

## **UC Irvine**

### **UC Irvine Previously Published Works**

#### **Title**

Developmentally Supportive Care in Congenital Heart Disease: A Concept Analysis

#### **Permalink**

<https://escholarship.org/uc/item/1g9289k5>

#### **Authors**

Peterson, Jennifer K  
Evangelista, Lorraine S

#### **Publication Date**

2017-09-01

#### **DOI**

10.1016/j.pedn.2017.05.007

Peer reviewed



Contents lists available at ScienceDirect

## Journal of Pediatric Nursing

journal homepage: www.elsevier.com



## Developmentally Supportive Care in Congenital Heart Disease: A Concept Analysis

Jennifer K. Peterson MS, RN, CCNS\*, Lorraine S. Evangelista PhD, RN, FAHA, FAAN,

Sue &amp; Bill Gross School of Nursing, University of California, Irvine, 299 Berk Hall, Irvine, CA, United States

## ARTICLE INFO

*Article history:*

Received 9 August 2016

Received in revised form 23 May 2017

Accepted 24 May 2017

Available online xxx

*Keywords:*

Concept analysis

Congenital heart disease

Pediatric nursing

Acute care

Critical care

## ABSTRACT

*Theoretical Principles*

Improved survival of infants and children with congenital heart disease experience has led to recognition that up to half of congenital heart disease survivors also experience developmental delay. Developmentally supportive care is a care model shown in Neonatal Intensive Care Units to be associated with improved outcomes, but developmentally supportive practices with premature infants may not be equally effective in the cardiac population that includes all ages.

*Phenomena Addressed*

The purpose of this paper is to present a concept analysis using the Walker and Avant method in order to identify and define characteristics of developmentally supportive care as it may be applied to the population of neonates, infants, and children with congenital heart disease. A theoretical definition of developmentally supportive care is presented.

*Research Linkages*

This concept analysis will provide nurses and allied health professionals with a theoretical basis to implement high quality, family-centered care that meets individual developmental needs in a population at high risk for developmental sequelae. Nursing implications for developmentally supportive care as it applies to infants and children with heart disease are discussed.

© 2017 Published by Elsevier Ltd.

## Introduction

Improvements in recognition, surgical techniques, and perioperative management of infants and children with congenital heart disease (CHD) have led to significantly improved survival; yet, up to half of CHD survivors face some degree of neurodevelopmental delay (Donofrio & Massaro, 2010). These delays may result from preoperative microcephaly and structural brain immaturity, right-to-left intracardiac shunting that may result in decreased cerebral oxygen delivery, intraoperative or postoperative use of extracorporeal life support, or low cardiac output (Donofrio & Massaro, 2010; Licht et al., 2009; Marino et al., 2012; Wernovsky, 2006). Exposure to these risk factors may be a single occurrence, or may continue throughout life in children who require staged palliation. The focus of the interprofessional team in the highly technological environment of the pediatric cardiac intensive care unit (PCICU) is, by necessity, cardiopulmonary stabilization and management of unstable hemodynamics, ongoing critical thinking and decision-making, and intensive intervention (Balachandran, Nair, & Kumar, 2010). Following stabilization, infants and children with CHD may be transferred to an acute care unit that specializes in cardiac care, frequently using a family-centered care model.

Developmentally supportive care (DSC) is a care model in Neonatal Intensive Care Units (NICUs) that has been associated with reduced length of stay, earlier transition to oral feeding, and improved neurodevelopmental outcomes in premature infants (Als, 1982; Als, 1998; Symington & Pinelli, 2006). The concept of DSC in the NICU was well described in a concept analysis by Aita and Snider (2003). This concept analysis focused on care the preterm infant in the NICU. Because the population of a PCICU and cardiac acute care unit is dramatically different from a NICU, it is reasonable that a DSC model for cardiac patients may differ from a DSC care model used in a NICU. These differences may include the characteristics of the concept as well as nursing interventions that operationalize the concept of DSC. Increased awareness of developmental delays in CHD survivors and interest in providing DSC leads to a need to revisit the concept and how it may be applied to a different population.

Concept analysis is an analytical method used to identify key characteristics of a concept in order to more clearly and concisely articulate conceptual structure and function, thereby improving its internal validity (Walker & Avant, 2010). Concepts also evolve over time due to cultural, contextual, and societal factors (Walker & Avant, 2010). The concept analysis method described by Walker and Avant (2010) includes eight iterative steps. These steps include selecting a concept, determining the aims of the analysis, identifying all uses of the concept, determining defining attributes of the concept, describing a model case, identifying other types of cases, identifying antecedents and consequences, and defining empirical referents

\* Corresponding author.

Email addresses: jkpeter1@uci.edu (J.K. Peterson); evangell@uci.edu (L.S. Evangelista)

(Walker & Avant, 2010). These steps will be further described as they are presented.

The purpose of this concept analysis is to identify and define the characteristics of DSC as applied to hospitalized infants and children with CHD. Understanding these characteristics may help guide nurses and other healthcare team members to provide holistic care that combines life-saving technology and scientific knowledge with interventions that meet the developmental needs of CHD survivors.

### Data Sources

A literature search was conducted using PsychINFO, PubMed, and Web of Science databases. Search terms included “developmentally supportive care” or “developmental care” in the title, abstract, or key words. Inclusion criteria included: (a) paper published in English; (b) for research reports: subjects were between 0 and 18 years of age; and (c) paper available in full text. Publication time limit was not specified in order to capture the important early work related to DSC. Papers that reported transition of care, those reporting psychometric properties of instruments, those reporting exclusively staff or parental outcomes, those reporting effects of a single DSC intervention, and those reporting staff education or DSC implementation strategies were excluded. After duplicates were removed, the abstracts were reviewed for relevance to the concept of DSC. A total of 58 papers were selected that utilized the concept of DSC and met inclusion criteria. There were 34 empirical studies and 24 theoretical papers. The sample size ranged from 20 to 261 (mean 76.2) for empirical studies. Only two theoretical papers specifically referenced infants and children with CHD. The papers were reviewed and analyzed for their use of the concept of DSC and unique characteristics of DSC.

### Results

#### *Identifying Uses of the Concept of Developmentally Supportive Care*

After reviewing the literature, the next step in concept analysis is to identify all uses of the concept in order to understand how different disciplines define and use the concept (Walker & Avant, 2010).

#### *From Dictionaries*

“Developmental care,” according to the Free Dictionary, is a nursing intervention that consists of “structuring the environment and providing care in response to the behavioral cues and states of the preterm infant” (available at <http://medical-dictionary.thefreedictionary.com/developmental+care>). This definition limits the concept to care of premature infants. The Merriam-Webster dictionary (no date) defines “developmental” as an adjective “of or relating to the growth or development of someone or something.” “Supportive” is an adjective meaning “to promote the interests of,” “to hold up,” or “to provide help or encouragement to.” “Care” may be used as a noun, meaning “effort made to do something correctly or safely, or to keep someone safe or healthy, or to keep something in good condition.” “Care” can also be used as a verb, meaning “to feel interest or concern, to feel affection, or to want to do or to be something.” The use of “care” helps to tie the concept to nursing practice, although DSC originated in the field of psychology.

#### *Psychology*

The concept of DSC was first described by Als, in early work that described synchronous communication between a mother/infant dyad, and later work that outlined a Syntactic Theory of Infant De-

velopment (Als, 1977, 1982). This model outlines a hierarchy of dynamic, interrelated systems within the neonate that direct the relationship with the environment, with the ultimate goal of self-regulation (Als, 1982; Als et al., 1986). 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” (Als, 1998). The family is seen as the infant’s “primary co-regulator” and the focus of care is to maximize strengths and reduce stressors for both infants and families (Als, 1998). Developmentally supportive care measures were first described in a study by Als et al. (1986) that compared outcomes between premature neonates with pulmonary complications who received standard care versus those who received DSC interventions. The infants who received DSC required fewer mechanical ventilation days, had earlier feeding, and demonstrated improved developmental outcomes assessed at 3, 6, and 9 months of age (Als et al., 1986). As a result, a program called Newborn Individualized Developmental Care and Assessment Program (NIDCAP) was established to guide care of premature infants hospitalized in the NICU (Als & Gilkerson, 1997).

#### *Nursing*

From the important early work on the field of psychology, nursing care of premature infants in the NICU became focused on DSC. Als’ Syntactic Theory of Development was expanded by Gibbins and colleagues as the Universe of Developmental Care (UDC) model, to include the idea of a “shared care surface,” or context where the infant and the environment directly and dynamically interact; it is this confluence where nursing care is delivered (Gibbins, Hoath, Coughlin, Gibbins, & Franck, 2008). The UDC model defines developmental care as a patient and family-centered process in which caregivers interact with the infant and the NICU environment at the level of the shared care surface to implement an individualized plan of care (Gibbins et al., 2008). Core measures of DSC include protected sleep, pain and stress assessment and management, developmental activities of daily living, family-centered care, and the healing environment (Coughlin, Gibbins, & Hoath, 2009). Further modification of the UDC model into the Neonatal Integrative Developmental Care Model re-categorized core measures of neuroprotective neonatal care into healing environment (both physical and sensory), partnering with families, positioning and handling, safeguarding sleep, minimizing stress and pain, protecting skin, and optimizing nutrition (Altimier & Phillips, 2013). Nursing interventions within this care model include environmental modifications such as protection for excessive light and sound, protection from cold stress, flexed positioning using supportive materials, minimizing unnecessary handling and sleep interruptions, providing adequate analgesia for painful procedures, use of parental skin-to-skin or “kangaroo care”, and cue-based feeding. This model stresses development of the neurological system of the pre-term infant, and defines DSC as care that “decreases the negative effects of fetal development occurring in the extrauterine environment of the NICU and helping to minimize these impairments” (Altimier & Phillips, 2013).

Infants with major structural abnormalities or congenital anomalies, including CHD, have generally been excluded from studies on DSC. One large pediatric cardiac program has published their experiences in implementing interdisciplinary care rounds to increase the use of DSC in the neonatal and infant cardiac population, using the UDC model as a framework (Lisanti, Cribben, Connock, Lessen, & Medoff-Cooper, 2016; Torowicz, Lisanti, Rim, & Medoff-Cooper, 2012). The Pediatric Cardiac Intensive Care Society Nursing Writing Group has collaborated to produce recommendations for devel-

opmental care of children of all ages with CHD (Rachwal et al., 2015).

### *Education*

Developmentally supportive care is also used in education. Developmentally supportive is defined as strategies that support and nurture developmental progress, using a developmental stages theoretical framework such as Piaget or Erikson (Cataldo, 1984). Although developmentally supportive educational strategies are still important, more recent work in teacher education has focused on education that is also culturally and contextually sensitive, reflecting the increasing diversity and globalization of children's experiences (Ryan & Grieshaber, 2005).

### *Parenting*

Developmental care in parenting is defined as "activities that deliberately stimulate children's cognitive skills such as talking, reading, teaching and playing" (Thomsen, 2015). DSC in the NICU emphasizes the crucial role of the parent as the primary sources of comfort, support, and learning for the infant. DSC also promotes that the infant learns by reciprocal interaction with their environment, so parental behaviors like talking, reading, and playing are educational and developmentally supportive for the infant or child.

### *Allied Health*

Developmentally supportive care in the NICU is interdisciplinary, including speech/language pathologists, physical and occupational therapy, child/family life therapists, respiratory therapy, psychology, social work, dietitians, lactation consultants, in addition to nurses and physicians. Developmentally supportive speech/language pathology care incorporates knowledge of the "typical course of communication, speech, language, and emergent literacy development as well as appreciation of individual differences and communication styles...based on the needs of each family and a clear understanding of each child's physiological, behavioral, and developmental responsiveness to his or her environment" (Paul & Roth, 2011). The focus of occupational therapy is to support the development of infant occupations, which include responding to the environment, maintaining homeostasis, beginning social interactions with caregivers, and feeding (Barbosa, 2013). In the NICU, the primary role of speech/language pathologists and occupational therapists is to help the premature infant to develop skills to coordinate oral feeding, a major developmental task, as well as a hospital discharge metric. The physical therapist provides developmental care by promoting sensorimotor development, including posture, range of motion, and regulation of behavioral state (Barbosa, 2013). The NICU environment is often not developmentally focused, with bright lights, loud sounds, and often painful medical procedures throughout the day and night. One focus of DSC for premature infants is to reduce these harsh environmental stimuli to recreate a more "womb-like" environment for these premature infants to continue their development. Such interventions such as providing developmentally supportive positioning using nesting materials and supporting flexion help reduce stress. Child/Family Life practice is based in knowledge and application of child development theories, family systems, stress and coping, and play. Child/Family Life Specialists reduce stress and promotes effective coping and emotional, social, and developmental well-being of hospitalized infants and children, as well as their families (Smith, Desai, Sira, & Engelke, 2014).

### *Determine the Defining Attributes*

Defining attributes of a concept are qualities or characteristics that are always present in any context that the concept is utilized, and are therefore helpful in recognizing the concept (Walker & Avant, 2010). Attributes for DSC applied to infants and children with CHD are: 1) adapted to unique individual needs; 2) family-centered; and 3) interrelational.

### *Adapted to Unique Individual Needs*

Developmentally supportive care is individualized to meet the unique needs of the patient (Als, 1998; Gibbins et al., 2008; Paul & Roth, 2011). Developmentally supportive care for the infant or child with CHD is adapted to meet individual needs at a point in time, but also evolves to meet changing needs throughout the continuum of health and illness experienced. A child's developmental status may also change due to the stress of illness; a 3 year old child may regress developmentally and need DSC that meets his/her needs at that point in time.

### *Family-centered*

Developmentally supportive care is also family-centered (Altimier & Phillips, 2013; Coughlin et al., 2009; Gibbins et al., 2008; Torowicz et al., 2012). Family-Centered Care is the pediatric nursing care model adopted and endorsed by the American Nurses Association and the Society of Pediatric Nursing (American Nurses Association, 2008; Harrison, 2010). The family is the most important source of support for an infant/child, and the central role and unique knowledge of the parent(s) must be respected and incorporated into all aspects of care. With DSC, parents are respected and supported in their parental roles as caregivers, teachers, and advocates. New parents may need education in recognizing an infant's subtle behavioral cues, while many parents of children with chronic healthcare needs often become highly knowledgeable about their child's CHD and health management.

### *Interrelational*

Developmentally supportive care recognizes the unique interrelationship of the infant or child and their environment as a source of learning, exploration, and development (Als, 1982; Als, 1998; Als et al., 1986; Barbosa, 2013). The infant/child responds to their environment with behavioral cues, which may be subtle. A study by Lobo (1992) reported that parent/infant infants with CHD displayed less caregiver responsiveness and less clear behavioral cues during feeding than infants without CHD. Parents may need education and support to recognize and interpret subtle behavioral cues. The hospital environment should be assessed for ways to make it more developmentally supportive, such as attention to circadian rhythms, opportunities for appropriate play and social interaction, and a developmentally considerate approach to medical procedures.

### *Constructed Cases*

Constructed cases are examples of the concept, with changes to the attributes that allow demonstration of the concept being examined and allow better understanding of the attributes that define the concept (Walker & Avant, 2010).

### *Model Case*

The PCICU nurse is caring for a term neonate one day after an arterial switch procedure for d-transposition of the great arteries. The

infant has an open sternum, and requires frequent titration of vasoactive infusions to maintain an adequate cardiac output. The infant is receiving mechanical ventilation and is heavily sedated. The nurse implements developmentally supportive positioning while being careful to maintain patency of the chest tubes, and exchanges scent cloths with the infant's mother to place near the infant's face. The nurse recognizes that the mother is overwhelmed and provides answers to her many questions, and encourages her to attend to her own needs for food and rest. Five days later, the infant is extubated and is stable from a cardiopulmonary perspective. The nurse consults with the speech therapist to assess oral feeding readiness, offers skin-to-skin care to the mother to promote bonding and breastmilk production, and encourages the parents to continue participating in the infant's care. The nurse assesses the infant's physiological and behavioral reaction to stimulation for adverse cardiopulmonary effects. The infant displays rooting behavior and is in a quiet, alert state, so the nurse assists the mother to initiate feedings, by bottle initially to assess the infant's tolerance. The mother's goal is to breastfeed, so feedings are transitioned to breast when the infant demonstrates safe oral intake. The nurse assists the mother with feeding positions to facilitate latching and obtains a lactation consult to assist the new mother with successful breastfeeding.

All of the defining attributes are present in this case. The nurse implements DSC based on the infant's health status at the time, and evolves the plan of care as the infant's condition changes. The nurse provides family-centered care by supporting the mother during the highly stressful time, facilitates parental participation in care, and advocates for the mother's desire to breastfeed. The nurse recognizes and incorporates relational aspects of care, including the infant's relationship to the environment such as physiological stability, ability to interact with mother, and ability to coordinate breathing and feeding. The nurse also supports the mother's relationship to the situation; from being overwhelmed to the developing relationship between infant and mother.

#### *Borderline Case*

A five year old with single ventricle Fontan physiology has developed protein-losing enteropathy and ventricular dysfunction. He was admitted two days ago for intensive medical management and heart transplant evaluation. The cardiac acute care nurse consults with the Child Life Specialist for appropriate distraction techniques, and with the dietician to assist the child's mother to select appropriate low fat, high protein foods that the child likes to eat. The child needs to have another intravenous line inserted, and the nurse tells the child's mother to leave during the procedure in order to reduce the child's distress. The child cries throughout the procedure, calling for his mother.

This is an example of a borderline case because the situation lacks at least one defining attribute; the attribute of family-centered care is missing. The nurse telling the mother to leave during a painful procedure discounts her role as the child's primary caretaker and primary source of comfort. Neither the child's nor the mother's preferences for how to cope with painful procedures are solicited.

#### *Related Case*

A six month old infant with trisomy 21 underwent atrioventricular septal defect repair four days previously. The cardiac acute care nurse requests age-appropriate toys from the Child Life Specialist because the infant should be participating in daily "tummy time" and transferring toys from one hand to another at 6 months of age.

A related case is an example that incorporates a similar concept to the one being examined. In this case, the nurse is utilizing a devel-

opmental theory perspective that indicates what skills the infant should have. A child with trisomy 21 may or may not be able to perform developmental stage activities, but at four days postoperatively, should not be forced into a prone position due to stress on the sternum.

#### *Contrary Case*

A sixteen year old underwent aortic valve replacement two days previously. She is cared for in the adult ICU because a PCICU bed was not available. Visiting hours are 9 am to 6 pm for 2 adult visitors only. Despite the patient's requests, her three closest friends are not allowed to visit. Cardiac rehabilitation is consulted per protocol, and the patient is scheduled for twice daily sessions. She attends a class on Coumadin management, but her mother is unable to attend because she is caring for the patient's five year old sibling.

A contrary case is a clear example of what is not the concept being examined. In this example, the teenager is subjected to strict hospital rules for visiting, cardiac rehabilitation schedule, and attendance at patient education. Her own wishes as well as support from her mother are ignored in order to adhere to the rules and policies. Her developmental needs are not assessed and her care is based on protocols.

#### *Identify Antecedents and Consequences*

Antecedents are events or conditions required prior to the occurrence of the concept (Walker & Avant, 2010). The primary antecedents for the concept of DSC for infants and children with CHD are 1) understanding; 2) collaboration and communication; and 3) resources.

#### *Understanding*

In order to provide DSC to infants and children with CHD, the healthcare team members must demonstrate understanding of the different types of CHD and its physiological effects, CHD repair and anticipated perioperative course, and the mechanisms affecting growth and development. Nursing orientation and training includes specialty content on CHD and its unique physiology, but may lack up-to-date information on how CHD impacts growth and development or family functioning. Nursing care of infants and children with CHD is highly subspecialized, with unique pathophysiology and highly complex care. One study of nurses in a multidisciplinary pediatric ICU that provided care for postoperative CHD patients, reported that although nurses received additional education and training in the care of cardiac patients, they felt more unprepared to care for CHD patients than any other type of patient (Kane & Preze, 2009).

There is an important difference between having knowledge and having understanding. Understanding is a more complex process, and requires not only knowledge but also experience to see the bigger picture. Benner's Novice to Expert theory can be used to identify the novice and advanced beginner nurse, who develop knowledge, from the competent stage nurse who is able to begin to see and understand a larger scope, to the proficient and expert nurse who have real understanding of their practice (Benner, 1982). A study of congenital heart surgery programs also found that decreased pediatric cardiac surgery mortality was associated with a larger proportion of experienced nurses (Hickey, Gauvreau, Curley, & Connor, 2014). Translating knowledge into understanding takes time, as well as experience; there is a crucial role for experienced nurses at the bedside and in advanced practice roles to assist developing nurses to develop knowledge and understanding.

### *Collaboration*

Interdisciplinary collaboration requires excellent communication skills, and can both increase knowledge of the team members and improve interprofessional teamwork. Collaboration is crucial to ensure that the appropriate interdisciplinary team members, with their unique skills, are implementing DSC interventions to meet the patient's unique needs. It is also important that bedside nurses and advanced practice nurses who have in-depth knowledge and understanding of the patient's unique physiology and family functioning be able to communicate and collaborate their assessment with other healthcare team members, who may not have as much knowledge of the unique physiology of CHD patients.

### *Resources*

Finally, having access to resources needed to implement practice changes is essential. Resources may include equipment to promote developmentally supportive positioning for infants or activities for older children, or funding to provide training in complimentary therapies such as massage. Resources may also include electronic medical record system additions that incorporate DSC into care planning and evaluation, as well as documentation of interventions. Some aspects of a primarily surgical unit population provide challenges to implementing DSC, such as shorter length of stay, complexity of care required, and limited staff availability to perform "extra" care (Laing, Spence, McMahon, Ungerer, & Badawi, 2012). It is vitally important that leadership at all levels be involved in implementing DSC, including management, advanced practice nurses, and bedside practitioners via unit-based practice councils, in order to advocate for and obtain resources. With inadequate resources, including equipment, money, time, and personnel, practice change is doomed to fail.

Consequences are the results or outcomes of the concept (Walker & Avant, 2010). Consequences of DSC in infants and children with CHD include improved: 1) development; 2) performance; and 3) satisfaction.

### *Development*

The short-term outcomes of DSC in premature infants include increased weight gain, improved oral feeding, and improved brain maturation (Als et al., 2012; McAnulty et al., 2009; McAnulty et al., 2010). Longer term outcomes of NIDCAP programs in premature infants have demonstrated improved executive functioning and less overall mental disability, but mixed results in cognitive or psychomotor function (Maguire et al., 2009; McAnulty et al., 2013; Peters et al., 2009). These results of DSC in premature infants support that improved development is a consequence of DSC. The outcomes of DSC have not been reported in infants and children with CHD. Two case studies of skin-to-skin care in infants with severe CHD reported improved cardiorespiratory parameters during skin-to-skin care and no adverse effects, suggesting that this intervention is safe in the infant cardiac surgical population (Gazzolo, Masetti, & Meli, 2000; Harrison & Ludington-Hoe, 2015).

### *Performance*

Improved family functioning or performance results from DSC. Developmentally supportive care recognizes the centrality of the family in the infant's life. Incorporating parents as decision-makers and advocates empowers them and supports their role. Teaching parents to recognize and interpret subtle infant behavioral cues to their environment allows parents to be more responsive and reduces parental stress. Parents of children with CHD often report tremendous family stress associated with the care of child with CHD, and these

phases of stress response are overlapping and re-emerging as their child's condition changes over time (Rempel, Ravindran, Rogers, & Magill-Evans, 2013). Because DSC is family-centered and both empowers and support parents, the functioning of the family overall is supported.

### *Satisfaction*

One other important consequence of DSC is increased parental satisfaction with care. One qualitative study of a developmentally supportive care program for hospitalized infants reported that parents valued focus on their child's development as a part of their care (So et al., 2014). Another report of developmental rounds in a large PCICU reported that parents appreciated the rounds as an opportunity to share their concerns and questions (Torowicz et al., 2012). Developmental rounds also incorporate parents into the plan of care and reinforces their crucial role as members of the healthcare team.

### *Define Empirical Referents*

Empirical referents are events or experiences that demonstrate the concept, and are "the means by which you can recognize or measure the defining attributes of the concept" (Walker & Avant, 2010). Empirical referents of DSC in infants and children with CHD include developmentally supportive programs that incorporate interventions such as developmentally supportive positioning, skin-to-skin care, massage, developmentally appropriate play activities and procedural support, and sleep hygiene programs (Gazzolo et al., 2000; Harrison & Ludington-Hoe, 2015; Rachwal et al., 2015). Parent/child participation in interprofessional rounds and bedside shift report, and interprofessional collaboration with the child and parents in developing a plan of care to meet the infant or child's developmental needs are also empirical referents for DSC (Lisanti et al., 2016; Torowicz et al., 2012).

### **Definition**

The end result of a concept analysis is development of a conceptual definition (Walker & Avant, 2010). Based on the uses of the concept, defining attributes, model cases, antecedents and consequences, and empirical referents, the following conceptual definition evolved from the literature. 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.

### **Summary and Implications for Pediatric Nursing Practice**

This concept analysis has identified defining attributes, antecedents, and consequences of developmentally supportive care of infants and children with CHD, resulting in a conceptual definition. Implications for nursing are described below.

Nursing care of infants and children with CHD has evolved with advancements in healthcare into a high technology, high acuity, and high intensity subspecialty. The focus of care is often on life-saving technology and specialized knowledge of the unique pathophysiology that these children demonstrate. While this focus is crucial in reducing mortality associated with CHD, it is not always conducive to

supporting neurodevelopment in children with CHD, who are at risk for cognitive, psychomotor, and psychosocial delays. However, the two approaches need not be at odds with each other. In addition, the components of DSC used in the NICU with primarily premature infants cannot be assumed to also be beneficial for infants and children with CHD because the two populations are very different.

The conceptual definition of DSC for infants and children with CHD should be thought of as a starting point for nursing practice discussions at a unit and program level. Measures that support DSC can be implemented in parallel with high-technology care even in patients who are critically ill, and ongoing reassessment will indicate when other DSC interventions are appropriate to the child's status. The Universe of Developmental Care model has been utilized as a framework and applied to the care of cardiac patients (Lisanti et al., 2016). Organizations and units with a shared governance-type structure have the ability to prioritize implementation of a DSC care model. Identification of "champions" from the stakeholder disciplines, including nursing, speech therapy, occupational therapy, physical therapy, psychology, social work, lactation, Child/Family Life, and physicians can be helpful in implementing change, and incorporating these stakeholders into a developmental care committee would facilitate care model and practice changes. Nursing champions should encompass all levels of nursing practice, from bedside nurses to advanced practice nurses to nursing management/leadership. Bedside nurses can identify developmentally supportive interventions to incorporate into practice, and implement change within their unit. Advanced practice nurses provide support to bedside nurses through development of appropriate policies and standards of care, facilitating interventions such as developmental care rounds or family participation in daily multi-disciplinary rounds, and leading evaluation of outcomes through quality improvement and research. Collaboration with stakeholder disciplines allows optimal utilization of the unique skills and knowledge of the individual disciplines, such as implementation of cue-based feedings with speech and occupational therapists. Nursing management/leadership support and involvement is also crucial; staffing matrices will need to be evaluated and perhaps modified to allow additional nursing interventions, and performance evaluations should include provision of DSC as a standard. Education may be necessary to implement different types of developmentally supportive interventions, such as positioning, massage, music, or feeding strategies. Nurses may also need education and support in implementing unit practice changes, which provides opportunities for advanced practice nurses and unit leadership to provide mentoring.

Because of the paucity of research on the effectiveness of developmentally supportive interventions in infants and children with CHD, it is important that these interventions be studied in well-designed and well-powered studies. This may require multi-center collaboration in order to achieve sufficient sample size.

## Conclusion

Infants and children with CHD are at risk for neurodevelopmental morbidity related to their heart disease and its treatment, so it is vitally important to support their optimal neurodevelopment by providing developmentally supportive care. Through the process of concept analysis, a conceptual definition of DSC for infants and children with CHD was developed. Developmentally supportive care for infants and children with CHD incorporates unique knowledge and understanding of CHD and its effects on family functioning and development in order to provide excellent family-centered care through inter-professional collaboration and communication that meets the unique and evolving developmental needs of the infant or child with

CHD as they interact with their environment, promoting family functioning and improving satisfaction with care. Developmentally supportive care interventions can be implemented into the care of even the most crucially ill child, and evolve to meet the child's needs at any point in the continuum of their health.

## Funding

This work is supported by American Heart Association Western States Affiliate Winter 2015 Predoctoral Fellowship (15PRE25300024).

## Previous Presentation

A similar work was presented as a poster at the Western Institute of Nursing Annual Communicating Nursing Research Conference, in Albuquerque, New Mexico in April 2015.

## Commercial Financial Support

None.

## References

- Aita, M., Snider, L., 2003. The art of developmental care in the NICU: A concept analysis. *Journal of Advanced Nursing* 41 (3), 223–232. <http://dx.doi.org/10.1046/j.1365-2648.2003.02526>.
- Als, H., 1977. The newborn communicates. *Journal of Communication* 27 (2), 66–73. <http://dx.doi.org/10.1111/j.1460-2466.1977.tb01828.x>.
- Als, H., 1982. Toward a syntactic theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health Journal* 3 (4), 229–243. [http://dx.doi.org/10.1002/1097-0355\(198224\)3:4](http://dx.doi.org/10.1002/1097-0355(198224)3:4).
- Als, H., 1998. Developmental care in the newborn intensive care unit. *Current Opinion in Pediatrics* 10 (2), 138–142.
- Als, H., Duffy, F.H., McNulty, G., Butler, S.C., Lightbody, L., Kosta, S., ... Warfield, S.K., 2012. NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction. *Journal of Perinatology* 32 (10), 797–803. <http://dx.doi.org/10.1038/jp.2011.201>.
- Als, H., Gilkerson, L., 1997. The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Seminars in Perinatology* 21 (3), 178–189.
- Als, H., Lawhon, G., Brown, E., Gibes, R., Duffy, F.H., McNulty, G., Blickman, J.G., 1986. Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and developmental outcome. *Pediatrics* 78 (6), 1123–1132.
- Altimier, L., Phillips, R.M., 2013. The neonatal integrative developmental care model: Seven neuroprotective core measures for family-centered developmental care. *Newborn and Infant Nursing Reviews* 13 (1), 9–22. <http://dx.doi.org/10.1053/j.nainr.2012.12.002>.
- American Nurses Association, 2008. *Pediatric nursing: Scope and standards of practice*, 1st ed. Silver Spring, Md: Amer Nurses Assn.
- Balachandran, R., Nair, S.G., Kumar, R.K., 2010. Establishing a pediatric cardiac intensive care unit - Special considerations in a limited resources environment. *Annals of Pediatric Cardiology* 3 (1), 40–49. <http://dx.doi.org/10.4103/0974-2069.64374>.
- Barbosa, V.M., 2013. Teamwork in the neonatal intensive care unit. *Physical & Occupational Therapy in Pediatrics* 33 (1), 5–26. <http://dx.doi.org/10.3109/01942638.2012.729556>.
- Benner, P., 1982. From novice to expert. *Journal of Nursing* 82 (3), 402–407.
- Cataldo, C.Z., 1984. Infant-toddler education: Blending the best approaches. *Young Children* 39 (2), 25–32.
- Coughlin, M., Gibbins, S., Hoath, S., 2009. Core measures for developmentally supportive care in neonatal intensive care units: Theory, precedence and practice. *Journal of Advanced Nursing* 65 (10), 2239–2248. <http://dx.doi.org/10.1111/j.1365-2648.2009.05052.x>.
- Donofrio, M.T., Massaro, A.N., 2010. Impact of congenital heart disease on brain development and neurodevelopmental outcome. *International Journal of Pediatrics* 2010, 1–13. <http://dx.doi.org/10.1155/2010/359390>.
- Gazzolo, D., Masetti, P., Meli, M., 2000. Kangaroo care improves post-extubation cardiorespiratory parameters in infants after open heart surgery. *Acta Paediatrica* (Oslo, Norway: 1992) 89 (6), 728–729.

- Gibbins, S., Hoath, S.B., Coughlin, M., Gibbins, A., Franck, L., 2008. The universe of developmental care: A new conceptual model for application in the neonatal intensive care unit. *Advances in Neonatal Care: Official Journal of the National Association of Neonatal Nurses* 8 (3), 141–147. <http://dx.doi.org/10.1097/01.ANC.0000324337.01970.76>.
- Harrison, T.M., 2010. Family centered pediatric nursing care: State of the science. *Journal of Pediatric Nursing* 25 (5), 335–343. <http://dx.doi.org/10.1016/j.pedn.2009.01.006>.
- Harrison, T.M., Ludington-Hoe, S., 2015. A case study of infant physiologic response to skin-to-skin contact after surgery for complex congenital heart disease. *The Journal of Cardiovascular Nursing* 30 (6), 506–516. <http://dx.doi.org/10.1097/JCN.0000000000000202>.
- Hickey, P.A., Gauvreau, K., Curley, M.A.Q., Connor, J.A., 2014. The effect of critical care nursing and organizational characteristics on pediatric cardiac surgery mortality in the United States. *JONA: The Journal of Nursing Administration* 44, S19–S26 (Supplement) 10.1097/NNA.0000000000000120.
- Kane, J.M., Preze, E., 2009. Nurses' perceptions of subspecialization in pediatric cardiac intensive care unit: Quality and patient safety implications. *Journal of Nursing Care Quality* 24 (4), 354–361. <http://dx.doi.org/10.1097/NCQ.0b013e3181aa4908>.
- Laing, S., Spence, K., McMahon, C., Ungerer, J., Badawi, N., 2012. Challenges in conducting prospective research of developmentally directed care in surgical neonates: A case study. *Early Human Development* 88 (3), 171–178. <http://dx.doi.org/10.1016/j.earlhumdev.2011.08.003>.
- Licht, D.J., Shera, D.M., Clancy, R.R., Wernovsky, G., Montenegro, L.M., Nicolson, S.C., ... Vossough, A., 2009. Brain maturation is delayed in infants with complex congenital heart defects. *The Journal of Thoracic and Cardiovascular Surgery* 137 (3) (529-536-537) 10.1016/j.jtcvs.2008.10.025.
- Lisanti, A.J., Cribben, J., Connock, E.M., Lessen, R., Medoff-Cooper, B., 2016. Developmental care rounds: An interdisciplinary approach to support developmentally appropriate care of infants born with complex congenital heart disease. *Clinics in Perinatology* 43 (1), 147–156. <http://dx.doi.org/10.1016/j.clp.2015.11.010>.
- Maguire, C.M., Walther, F.J., Sprij, A.J., Cessie, S.L., Wit, J.M., Veen, S., 2009. Effects of individualized developmental care in a randomized trial of preterm infants < 32 weeks. *Pediatrics* 124 (4), 1021–1030. <http://dx.doi.org/10.1542/peds.2008-1881>.
- Marino, B.S., Lipkin, P.H., Newburger, J.W., Peacock, G., Gerdes, M., Gaynor, J.W., ... Mahle, W.T., 2012. Neurodevelopmental outcomes in children with congenital heart disease: Evaluation and management a scientific statement from the American Heart Association. *Circulation* 126 (9), 1143–1172. <http://dx.doi.org/10.1161/CIR.0b013e318265ee8a>.
- McAnulty, G., Duffy, F., Butler, S., Parad, R., Ringer, S., Zurakowski, D., Als, H., 2009. Individualized developmental care for a large sample of very preterm infants: Health, neurobehaviour and neurophysiology. *Acta Paediatrica (Oslo, Norway: 1992)* 98 (12), 1920–1926. <http://dx.doi.org/10.1111/j.1651-2227.2009.01492.x>.
- McAnulty, G., Duffy, F.H., Kosta, S., Weisenfeld, N.I., Warfield, S.K., Butler, S.C., ... Als, H., 2013. School-age effects of the newborn individualized developmental care and assessment program for preterm infants with intrauterine growth restriction: Preliminary findings. *BMC Pediatrics* 13, 25. <http://dx.doi.org/10.1186/1471-2431-13-25>.
- McAnulty, G.B., Duffy, F.H., Butler, S.C., Bernstein, J.H., Zurakowski, D., Als, H., 2010. Effects of the newborn individualized developmental care and assessment program (NIDCAP) at age 8 years: Preliminary data. *Clinical Pediatrics* 49 (3), 258–270. <http://dx.doi.org/10.1177/0009922809335668>.
- Paul, D., Roth, F.P., 2011. Guiding principles and clinical applications for speech-language pathology practice in early intervention. *Language, Speech, and Hearing Services in Schools* 42 (3), 320–330 (11 pp.) 10.1044/0161-1461(2010/09-0079).
- Peters, K.L., Rosychuk, R.J., Hendson, L., Coté, J.J., McPherson, C., Tyebkhan, J.M., 2009. Improvement of short- and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial. *Pediatrics* 124 (4), 1009–1020. <http://dx.doi.org/10.1542/peds.2008-3808>.
- Rachwal, C.M., Imperial-Perez, F., Guerrero, M., Hagberg, N., Rempel, G., Rummell, M., 2015. Neonatal and pediatric developmental guidelines in the care of neonatal/child/adolescent cardiovascular patient. What the direct care nurse needs to know (Retrieved from). [http://pcics.societyhq.com/wp-content/uploads/2014/12/Neo\\_Pedia\\_Guidelines\\_Developmental\\_Care.pdf](http://pcics.societyhq.com/wp-content/uploads/2014/12/Neo_Pedia_Guidelines_Developmental_Care.pdf)
- Rempel, G.R., Ravindran, V., Rogers, L.G., Magill-Evans, J., 2013. Parenting under pressure: A grounded theory of parenting young children with life-threatening congenital heart disease. *Journal of Advanced Nursing* 69 (3), 619–630. <http://dx.doi.org/10.1111/j.1365-2648.2012.06044.x>.
- Ryan, S., Grieshaber, S., 2005. Shifting from developmental to postmodern practices in early childhood teacher education. *Journal of Teacher Education* 56 (1), 34–45. <http://dx.doi.org/10.1177/0022487104272057>.
- Smith, J.G., Desai, P.P., Sira, N., Engelke, S.C., 2014. Family-centered developmentally supportive care in the neonatal intensive care unit: Exploring the role and training of child life specialists. *Children's Health Care* 43 (4), 345–368. <http://dx.doi.org/10.1080/02739615.2014.880917>.
- So, S., Rogers, A., Patterson, C., Drew, W., Maxwell, J., Darch, J., ... Pollock-BarZiv, S., 2014. Parental experiences of a developmentally focused care program for infants and children during prolonged hospitalization. *Journal of Child Health Care* 18 (2), 156–167. <http://dx.doi.org/10.1177/1367493513485476>.
- Symington, A.J., Pinelli, J., 2006. Developmental care for promoting development and preventing morbidity in preterm infants. In: *Cochrane Database of Systematic Reviews*. John Wiley & Sons, Ltd. (Retrieved from) <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001814.pub2/abstract>.
- Thomsen, M.K., 2015. Parental time investments in children evidence from Denmark. *Acta Sociologica* 58 (3), 249–263. <http://dx.doi.org/10.1177/0001699315572159>.
- Torowicz, D., Lisanti, A.J., Rim, J.-S., Medoff-Cooper, B., 2012. A developmental care framework for a cardiac intensive care unit: A paradigm shift. *Advances in Neonatal Care: Official Journal of the National Association of Neonatal Nurses* 12 (Suppl. 5), S28–S32. <http://dx.doi.org/10.1097/ANC.0b013e318265aeef>.
- Walker, L.O., Avant, K.C., 2010. *Strategies for theory construction in nursing*, 5th ed. Prentice Hall, Boston.
- Wernovsky, G., 2006. Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. *Cardiology in the Young* 16 (Suppl. 1), 92–104. <http://dx.doi.org/10.1017/S1047951105002398>.