD detection, surgical techniques, and perioperative management over the past 2 decades have resulted in significant improvement in CHD mortality. Today, 85% of patients with CHD are expected to survive to adulthood.² However, this decreased mortality has uncovered a significant percentage of CHD survivors with neurodevelopmental delays of varying degrees. The “neurodevelopmental phenotype” of CHD includes mild cognitive delay; delays in gross and fine motor skills, communication and pragmatic language skills, visual/motor and visual/spatial integration, and executive functioning; and difficulties with inattention, hyperactivity, and impulsivity.³ Risk factors for developmental delays following surgical treatment of CHD include prenatal, preoperative, and perioperative factors, many of which are not modifiable beyond a certain extent.^{4–6} Nonmodifiable risk factors include genetic abnormalities such as trisomy 21. Children with trisomy 21 and CHD have higher levels of developmental delay following cardiac surgery than children without genetic abnormalities or children with trisomy 21 and no CHD.^{7–9}

Other risk factors for developmental delay that are partially modifiable include cardiopulmonary bypass time, use of deep hypothermic circulatory arrest, and perioperative hemodynamic instability or cardiac arrest.^{4,6} Critical care nurses may be able to mitigate some of these effects through interventions that support hemodynamic and respiratory stability and through vigilant assessment and recognition of changes in patient status. Recent research has also suggested that the brain of a term neonate with significant CHD is similar, structurally and functionally, to the brain of a preterm infant with a gestational age of 36 weeks. This delayed maturation may increase the risk of brain injury during complex neonatal cardiac surgery.^{10,11} Some syndromes that are associated with cardiac anomalies, such as 22q11 microdeletion syndrome (DiGeorge syndrome) and CHARGE association (a syndrome including coloboma, heart anomaly, atresia choanae, growth retardation, genital abnormalities, and ear abnormalities), are also associated with functional neurologic or sensory abnormalities. Because of the high incidence of neurodevelopmental delay in CHD survivors, the American Academy of Pediatrics and American Heart Association have recently developed recommendations for neurodevelopmental surveillance, evaluation, and management of all children with CHD.² The impact of early neurodevelopmental interventions on outcomes in children with CHD have not been described to date. Programs for intensive follow-up and referral to early intervention programs are in place, and long-term studies are under way.^{12–14} Interventions may further reduce the impact of partially modifiable risk factors on developmental outcomes.

The intensely technological environment of the pediatric cardiac intensive care unit (PCICU) makes improved survival following surgical treatment of CHD possible. The focus of the interdisciplinary team is, by necessity, on critical decision-making in rapidly changing, complex conditions to achieve and maintain cardiopulmonary stability in the most fragile patients. This focus is crucial but may reduce the priority of providing care that is also developmentally supportive. The concept of developmentally supportive care (DSC) originated in the neonatal intensive care unit (NICU):

Developmental care is a framework that encompasses all care procedures as well as social and physical aspects in the newborn intensive care unit. Its goal is to support each individual infant to be as stable, well-organized, and competent as possible.¹⁵

Further evolution of DSC led to the Neonatal Integrative Developmental Care Model, whose core measures of neuroprotective neonatal care include the healing environment (both physical and sensory), partnering with families, positioning and handling, safe-guarding sleep, minimizing stress and pain, protecting skin, and optimizing nutrition.¹⁶ Given the important differences between the NICU and PCICU populations, DSC nursing practices cannot be automatically transferred, and rigorous studies of DSC practices in the cardiac population have not yet been reported. A definition of DSC for patients with CHD has recently been proposed using concept analysis:

Developmentally supportive care practices used in the NICU may not be appropriate for infants and children with CHD.

Developmentally supportive care for infants and children with CHD is family-centered nursing care that is adapted to meet the individual's unique needs as the individual interrelates with their environment. Developmentally supportive care for infants and children with CHD incorporates unique understanding of CHD and its effects on both the child and their family in order to provide excellent family-centered care through interprofessional collaboration and appropriate resources that promotes improved development, family performance, and satisfaction with care.¹⁷

Some recommendations for developmental care practices in the pediatric cardiac patient population have been developed recently.¹⁸ Despite interest in providing DSC to infants and children with CHD, organizations have reported varying degrees of implementation success.¹⁹ Although the outcomes of developmentally supportive interventions in this high-risk population are not completely known, it seems logical that interventions that may support neurodevelopmental potential and do not add risk to care should be incorporated into critical care nursing. The purpose of this review is to describe nursing interventions for infants and children with CHD that may be developmentally supportive and complementary to high-technology, lifesaving interventions to help achieve patients' developmental potential and maximize survival following treatment of CHD.

Implementing DSC

To successfully implement DSC at a programmatic level, it is necessary to use principles of effective change. Adoption of change requires support and active involvement at all levels, from senior leadership to advanced practice nurses, physicians, allied health professionals, and bedside nurses. Unit-based shared governance councils and advanced practice nurses can provide "champions" who support practice change, lead staff educational efforts, and establish a unit developmental care committee. One method of promoting DSC and implementing DSC measures is conducting developmental rounds in the PCICU.^{20,21} These weekly interdisciplinary rounds, led by a clinical nurse specialist, also include allied health professionals such as an occupational therapist, a speech language pathologist, a lactation consultant, and a child/ family life specialist, as well as the bedside nurse and the parents. The initial purpose of developmental rounds was to increase nurses' awareness of developmental issues in patients they cared for. The purpose evolved over time to focus on collaborative dialogue between parents, the bedside nurse, and the developmental team to identify potential developmental problems and strategies to meet developmental needs of the

infant or child.²⁰ This supportive care is family centered, and supporting and empowering families to participate in their child's care is a crucial component of DSC. Another potential benefit of developmental rounds is identification of developmental concerns that may benefit from patient referral to inpatient or postdischarge outpatient therapy. Developmental rounds can also help identify and overcome barriers to providing DSC and can therefore lead to successful implementation.

Massage

Massage is a form of nurturing touch and has been associated with improved weight gain and oral feeding ability in stable premature and healthy term infants.^{22,23} Infant massage and maternal touch have been shown to attenuate physiological and behavioral responses to stress and pain, decrease levels of cortisol, accelerate maturation of electroencephalograph and visual acuity, improve the quality of mother-infant interaction, and improve developmental scores.^{23–27} Infant massage study populations have typically included medically stable preterm infants and healthy term infants, with few studies involving medically fragile infants in an intensive care unit.²⁸

One study of massage in critically ill children reported that parasympathetic activity increased following hand and foot massage and persisted after repeated sessions.²⁹ Massage has also been used in hospitalized children to reduce pain and anxiety.^{30,31} Pediatric critical illness is increasingly recognized as a trigger for development of posttraumatic stress disorder and related mental health concerns, and activation of the autonomic nervous system is one potential causal mechanism.^{32,33} Massage for critically ill infants and children with CHD has not been reported in the literature, yet anecdotally this practice is not uncommon. However, it is often modified to meet the needs of critically ill children, such as by avoiding incisions and invasive device sites. Passive range of motion and stretching, which is similar to massage, was recently evaluated in neonates during recovery from stage 1 palliation (Norwood procedure) for hypoplastic left heart syndrome. This pilot study of 19 neonates reported that a passive stretching intervention performed by physical therapists for 15 to 20 minutes once daily for 21 days was both safe and feasible in infants with single-ventricle physiology and may positively influence somatic growth.³⁴ Although many studies of the effects of infant massage have used a randomized controlled design, most are not blinded, are single-center studies, and have small sample sizes and short-term follow-up.^{22–24,28,30,34}

Skin-to-Skin (Kangaroo) Care

Kangaroo care involves skin-to-skin contact between the infant and parent and is routinely used in normal newborn care as well as the care of preterm infants.^{35,36} The benefits of kangaroo care for infants include improved physiological and behavioral state regulation, reduced cortisol level, attenuated stress response, improved bonding with the caregiver, and improved breastmilk production in mothers.^{35–37} These studies included 2 randomized controlled trials, including 1 with longitudinal follow-up for 10 years, which adds to the quality of evidence supporting skin-to-skin care. Although kangaroo care is safely used in NICUs with premature infants requiring mechanical ventilation, there is some risk of unplanned extubation or inadvertent removal of monitoring catheters, which may be poorly

tolerated in infants with CHD. Therefore, it is important to develop protocols for safe use of kangaroo care as part of an overall plan for providing DSC.³⁸ Two case reports of kangaroo care in infants with CHD found that it was well tolerated, with no adverse events at the time of the intervention.^{39,40}

Developmentally Supportive Positioning

Motor development and development of self-regulatory behavior in infants rely on stable posture that is developmentally appropriate.⁴¹ All too often, infants and children in the PCICU are positioned in a “frog-legged” supine position with arms extended 90° to the side, which promotes hip and leg external rotation and may lead to abnormal muscle development over time. In preterm infants, developmentally supportive positioning has been shown to improve postural and musculoskeletal development⁴¹ and has also been associated with reduced pain scores following routine nursing care.⁴² Another study comparing 2 methods of developmentally supportive positioning in preterm infants demonstrated less asymmetry in reflex and motor responses in infants who were positioned using an experimental positioner.⁴³ However, these randomized controlled trials were single-center studies with relatively small effects reported. Long-term outcomes of developmentally supportive positioning have not been studied, but prevention of abnormal postures and muscle development is consistent with the goals of DSC. Developmentally supportive positioning techniques that are implemented as soon as medically feasible reduce stress on the infant or child and may promote motor development. These techniques gently flex and align the limbs and spine, with the arms positioned inward toward the body. Blanket rolls and positioning devices can be used to facilitate and maintain developmentally supportive positioning, with care taken to also reduce the risk of pressure ulcer formation, especially in patients with cardiopulmonary instability.⁴⁴

Cue-Based Feeding

Feeding infants with CHD can be especially challenging because of tachypnea related to underlying CHD, oral-motor dysfunction, and behavioral state dysregulation; in addition, infants with CHD may display less clear behavioral signs of fatigue and disengagement.⁴⁵ However, the infant’s ability to consume adequate calories and volume are important prerequisites for hospital discharge, so to reduce the length of stay, feeding goals may neglect the infant’s tolerance for and development of successful feeding experiences crucial for later development.⁴⁶ Cue-based feeding incorporates the infant’s cues of readiness to eat, engagement in the eating process, and satiety as drivers of the feeding experience and has been shown to result in shorter hospitalization and improved weight gain in preterm infants.^{47–49} Studies of the effects of cue-based feeding are generally single-center reports focusing on hospitalization outcomes such as length of stay. Infants with cyanotic heart disease, in particular, have been shown to have delayed feeding readiness and oromotor skills following cardiac surgery.⁵⁰ Studies of the effects of cue-based feeding in infants with CHD are lacking, but this intervention is important in DSC as the ability to achieve oral feedings is an important developmental task.

Implementing developmentally supportive care requires support and involvement at all levels.

Pain Management and Procedural Support

Outside the neonatal time period, hospitalization and invasive procedures for CHD are often elective or semielective in nature, affording the opportunity for preadmission preparation and planning for pain management and coping strategies. Pain is one potential factor associated with development of posttraumatic stress symptoms as well as less severe forms of psychological distress and is potentially modifiable with adequate preparation and planning.^{33,51,52} In neonates and infants, there is strong empirical evidence that concentrated sucrose solutions are effective at providing relief of brief procedural pain.^{53,54} However, sucrose solutions have not been found to be as beneficial in older children.⁵⁵ Preprocedural psychological preparation and intervention for painful or invasive procedures, based on developmental principles, have been reported to reduce pain and anxiety.^{56–58} Play therapy has been shown to be as effective as inhaled nitrous oxide in reducing procedural pain scores in preschool and school-aged children.⁵⁹ Distraction with interesting visual aids or computer tablets has also been shown to reduce procedural pain in toddlers and school-aged children, with strong evidence to support this practice.^{56,60,61} Among all types of DSC modalities, interventions for pain management and procedural preparation have been the most rigorously studied. These interventions should be used as appropriate, including by allied health professionals such as child/family life specialists and psychologists, and should include both pharmacologic and nonpharmacologic interventions as indicated by the patient's needs assessment.

High-technology critical care is necessary for survival, but at some point during recovery it is appropriate to incorporate a more developmentally supportive focus

Conclusions and Implications for Practice

An important consideration in implementing DSC interventions is that the quality of evidence supporting some interventions is not strong, with small sample sizes, selection biases, short follow-up, and other methodological problems limiting internal validity and applicability to other settings. Importantly, most studies of DSC interventions do not include patients with CHD, so the effects of DSC interventions in this high-risk population are not known.

Patients with CHD are at risk for developmental delay, with the greatest risk in those with the most complex forms of CHD and those who require complex intervention early in life. High-technology critical care is crucial to the infant's or child's survival, yet at some point during recovery it is appropriate to incorporate a more developmentally supportive focus. Interventions appropriate for providing DSC in the NICU may not be automatically transferrable to the pediatric cardiac patient population. For example, environmental modification in the NICU for preterm infants might include creating a more "womb-like" environment protected from light and sound and creating a nestlike surface. This would not be appropriate for a toddler recovering from surgical treatment of CHD, but certainly

environmental modification to reduce the cacophony of equipment alarms and voices of strangers at all hours would be beneficial to restore circadian rhythms and reduce stress.

Implementing a developmental care program within a PCICU requires careful consideration of strategies to successfully implement change and interdisciplinary support from all levels of health care professionals. In addition to these challenges, it is crucial that DSC interventions in infants and children with CHD be the focus of ongoing research to identify their impact on patient and family outcomes, both short-term and long-term. Recommendations for ongoing assessment and evaluation of developmental status in CHD survivors must be met with evidence-based interventions that promote achievement of individual developmental potential and optimal family functioning. Developmentally supportive care is a family-centered model that may help unite and direct the health care team caring for infants and children with CHD in a common goal of improving neurodevelopmental outcomes. CCN

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