A Developmental Care Framework for a Cardiac Intensive Care Unit

A Paradigm Shift

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ABSTRACT

Within the past several decades, medical and surgical advancements have dramatically decreased mortality rates in neonates and infants with congenital heart disease. Although patients are surviving in greater numbers, little research is reported on issues related to newborn care for these at-risk infants. A developmental care model was introduced to the nursing staff at the Children's Hospital of Philadelphia, which included 5 core measures to support evidence-based developmental care practices: (1) sleep, pain, and stress assessment; (2) management of daily living; (3) positioning, feeding, and skin care; (4) family-centered care; and (5) a healing environment. The care practices were adapted to the specific issues of the late preterm and full-term infant who has experienced neonatal cardiac surgery. The purpose of this article is to review the process of implementing a development model of care in a cardiac intensive care unit.

Key Words: congenital heart disease, developmental care, infant

Within the past several decades, medical and surgical advancements have dramatically decreased mortality rates in neonates and infants with congenital heart disease (CHD). Although patients are surviving in greater numbers, little research has been reported on issues related to newborn care for at-risk infants.[1] When critically ill infants near or in a children's hospital are diagnosed with CHD, they are immediately transferred to a cardiac intensive care unit (CICU) for advanced hemodynamic monitoring and observation for hemodynamic instability related to their heart defect. Infants born with the most complex heart defects undergo surgery within the first week of life. Many infants return to the CICU, with an open chest, thoracic incision, and peripheral, central, or intracardiac catheters, and on multiple intravenous administrations as well as being restrained.

There is a growing recognition of adverse neurologic sequelae in infants with CHD, which are found to be similar to the neurologic findings seen in premature infants. Periventricular leukomalacia, the most common ischemic brain injury in premature infants, may be present in up to 50% of all infants with hypoplastic left heart syndrome. Periventricular leukomalacia has been hypothesized to be an additive cause in predisposing infants with CHD to the susceptibility for neurologic insults in the preoperative, intraoperative, and postoperative periods.[2]

Support techniques used during heart surgery such as cardiopulmonary bypass and deep hypothermic circulatory arrest appear to be 2 further causes of cerebral injury.[2] As with premature infants, infants with decreased neurologic integrity are more likely to demonstrate greater physiologic instability when handled.[3] Wernovsky et al.[4] suggest that the brain of the full-term neonate with CHD structurally resembles that of a preterm neonate. Interestingly, school-aged survivors of complex heart surgery have developmental findings that parallel premature

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infants. The previously cited findings suggest that individualized developmentally supportive nursing care may be helpful in both preoperative and postoperative periods in infants with CHD and may promote neurologic and motor development using the following strategies: positioning, thermoregulation, comfort measures, and feeding. To address the issues cited, a developmental care model was introduced to the nursing staff at the Children's Hospital of Philadelphia (CHOP), which included 5 core measures to support developmental care practices (infant positioning, infant feeding, infant pain management, parental stress, and family-centered care).[5] The care practices were adapted to the specific issues of the late preterm and full-term infants who have experienced neonatal cardiac surgery. The purpose of this article was to review the process of implementing a development model of care in a CICU.

DEVELOPMENTAL CARE

The literature is replete with evidence on the benefits of developmental care in neonatal intensive care units (NICU).[6-8] Positive outcomes reported in premature infants include decreased length of stay in hospital, improved weight gain, increased cognitive performance, and improved psychomotor functioning.[9] However, a major gap in the literature exists on developmental care practices with at-risk infants in CICUs.

The Cardiac Center at CHOP cares for medically fragile, pre- and postoperative surgical neonates and infants with CHD. Clinical observation of patients in the CICU has revealed that the standard newborn care practices that enhance behavioral organization are not routinely practiced in the CICU setting. The authors' contention, given the neurologic risk factors, the physiologic acuity of the infants postsurgery, and the very fact that nursing is caring for newborns, is that implementation of developmental care model would be beneficial to infants with CHD and their families.

The developmental care project was identified by nursing leadership in the Cardiac Center. A newly hired clinical nurse specialist (CNS) was asked to take on the project under the mentorship of a nurse scientist with expertise in developmental care. Shared governance is a cornerstone of nursing at CHOP, and staff participation is paramount in ensuring the success of any practice change. Therefore, the centerwide process began by recruiting nursing staff with an interest in developmental care and inviting them to join a "developmental care" committee.

Transitioning to a model of developmental care in the CICU was a process that occurred over 2 years and in 3 concurrent phases: (1) creation of a developmental care committee, (2) nursing developmental rounds, and (3) interdisciplinary rounds. The process of educating the nursing staff to the developmental care model has occurred throughout all phases (Table). Facilitated by the CICU CNS, the committee met for 1 hour each month. Thirty minutes were devoted to reviewing the literature in the format of a journal club. Articles were selected by the CNS and distributed throughout the CICU for nursing staff to review. Because many of the bedside nurses had limited exposure to the developmental care literature, the articles focused on instituting a basic developmental care framework. Particular attention was given to interpreting and extrapolating the evidence found in the premature infant and how the evidence could be applied to the full-term or late preterm infant with CHD. The second phase of the model, nursing developmental rounds, began within a few months of launching the developmental care committee.

Developmental rounds were conducted with infants in the CICU who were referred by the interdisciplinary CICU care team (physicians, fellows, nurse practitioners, staff nurses). The developmental team included the CNS, a nurse scientist, members of the developmental care committee, and bedside nurses. All care providers were asked for potential referrals. The developmental care team consulted

TABLE. The Process of Initiating Developmental Care in a Cardiac Intensive Care Unit

Observations of developmental care given in the unit (containment, restraint use, holding)
In-service education during skills program
Second observation of use of developmental care principles
Developmental care work group with journal club
Weekly developmental care rounds at the bed side
Rounds include nursing
Rounds moved to include nursing, occupational therapy, physical therapy, speech therapy, and child life
Parents are included in the discussion
Developmental care card for parents to fill out regarding infant comfort measures
Parent stories are elicited concerning identification of infant's congenital heart disease, delivery, and their concerns
Goal 1: Increase nondrug comfort measures, positioning, progressed to feeding issues
Goal 2: Hear parent stories, include them in infant care decisions
Goal 3: Increase parent holding, skin-to-skin care, and putting infants to the breast

with 3 to 4 bedside nurses and families each week. Although parents were invited to participate in the discussion, the initial focus was on the education of the patient's bedside nurse. Developmental rounds focused on cue-based care, infant positioning, pain management, procedural support, parent-infant bonding, and environmental issues such as noise and light. The developmental nursing team created a developmental care card adapted from the neonatal literature to use as a tool during rounds (Figure 1). Both nurses and parents could use the card to record information about each infant's individual preferences for comfort behaviors and positioning. As the infant developed behaviorally and physiologically, the bedside nurse and caregivers were encouraged to update the developmental care card. The cards were posted at the patient's bedside for staff to review and thereby provided individualized care according to the infant's stage in development.

The initial goal of rounds was education of the bedside nurses. However, once rounds were initiated, one of the unexpected findings was that parents appreciated rounds as a venue to share their stories and concerns about their child. The parents often shared the story of the birth of the infant (70% of the families delivered in CHOP's special delivery unit), the discovery of the infants' heart defect, and their day-to-day experiences in the CICU. The nursing developmental care team explored how parents were dealing with the stress of being at the bedside throughout the day and encouraged them to find a way to have their own "time out." The team also assessed the parents' support systems and offered resources when appropriate. The nursing developmental care team established a rapport with families, especially those whose infants were admitted to the CICU and who were there for several weeks or even months. It became obvious that many families needed this type of support as they expressed their gratitude on multiple occasions. One family, in particular, nicknamed the developmental rounding team "the warm and fuzzies," appreciating that the team prioritized nonmedical issues for discussion. During rounds, the team discovered that the rounding venue provided opportunities for families to improve social and physical interactions by touching and engaging their infants with support of the team.

The clinical observations made during our rounds on developmental care in the CICU led the developmental care leadership team to apply for a grant from "The Big Hearts Little Hearts Foundation" (http://bighearts2littlehearts.com), a parent-funded organization, to further understand the state of developmental care in CICUs at various children's hospitals. The grant provided funding for the team to assess developmental care practices instituted in CICUs around the country as well as visits to several other children's hospitals that also had busy cardiac centers. A questionnaire was developed on developmental care practices and distributed to members of the Society of Pediatric Cardiac Nurses. Nursing staff and advanced practice nurses within and outside the United States responded to the survey (Figure 2). Findings from the survey revealed an awareness of developmental practices, with most nurses rating their care as development-based. However, clinical observations conducted by one of the authors revealed that developmental care practices outlined by the questionnaire were not consistently in use in some of the cardiac centers within a children's hospital.

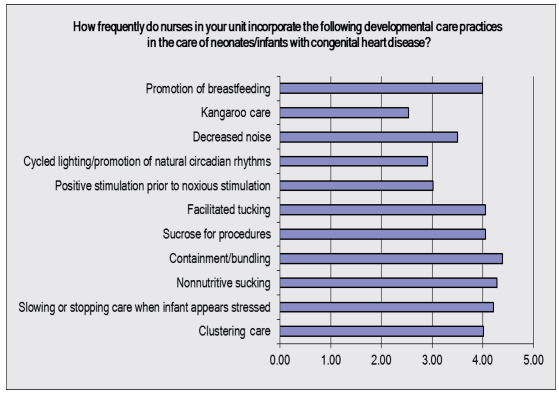
FIGURE 1.

Developmental care card.

INTERDISCIPLINARY DEVELOPMENTAL ROUNDS

Developmental rounds were established as a nurse-driven initiative focusing on nursing practices that foster developmental care. The team wanted nursing to take primary ownership of the initiative. When developmental rounds were firmly established in the CICU, nursing staff from child life, physical therapy, occupational therapy, and speech therapy and physicians were invited to join the developmental care team in rounds. As physicians and front-line providers (hospitalists, advanced practice nurses, residents, fellows) were in rounds for the greater part of each morning, most chose not to join the team. If any issues discovered during rounds needed medical attention (eg, pharmacologic interventions for pain), the medical team was consulted. At that time, the emphasis moved from increasing nursing awareness of developmental issues to a collaborative dialogue between the bedside nurse, parents, and the developmental team. Feeding concerns, infant behaviors, stimulation techniques, and positioning techniques to enhance interactions with the environment were common discussions among the participants.

FIGURE 2.



Developmental care practices survey (0 = never; 5 = always).

CHANGES IN CARE PATTERNS

Infant positioning was the first area that the developmental care committee wanted to address. Prior to the initiative, postsurgical infants were more likely to be in a supine position with little containment. To establish a baseline for infant positioning, several members of the developmental care committee conducted an audit of infant positioning on all infants admitted to the CICU every day for 1 week. The positioning audit tool was a 7-item instrument that quantifies the presence of 7 components of proper infant positioning: head midline, upper extremities flexed, hands close to mouth, hips rotated inward, lower extremities flexed, containment of upper extremities, and containment of lower extremities. One point was assigned for each positioning component observed at the time of the audit. When an infant was observed in a position that included all 7 elements, a score of 7 points was assigned to that observation. If there was an absence of any of the components to positioning, a score of 0 was assigned to that audit. Twenty-four infants were audited and found to have a mean score of 3.125. Upon completion of the audit, nursing staff were educated on the techniques of proper infant positioning by the CNS. One month later, a second audit was conducted in 26 patients; the mean score increased to 4.54. To sustain optimal positioning as a developmental intervention, infant positioning was discussed with the nursing staff at the bedside with patients and families. When the CNS made rounds, positioning education was reinforced and nursing staff were coached on optimal infant positioning. A third audit was conducted again in 6 months; the mean score increased to 6. The positioning audits were used as a marker to determine whether the developmental paradigm had changed in the unit. Evidence of the sustainability in staff engagement through committee work, weekly developmental rounds, CNS coaching, role modeling, and mentoring of nursing staff was apparent 2 years after the educational program ended. The last audit conducted at the end of year 2 was completed in 71 infants over a 1-month period in the CICU. The audit demonstrated a mean score of 5.4, clearly indicating sustainability in positioning as development care initiative and adoption of an evidence-based practice among seasoned and new staff nurses in the CICU.

The emphasis of a developmental care paradigm is on holistic care. As such, the developmental care team identified 3 areas of infant care, which appeared to be indispensable and yet not addressed in current care practices: increased parent holding, increased use of skin-to-skin care (kangaroo care), and receiving and transitioning infants to the breast for feeding. Although routine in a NICU, each of these 3 activities was far from routine in a CICU where infants are often connected to a multitude of tubes and wires for long periods of time. Infant holding preoperatively has been routine in the CICU, but only for a very limited period of time and usually immediately before the infant left the unit to undergo open-heart surgery. Routine holding postoperation, however, was not the case. Parents would often go many days or even weeks without holding their infants. The developmental rounding team identified patients who would be good candidates for holding on an individual basis. Because of the nature of caring for infants who are critically ill and at risk for hemodynamic instability, the bedside nurse and CNS would discuss candidates for holding and a plan would be made with the interdisciplinary team during morning rounds. The CNS would assist nursing staff in transferring patients with catheters or tubes to parents' arms and into kangaroo care.

PARENTAL HOLDING AND KANGAROO CARE

After a year of facilitation on an individual basis, the developmental team implemented a formal process for holding infants in the CICU. Guidelines for holding were developed delineating which catheters or tubes could be present for infant holding and which ones necessitated that the infant could not be held. Catheters and tubes that were determined safe for infant holding included chest tubes, pleural catheters, a tracheostomy, umbilical venous catheters, umbilical arterial catheters, peripherally inserted central catheters, central venous catheters, enteral feeding tubes (eg, nasogastric, gastric), and temporary epicardial pacing wires not in use. Catheters and tubes requiring a discussion with the attending physician before infant holding included peripheral arterial catheters, temporary epicardial pacing wires

in active use, and endotracheal tubes. To ensure patient safety, the guidelines stipulated that a respiratory therapist must be present with the bedside nurse during transfer of an infant with an endotracheal tube. Finally, catheters and tubes that would place infants at increased risk during transfer were extracorporeal membrane oxygenation cannulae, a fresh tracheostomy prior to first tracheostomy tube change, a critical airway, and intracardiac catheters. Infants with an open chest were also excluded from holding until chest was closed and stabilized.

Once drafted, the guidelines were approved by the CICU's Quality and Patient Safety Committee, which included the nursing leadership team, respiratory therapy team, as well as key cardiologists and cardiothoracic surgeons. "Holding" guidelines were shared at mandatory staff education forums and during nursing orientation. Nurses were encouraged to bring any concerns to the attending physician before holding so as to maximize patient safety and allow for the flexibility necessary to address the needs of complex infants in the unit. The CICU "holding plan" is always contingent on the infant's physiologic status, which can change day to day or even hour to hour.

TRANSITION TO BREAST

Transitioning infants to the breast for feeding would seem to be an essential part of routine infant care; however, this is not necessarily true in a CICU. While there are high rates of infants receiving breast milk, slow progress has been made in transitioning infants to the breast. One of the major challenges in implementing change is often the struggles of an infant with mastering a coordinated suck-swallow-breathe pattern and inability to suck efficiently to achieve adequate calories. Other barriers include the need to fortify the caloric intake for adequate growth and the mistaken concern that breastfeeding consumes more energy than bottle-feeding. After a year and a half of developmental rounds in the CICU, 2 nurses applied for and were granted a leadership grant through Sigma Theta Tau in collaboration with a nurse scientist with expertise in lactation. The group developed and implemented a unit project to improve the rates of human milk use and transition to breast prior to discharge. Staff received education on the benefits of human milk and a pathway to infant breastfeeding, including steps of nonnutritive sucking at the breast, skin-to-skin care, and breastfeeding. The work of this team, along with the continued developmental bedside rounds, promoted culture change in the unit to embrace the practices of skin-to-skin care and breastfeeding. The project findings of the initiative are being readied for dissemination.

SUMMARY

Implementing developmental care practices outside a NICU requires a thoughtful and well-planned process to ensure successful adaptation of the practice change. Success begins with institutional commitment and a strong commitment from nursing leadership at the local level, a change agent (the CNS in this example), a strong mentor (the nurse scientist), staff engagement (the developmental care committee), and a concentrated focus on physician education. The process to ensure sustainability is engrained at the unit level through the professional practice committee, the developmental committee, and continual reinforcement by the team during the rounding process. Within the holistic paradigm of care, the other aspects of care (kangaroo care, parental holding, and transition to breast) fell into place and were sustained even during the absence of the CNS as a result of staff engagement. Lastly, now that the change is firmly in place, opportunities to address environment lighting, noise, and developmental play within the CICU have begun.

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