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

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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.

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## 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 (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.

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