



CHOC Children's Hospital
Best Evidence and Recommendations

Individualized Developmental Care Plans for Infants with Congenital Heart Disease

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PICO: Can immediate post-extubation implementation of an individualized developmental care plan for infants with congenital heart disease (CHD) under six months of age impact patient/family satisfaction scores, feeding outcomes, and LOS?

P (Population/problem): Infants <6 months old with CHD

I (Intervention/issue): Individualized developmental care plans

C (Comparison): current standard of care (no individualized developmental care plan)

O (Outcome): patient/family satisfaction scores, feeding outcomes, length of stay

Background:

Individualized family-centered developmental care (IFDC) is a well-documented approach to promoting developmentally supportive interventions and decreasing the adverse effects of the neonatal intensive care unit (NICU) environment on the preterm infant. Neonates born prematurely are exposed to light, sound, and touch experiences which their immature nervous systems are not ready to process, resulting in a high risk for developmental concerns (Pineda, Rainey & Smith, 2019). There are various definitions of IFDC, but all include of individualized interventions to minimize infant stress, facilitate neurological development, and decrease the risk of long-term developmental delays through modification of the environment and education to caregivers and medical staff. In a concept analysis, Macho & Zukowsky (2017) defined IFDC as “an approach to providing care to infants in the NICU and their family based on their cues and responses to care. Care must be individualized and collaborative between the infant, their family, and all healthcare personnel. Care also needs to include the ability to alter the infants’ care and environment to decrease stress to the infant and their family and maximize neurological, cognitive, and behavioral outcomes” (p.169). A systematic review of developmentally supportive care of the preterm infant by Lubbe, Van der Walt, and Klopper (2012) revealed improved health outcomes, earlier transition to oral feeds, decreased length of hospitalization, and improved neurobehavioral function at discharge.

With growing evidence that children with congenital heart defects (CHD) are at high risk for neurodevelopmental delays, studies over the past few decades have focused on the importance of developmental care practices for the pediatric cardiac population (Marelli, Miller, Marino, Jefferson & Newburger, 2016).



In addition to gross and fine motor delays, common clinical findings among infants with CHD include seizures, hypotonia, hypertonia, inability to suck, motor asymmetry, cranial nerve abnormalities, lethargy, restlessness, agitation, and poor behavioral state regulation (Khalil et al., 2014; Majnemer et al., 2009). Findings observed in a cohort study by Miller et al. (2007) suggest that newborns with CHD have impaired brain development in utero, as demonstrated by abnormal white matter and brain metabolism on MRI and MRS imaging. Brain imaging has also revealed that the neurological structures of full-term infants with CHD are similar to that of preterm infants, despite being full-term. These abnormal and immature brain structures indicate that term neonates with CHD are, in fact, more susceptible to brain injury (Licht et al., 2009; Miller et al., 2007). Panigrahy and colleagues (2015) identified that altered white matter microstructure is correlated with neurocognitive dysfunction even amongst adolescents with CHD. While infants with CHD are at high risk for brain injury, studies have shown that brain immaturity is more strongly associated with neurodevelopmental outcomes, specifically feeding abilities. A prospective cohort study looking at 48 term neonates with single ventricle physiology concluded that delayed brain maturation, as opposed to perioperative brain injury and the degree of heart failure (measured by the number of cardiac medications prescribed), was associated with the need for tube-assisted feeding at the time of hospital discharge after stage I surgical repair (Hsieh et al., 2019). Based on these findings, the importance of implementing developmental care practices to optimize infant brain development is becoming increasingly apparent.

IFDC has been documented to improve overall developmental outcomes in preterm infants in the NICU, leading to the need to implement similar concepts in caring for infants with CHD. Infants with CHD have unique needs, especially in a post-surgical intensive care environment secondary to multiple lines and drains, sedation/pain medications, sternal precautions, and the need for advanced respiratory support, all of which can be potentially damaging to the developing brain and sensory system. Research conducted in the CHD population thus far has focused on evaluating the risk factors and specific neurodevelopmental outcomes rather than prevention and intervention. There is a need to implement these evidence-based practices and continue to study the short and long-term effects on neurodevelopmental outcomes in this population. This project aims to establish consistent use of developmental care practices through education and collaboration to promote optimal neurodevelopment of the post-surgical infant with CHD.

Search Strategies and Databases Reviewed:

- Databases searched for this review included Google Scholar and Pub Med. Key search words: developmental care, CHD infants, parent stress CHD, neurodevelopmental delays CHD. This search yielded 37 articles.
- Email communication with other pediatric CVICU practitioners regarding the role of rehabilitation services in their unit yielded six responses.
- Email communication with clinical nurse specialists at CHOP yielded information regarding developmental care practices in their CVICU.

Synthesis of Evidence:



- Core components of IFDC identified in the literature (Aita & Snider, 2003; Legendre et al., 2011; Lubbe et al., 2012; Macho & Zukowsky, 2017)
 - Interaction.
 - Individualization.
 - Education (of infant development).
 - Professional collaboration.
 - Family involvement.
 - Modification of the physical environment.
- Impact of IFDC on outcomes (Aita & Snider, 2003; Legendre, et al., 2011; Lubbe, 2012; Macho & Zukowsky, 2017; Sabnis et al., 2019)
 - Fewer days on oxygen support.
 - Increased weight gain, improved feeding.
 - Improved motor outcomes.
 - Decreased length of hospital stay.
 - Increase in the organization of infant behaviors, including state regulation and attention.
 - Enhanced parenting skills and decreased parental stress
- A survey of developmental care practices in North American pediatric cardiac intensive care units revealed that there are targeted efforts to promote developmental care in the areas of (Sood et al., 2016):
 - Modifying the environment.
 - Improving self-regulation.
 - Positioning
- There is variation in practice among the centers regarding having a developmental care committee and developmental care rounds, as well as involving families in the care of the infant (Sood et al., 2016).
- A survey of 25 CVICUs revealed that while there is knowledge and competency in the individualized developmental care practice among nursing staff, the implementation of critical components is inconsistent (LaRonde et al. 2019).

Practice Recommendations:

IFDC has been shown in the literature to have positive benefits on the overall development of fragile infants and families in the NICU. Given the high prevalence of neurodevelopmental delays in infants with CHD, using developmental care practices in the CVICU would seemingly allow for similar outcomes in this population. The understanding of the concepts of IFDC is increasing in the CVICU; however, nursing practice surveys indicate inconsistencies in the implementation. The development of structured guidelines is needed to increase the use and consistency of IFDC practices.



- Establish automated orders for physical, occupational, and feeding therapy upon extubation for all post-surgical infants under six months of age.
- Obtain physical, occupational, and feeding therapy orders for post-surgical infants under six months of age at weekly rounds if they are still intubated after one week.
- Create a bedside tool for an individualized developmental care plan to be updated by the rehab team as the infant's needs evolve.
- Provide education to the medical and nursing staff regarding the importance and components of developmental care practice in the CVICU.
- Incorporate family into developmental care practice via education and demonstration.

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