

Gross Motor Toolkit: Developmental Care Community Webinar

May 17th, 2023



National Pediatric Cardiology
Quality Improvement Collaborative

Webinar Agenda

Topic	Time	Facilitator
Welcome, Overview of Toolkit, Share Shift	10 min.	Julia & Lauren
Developmental Care in CHD: Past, Present and Future	40 min.	Amy Jo Lisanti
Q&A	15 min.	Project Co-Leaders



Optimizing Neurodevelopment & Supporting Infant Gross Motor Outcomes Toolkit



This toolkit was created to share intervention strategies to promote optimal gross motor outcomes and describes supportive developmental care practices for both hospital and home settings. The target audience for this toolkit is interdisciplinary professionals and parents caring for infants with single ventricle CHD. The information in this toolkit can also be shared with infants' medical home providers, early intervention professionals, and key stakeholders, such as hospital administrators.

[Optimizing Neurodevelopment & Supporting Infant Gross Motor Outcomes Toolkit](#)



NPC-QIC Toolkit

Optimizing Neurodevelopment & Supporting Infant Gross Motor Outcomes

November 2022

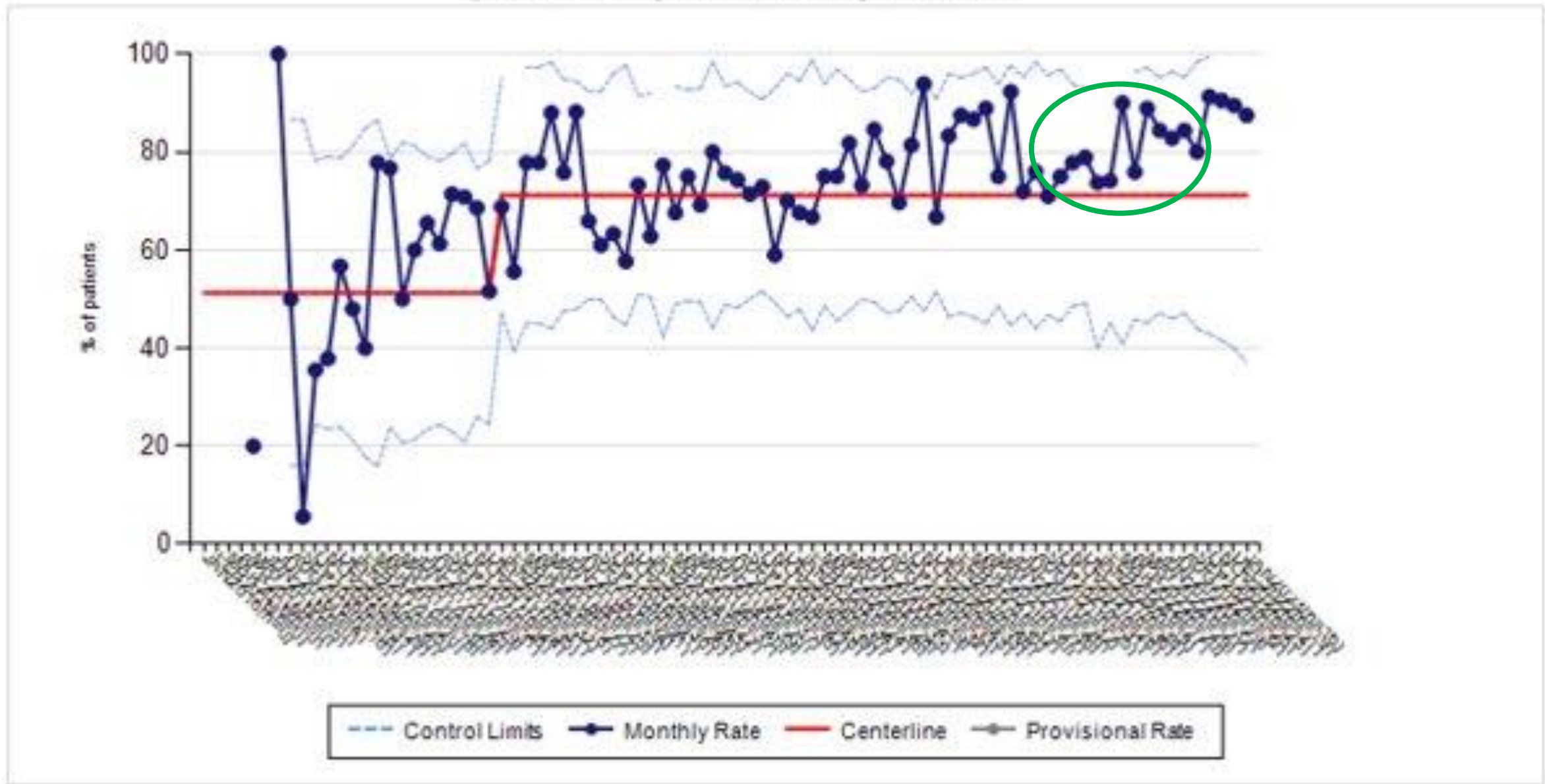
Tummy Time

Tummy time is an essential activity to promote an infant's motor skills, including head and trunk control, upper/lower extremity strength and weight bearing. The World Health Organization recommends infants under 1 year of age do at least 30 minutes of tummy time throughout the day^{xiii}. Infants with CHD who did less than 15 minutes of tummy time a day following cardiac surgery demonstrated more motor impairment^{xiv}. Starting tummy time work in the hospital is vital to model its importance to families and may help contribute to greater family comfort with the activity, ultimately improving improved participation with continuing tummy time at home. **Click here** to see how Children's Wisconsin increased tummy time practice in the ICU.



Developmental Plan at Stage 1 Palliation Discharge

Percent of patients whose parents are given a written, up-to-date developmental plan at Stage 1 Palliation discharge out of those patients discharged home after Stage 1 Palliation



Developmental Care in CHD: Past, Present and Future

Amy Jo Lisanti, PhD, RN, CCNS, FAHA

Assistant Professor

Family and Community Health, School of Nursing, University of Pennsylvania
Research Institute, Children's Hospital of Philadelphia
Children's Hospital of Philadelphia Cardiovascular Institute

Disclosures

- I am not a developmental specialist.
- I have no formal training in developmental interventions or assessment.
- I will be focusing this talk on my story as a cardiovascular critical care nurse, what I have learned along my career path and from the many collaborators, mentors, and experts along my journey.



Objectives



1. Brief
History

2. Current
Gaps

3. Future
Goals

What is developmental care?

- Developmental care is an overarching term that incorporates a constellation of interventions that can be integrated across the continuum of care.
- Key goals:
 - parent as primary care-givers
 - cue-based, family-centered care
 - reducing environmental stress and pain
 - positioning and motor support

The Past





A call for a
paradigm shift...



Developmental Care

A Developmental Care Framework for a Cardiac Intensive Care Unit

A Paradigm Shift

Deborah Torowicz, MSN, RN; Amy Jo Lisanti, MSN, RN, CCRN, CCNS;
Jeong-Sook Rim, BSN, RN; Barbara Medoff-Cooper, PhD, RN, FAAN

PubMed Search

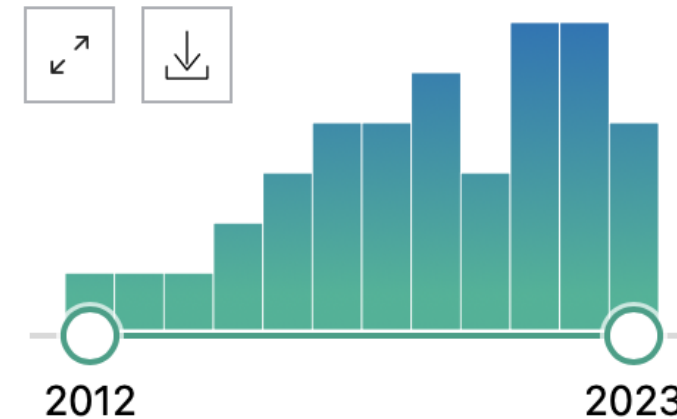
- ("developmental care" OR "neurodevelopmental care" OR "family centered" OR "family centred" OR "family-centred") AND ("congenital heart disease" OR "cardiac defect" OR "heart defect" OR "congenital heart defect") AND ("hospital*" OR "intensive care" OR "critical care")



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- 36 results from 2012 to 2023
- Narrowed to 26 articles addressing hospital care
 - 1 concept analysis
 - 1 study protocol DOI: 10.3389/fped.2021.666904
 - 2 instrument development/validation studies
 - 4 qualitative studies on parent experiences with family-centered care themes
 - 3 benchmarking studies
 - 0 Clinical Trials, RCTs, or Meta-analyses

RESULTS BY YEAR



PubMed Search

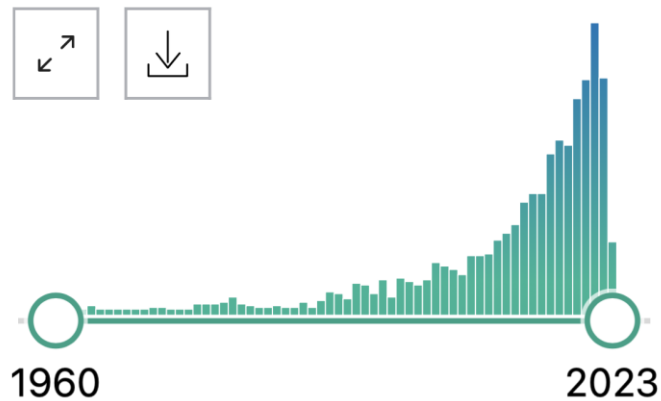
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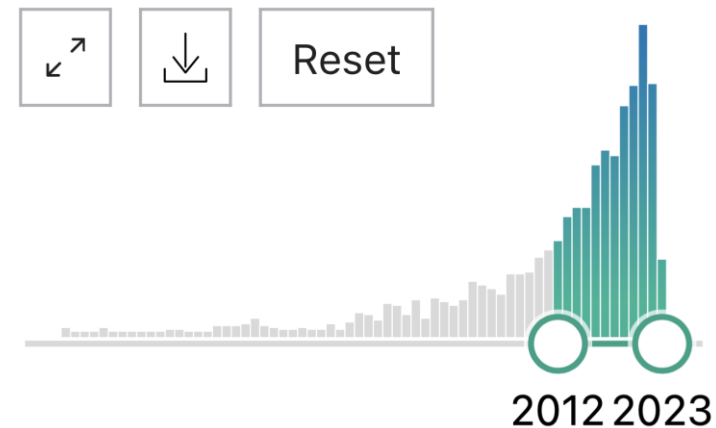
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RESULTS BY YEAR



1380 results

RESULTS BY YEAR



931 results

Original Article

Cite this article: Lisanti AJ, Vittner DJ, Peterson J, Van Bergen AH, Miller TA, Gordon EE, Negrin KA, Desai H, Willette S, Jones MB, Caprarola SD, Jones AJ, Helman SM, Smith J, Anton CM, Bear LM, Malik L, Russell SK, Mieczkowski DJ, Hamilton BO, McCoy M, Feldman Y, Steltzer M, Savoca ML, Spatz DL, and Butler SC (2023). Developmental care pathway for hospitalised infants with CHD: on behalf of the Cardiac Newborn Neuroprotective Network, a Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiology in the Young*, page 1 of 18. doi: [10.1017/S1047951123000525](https://doi.org/10.1017/S1047951123000525)

Developmental care pathway for hospitalised infants with CHD: on behalf of the Cardiac Newborn Neuroprotective Network, a Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative

Amy J. Lisanti^{1,2} , Dorothy J. Vittner³, Jennifer Peterson⁴ ,
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Hema Desai⁹ , Suzie Willette¹⁰, Melissa B. Jones¹¹, Sherrill D. Caprarola¹² ,
Anna J. Jones¹³, Stephanie M. Helman¹⁴ , Jodi Smith¹⁵, Corinne M. Anton^{16,17} ,
Laurel M. Bear¹⁸, Lauren Malik¹⁹, Sarah K.
Bridy O. Hamilton⁸, Meghan McCoy²⁰, Yvet
Melanie L. Savoca²³, Diane L. Spatz²⁴ and

Journal of the American Heart Association

AHA SCIENCE ADVISORY

Developmental Care for Hospitalized Infants With Complex Congenital Heart Disease: A Science Advisory From the American Heart Association

Amy Jo Lisanti, PhD, RN, CCNS, Chair; Karen C. Uzark, PhD, PNP, FAHA, Vice Chair; Tondi M. Harrison, PhD, RN; Jennifer K. Peterson, PhD, APRN-CNS, CCNS, FAHA; Samantha C. Butler, PhD; Thomas A. Miller, DO; Kiona Y. Allen, MD; Steven P. Miller, MDCM, MAS; Courtney E. Jones, SLP; on behalf of the American Heart Association Pediatric Cardiovascular Nursing Committee of the Council on Cardiovascular and Stroke Nursing; Council on Lifelong Congenital Heart Disease and Heart Health in the Young; and Council on Hypertension

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The purpose was to:

- 1) briefly describe the burden of developmental disability/delay/disorders for infants with cCHD,
- 2) define the potential health and neurodevelopmental benefits of DC for infants with cCHD,
- 3) identify critical gaps in research aimed at evaluating DC interventions to improve neurodevelopmental outcomes in cCHD.

This Issue



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Vol 12, Issue 3

Table 1. Developmental Concerns for Children and Young Adults With Complex Congenital Heart Disease^{1,13}

Domain	Described delays and deficits
Cognition	Intelligence quotient Processing speed
Attention	Sustained and divided attention Conflict monitoring Alertness and vigilance
Executive function	Inhibitory control Organization and planning Working memory Problem solving Cognitive flexibility and decision making
Speech and language	Speech articulation, phonation, oral-motor coordination Pragmatics, fluency, phonological awareness, and sentence formulation
Visuospatial processing	Visual perceptual reasoning and processing Visuomotor integration and visuoperception
Memory	Visual and verbal memory
Motor	Fine motor (control, speed, and dexterity) Motor competence Manual dexterity and visual-spatial-motor integration Strength, balance, and endurance

Known factors only explain 1/3 of the variance in ND outcomes

Academic achievement	Special education and remedial services Academic challenges and learning disabilities
Social cognition and adjustment	Social functioning and social communication Theory of mind
Emotional and behavioral functioning	Internalizing (anxiety, depression, and social withdrawal) Externalizing (hyperactivity, aggression, oppositional behavior) Attention deficit/hyperactivity disorder Psychosocial functioning Emotional regulation
Adaptive skills	Conceptual and social skills Functional independence Practical daily living skills (self-care, community use, home living, leisure, and self-direction) Psychosexual development Effective disease management Oral feeding and oral-motor coordination
Quality of life	Physical and psychosocial Emotional, behavioral, and daily functioning

Where are our current gaps in knowledge?

General	
Developmental Care Goal	Developmental Care Interventions Needing Research in cCHD
Promote brain maturation and prevent brain injury.	<ul style="list-style-type: none"> • Evaluate effect of parent mental health support, infant pain control, decreasing stress, and controlling environmental stimulation on brain maturation and infant behavior. • Design and implement randomized control trials using brain imaging in infancy and later childhood to evaluate potential changes to brain function and structure following DC.
Enhance precision in measurement of infant stress using biomarkers.	<ul style="list-style-type: none"> • Describe infant behavior and stress responses for infants with cCHD using biomarkers, such as heart rate variability and cortisol, and their relationship to DD outcomes. • Define the impact of DC interventions on infant stress reactivity.
Promote enhanced medical management while in the hospital.	<ul style="list-style-type: none"> • Evaluate impact of DC on short term medical outcomes such as days on assistive breathing, days on tube feeding, incidence of stroke or seizure, weight gain, length of ICU and hospital stay.
Promote developmental care across institutions.	<ul style="list-style-type: none"> • Evaluate DC in multicenter, diverse populations to identify needed system supports and possible barriers to implementation. • Develop, implement, and evaluate DC curriculum into healthcare provider orientation and continuing education. • Develop and implement electronic medical record documentation that reflects implementation of DC practices.
Promote health equity and reduce disparities in developmental outcomes.	<ul style="list-style-type: none"> • Evaluate the extent of disparities existing in the provision of DC in units caring for infants with cCHD. • Develop, test, and implement DC interventions in underserved and minority populations, tailoring interventions as needed to address inequities and any other barriers to DC implementation.
Promote long-term development and increased quality of life.	<ul style="list-style-type: none"> • Design and implement longitudinal studies evaluating impact of DC on long-term physiology, development, executive functioning, school achievement, and mental health using standardized measures throughout childhood and into adulthood.

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Parents as Primary Caregivers:

Developmental Care Goal	Developmental Care Interventions Needing Research in cCHD
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Cue-based Family-Centered Care:

Developmental Care Goal	Developmental Care Interventions Needing Research in cCHD
Promote cue-based care by staff and parents.	<ul style="list-style-type: none"> Evaluate staff and parent knowledge of reading infant cues. Evaluate the impact of teaching parents to understand infant cues on feeding and ND outcomes Assess effect of cue-based care on infant stress response. Evaluate effect of cue-based interventions and stress response on brain maturation and developmental outcomes.
Promote oral feeding and the development of oral-motor skills.	<ul style="list-style-type: none"> Identify DC interventions to reduce complications associated with oral aversion and poor oral-motor skills. Assess effect of cue-based feeding on infant feeding outcomes and oral-motor skill development. Design and evaluate interventions to support parents as their infant's primary provider of nutrition and the impact on parent stress, infant weight gain, and infant feeding.
Promote developmentally supportive nutrition and somatic growth.	<ul style="list-style-type: none"> Test interventions to support the administration of human milk. Assess the dose effect of human milk and direct breastfeeding on long-term ND outcomes. Assess overall DC interventions on infant somatic growth and ND.
Promote health of the family unit	<ul style="list-style-type: none"> Evaluate the effect of DC on family health outcomes including parental mental health, sibling well-being, and family functioning over time.

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Reducing Environmental Stress and Pain:

Developmental Care Goal	Developmental Care Interventions Needing Research in cCHD
Provide positive visual and auditory interaction, while minimizing excess environmental stimuli.	<ul style="list-style-type: none">• Assess sound levels and evaluate interventions to reduce sound.• Test cycled lighting interventions to promote sleep and circadian rhythm development.• Evaluate the impact of visual and auditory stimuli on the behavior of infants with cCHD.
Optimize comfort and pain control through non-pharmacologic options to reduce side effects of pharmacotherapy.	<ul style="list-style-type: none">• Evaluate non-pharmacologic interventions (e.g., non-nutritive sucking, swaddling, containment, holding and rocking, human touch) on pain control, mobility, and infant behavior.• Identify effective combinations of pharmacologic and non-pharmacologic strategies in infants to reduce polypharmacy, oversedation and withdrawal.

Positioning and motor support:

Developmental Care Goal	Developmental Care Interventions Needing Research in cCHD
Promote musculoskeletal development.	<ul style="list-style-type: none">• Identify the effectiveness of developmental supports and therapeutic positioning including holding, hands to midline, and awake prone positioning on motor skill development.

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Overwhelmed yet?



I AM!



COLLABORATION IS KEY

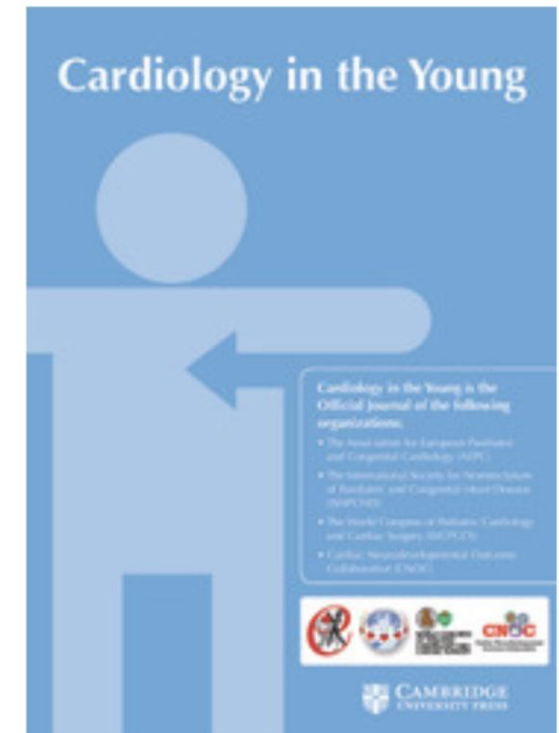
Original Article

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The purpose of this paper was to present clinical pathway based on evidence in the literature and/or expert consensus where evidence does not exist in the extant literature.



Inclusion Criteria

- All inpatient infants with CHD ≤ 3 months of age (or developmental equivalent).
- We acknowledge that infants with acquired heart disease would also benefit from developmental care. However, we focused our review of literature and discussion for this pathway on infants with CHD.

Developmental Care Pathway

Admission to the Hospital



I. Initiate and Document Developmental and Psychosocial Screening on Admission

Formal Evaluations and Initiatives

Assessments	Frequency and Interventions
Formal Developmental Evaluation	On admission and prior to discharge or after any significant clinical change: -identify both inpatient and outpatient developmental therapies needed
Parent Mental Health and Psychosocial Needs Assessment	On admission and prior to discharge: -identify inpatient and outpatient psychosocial services needed
Interdisciplinary Developmental Care Rounds	Perform interdisciplinary developmental care rounds early and on a regular basis -identify developmental progress, milestones, and needed developmental, therapy, and psychosocial interventions



Developmental Care Pathway

Admission to the Hospital



I. Initiate and Document Developmental and Psychosocial Screening on Admission

Formal Evaluations and Initiatives	
Assessments	Frequency and Interventions
Formal Developmental Evaluation	On admission and prior to discharge or after any significant clinical change: -identify both inpatient and outpatient developmental therapies needed
Parent Mental Health and Psychosocial Needs Assessment	On admission and prior to discharge: -identify inpatient and outpatient psychosocial services needed
Interdisciplinary Developmental Care Rounds	Perform interdisciplinary developmental care rounds early and on a regular basis -identify developmental progress, milestones, and needed developmental, therapy, and psychosocial interventions



II. Initiate and Document Daily Evidence-based Bundle of Care

DAILY EVIDENCE-BASED BUNDLE OF CARE – (Preoperative and Postoperative)
Goal: Individualize Developmental Care to the Changing Needs of the Infant and Family



III. Continue bundle of care daily until discharge. Repeat formal developmental and psychosocial screening prior to discharge.

The Daily Bundle

DAILY EVIDENCE-BASED BUNDLE OF CARE – (Preoperative and Postoperative)
 Goal: Individualize Developmental Care to the Changing Needs of the Infant and Family

Assessments	Interventions
<u>Continuous Behavior State Assessment</u>	<ul style="list-style-type: none"> - Cluster and pace care based on infant cues (organized versus disorganized behaviors) - Provide gentle human touch/talk/stimulation prior to procedural touch
<u>Pain, Sedation, Withdrawal, and Delirium Assessment:</u> - Routinely assess with validated tools	<ul style="list-style-type: none"> - Adequately measure and address pain, prioritizing non-pharmacologic approaches as often as possible to promote comfort and organized behavior - Minimize sedation/analgesic medications, avoid polypharmacy, judicious use, or avoidance of benzodiazepines - Implement strategies to prevent, measure, and treat delirium
<u>Assess Physical and Sensory Environment:</u> - Thermoregulation - Environmental sensory stimulation	<ul style="list-style-type: none"> - Infant dressed and bundled. If need to remain undressed for continuous assessment (e.g., postoperative lines/tubes, bleeding, open chest, etc.), place infant in artificial heat source in servo mode - Provision of low ambient light during the day and darkness at night, low sound levels, and gentle sensory input during care (e.g., four handed care, facilitated tucking, containment, massage, soft voices, gentle touch)
<u>Developmental and Motor Supports:</u> - PT/OT evaluation	<ul style="list-style-type: none"> - Positioning: maintain head midline with extremities flexed towards midline and use supportive devices to provide boundaries and containment (e.g., blanket rolls) - Promote early mobility through passive range of motion, stretching, massage and out of bed experiences to promote motor and sensory skills - Sternal Precautions/Tummy Time: encourage prone positioning pre- and post-surgery

The Daily Bundle

DAILY EVIDENCE-BASED BUNDLE OF CARE – (Preoperative and Postoperative)

Goal: Individualize Developmental Care to the Changing Needs of the Infant and Family

Assessments	Interventions
<p><u>Developmentally Supportive Feeding:</u></p> <ul style="list-style-type: none"> - Breastfeeding assessment/use of human milk: Parent plan of care - Pre-feeding readiness - Oral feeding assessment: - Red flags for oral feeding 	<ul style="list-style-type: none"> - Breast feeding/Use of Human Milk: Initiate Spatz 10 step model to promote and protect breastfeeding - Implement feeding therapist individualized feeding plan and interventions (Pre- and Post-op) - Pre-feeding Readiness Interventions (colostrum swabs, oral stimulation, non-nutritive sucking) - Oral Feeding Interventions: cue-based feeding, side-lying positioning, modify milk flow, paced-feeding - Oral Aversion Prevention and Intervention <p>**Contact feeding therapist for formal feeding assessments if any Red Flags identified per pathway**</p>
<p><u>Nutrition and Growth:</u></p> <ul style="list-style-type: none"> - Routine anthropometrics - Daily assessment of nutrition intake 	<ul style="list-style-type: none"> - Provide preoperative nutrition if demonstrating oral feeding readiness - Provide nutrition by mouth (breastfeeding or bottle feeding) if demonstrating oral feeding readiness - Implement nutrition interventions per standardized nutrition pathway and in collaboration with dietitian - Identify mode of nutrition (oral, enteral, and/or parenteral) based on clinical status - Support use of human milk (maternal human milk or pasteurized donor human milk: consent required)
<p><u>Parent Engagement and Caregiving Assessment</u></p>	<p>Encourage parent presence, touch, holding, and active participation in caregiving as tolerated by infant and based on parent preferences and needs, as well as presence and participation at bedside rounds</p>
<p><u>Discharge Readiness:</u></p> <ul style="list-style-type: none"> - Evaluation of medical home - Parent educational needs - Developmental surveillance 	<ul style="list-style-type: none"> - Remove positioning devices gradually as infant recovers to model back to sleep/safe sleep guidelines and to provide space for movement - Ensure consistent plan of care across transitions, using members of the interdisciplinary team (case management, nursing, social work, etc.) to support transitions within the hospital and to the community - Schedule all necessary follow-up appointments (cardiac neurodevelopmental follow-up, early intervention, cardiology, pediatrician, and/or other specialty providers) prior to discharge - Provide individualized parent education based on medical and developmental needs of the infant



Measurement Outcomes

- We recognize this pathway has not been tested.
- Table 2. Suggested instruments and clinical tools, with cited literature and specifically highlighting those that have been used in CHD.
- Future directions – want to implement the pathway and study outcomes.

Future directions

- MORE RESEARCH AND DATA-DRIVEN INITIATIVES.
- Multi-site collaborative projects.
- Advocacy, philanthropy, and development.
- Community-based collaborations.



American Heart Association®

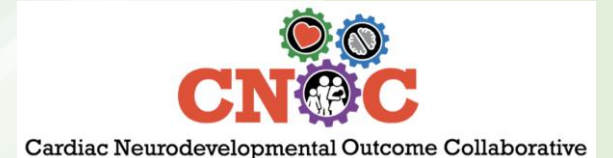
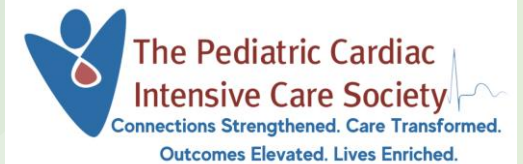


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Future directions

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- Community-based collaborations.



QUESTIONS?

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Q & A

Save the Dates

June 27th at 4pm ET

- Interstage Change Package Webinar

July 11th at 5pm ET

- Unplanned Reinterventions Project Network-Wide Webinar:
A Comprehensive Approach to the Management of Patients
With HLHS



Save the Date

NPC-QIC Fall 2023 Learning Session

September 21-23

Chicago, IL



Standard Feedback Polls



The webinar was a good use of my time.

- 1 – Definitely Disagree
- 2
- 3 – Neutral
- 4
- 5 – Definitely Agree

I learned or had reinforced a concept/idea that will improve outcomes for children with HLHS.

- 1 – Definitely Disagree
- 2
- 3 – Neutral
- 4
- 5 – Definitely Agree



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THANK YOU!

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