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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

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Abstract

Infants and children born with CHD are at significant risk for neurodevelopmental delays and abnormalities. Individualised developmental care is widely recognised as best practice to support early neurodevelopment for medically fragile infants born premature or requiring surgical intervention after birth. However, wide variability in clinical practice is consistently demonstrated in units caring for infants with CHD. The Cardiac Newborn Neuroprotective Network, a Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative, formed a working group of experts to create an evidence-based developmental care pathway to guide clinical practice in hospital settings caring for infants with CHD. The clinical pathway, "Developmental Care Pathway for Hospitalized Infants with Congenital Heart Disease," includes recommendations for standardised developmental assessment, parent mental health screening, and the implementation of a daily developmental care bundle, which incorporates individualised assessments and interventions tailored to meet the needs of this unique infant population and their families. Hospitals caring for infants with CHD are encouraged to adopt this developmental care pathway and track metrics and outcomes using a quality improvement framework.

Developmental care for hospitalizsed infants is a family-centered care approach that supports individualised care via observation and interpretation of the infant's behaviour and modification of the environment and caregiving to meet the needs of infants and their families. Developmental care is widely recognised as best practice for medically fragile infants born prematurely or who require surgical intervention after birth;[1,2] however, implementation of developmental care practices occurs mainly in neonatal iICUs and less often for sub-specialty paediatric cardiac ICUs. Over the past decade, literature has emerged calling for developmental care to be integrated into the care of infants with CHD.[3–7] The Cardiac Neurodevelopmental Outcomes Collaborative recently identified a priority for the CHD field to adapt and implement developmental care interventions in the CHD population.[8] However, wide variability in the clinical practice of developmental care has been consistently demonstrated.[9–12] Barriers identified for paediatric cardiovascular healthcare providers include lack of education, resources, and competing priorities to support developmental care with this specific infant population.[9,10] Given the well-documented risks for neurodevelopmental abnormalities associated with CHD,[13] and the similarities in brain maturity and structure between infants with CHD and infants born prematurely,[14,15] developmental care is a critical aspect to clinical practice during infant hospitalisation for cardiac surgery.[6]

One method to reduce variability in practice is a clinical pathway, which is a structured plan of care utilised by the interdisciplinary team to support clinical decision making with detailed steps and evidence-based guidelines.[16] Clinical pathways support standardisation in care, with improved patient outcomes and reduced complications.[16–18] The Cardiac Newborn Neuroprotective Network, a Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative, formed a working group of experienced paediatric cardiovascular clinicians and parents to create an evidence-based developmental care pathway to guide clinical practice in hospital settings caring for infants with CHD. Members represented the following paediatric sub-specialties: nursing, psychology, cardiology, critical care, physical therapy, occupational therapy, speech language pathology, nutrition, and parents. Members were assigned specific sections of the pathway based on their area of expertise and completed comprehensive reviews of the literature for each section. This paper presents the clinical pathway content generated by the working group based on evidence in the literature and/or expert consensus where evidence does not exist in the extant literature. The pathway was developed based on underlying assumptions and definitions (Table 1). The "Developmental Care Pathway for Hospitalized Infants with Congenital Heart Disease" (Fig 1) contains three sections:

I. Initiate and Document Developmental and Psychosocial Screening on Admission
II. Initiate and Document Daily Evidence-based Bundle of Care
III. Continue Bundle of Care Daily Until Discharge. Repeat Formal Developmental and Psychosocial Screening Prior to Discharge.

We describe each section in detail below and more granular information is available in the tables.

I. Initiate and document developmental and psychosocial screening on admission

Upon admission to the hospital, we recommend formal developmental and psychosocial screening for infants and their parents including documentation of findings in the medical record.

Formal developmental evaluation

Observable infant behaviour is an expression of neurobehavioural status and brain function that can be used to identify infants at risk for developmental delays.[19] Neurobehavioural assessments are used to determine infants' developmental strengths and vulnerabilities as well as infants' ability to attend and engage with environmental stimuli.[20] Neurobehavioural assessments may use observation or a facilitated examination to identify patterns of behaviour of infants. An important consideration is to be mindful of the infant's level of stress during the interaction, as well as understanding what strategies the infant uses to actively participate.[21] Most infant neurobehavioural assessments require additional training and certification prior to use in clinical settings with infants and families.[6,22] To fully assess infant state, motor skills, autonomic stability, self-regulation, and social interaction, we recommend developmental assessment measures that are based on the Brazelton Neonatal Behavioral Assessment Scale.[23] Other developmental assessment measures are listed in Table 2.

Parent mental health and psychosocial needs assessment

Parents of infants with CHD are at increased risk for mental health challenges such as traumatic stress, anxiety, and depression,[24,25] and those who lack social support and resources are more likely to endorse higher stress levels.[26] Following birth, parents of infants with CHD are exposed to multiple stressors including the ICU environment, cardiac disease diagnosis, newborn cardiac surgery, financial and vocational stress, hospitalisations and critical illness, increased caregiving demands, and disruption to the family system.[27–29]

We recommend routine parental mental health and psychosocial screening to identify psychosocial services to benefit families during infant hospitalisation and post-discharge.[30] Examples of parent mental health screening tools are listed in Table 2. Psychosocial assessments include screening for insurance needs, transportation insecurity, food insecurity, housing status, childcare for siblings, employment status, educational concerns, family support, supportive coping strategies, attachment and bonding, understanding of infant clinical status, and potential barriers to adjustment. Psychosocial team members can be utilised for support and resource identification, caregiver support groups, and continued screening and support following hospital discharge.[31]

Interdisciplinary developmental care rounds

Many organisations and hospital systems utilise interdisciplinary developmental care rounds as best practice to foster education and collaboration with families and healthcare professionals in providing developmentally appropriate care (Supplementary Table 1).[4,7,9,32] When establishing and performing interdisciplinary developmental care rounds, we recommend identifying consistent team members and timing for rounds to facilitate family presence and participation.[7,9,33] We recommend initiating interdisciplinary developmental care rounds on admission to establish a baseline and continuing on a regular basis during infant hospitalisation for ongoing care. Documentation and dissemination of recommendations to the bedside care team and family should be provided.

II. Initiate and document daily evidence-based bundle of care

We recommend a daily bundle of care to support individualised developmental care that responds to the changing strengths and

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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	
Assessments	Interventions
Continuous Behavior State Assessment	- Cluster and pace care based on infant cues (organized versus disorganized behaviors) - Provide gentle human touch/talk/stimulation prior to procedural touch
Pain, Sedation, Withdrawal, and Delirium Assessment: - Routinely assess with validated tools	- 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
Assess Physical and Sensory Environment: - Thermoregulation - Environmental sensory stimulation	- 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)
Developmental and Motor Supports: - PT/OT evaluation	- 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
Developmentally Supportive Feeding: - Breastfeeding assessment/use of human milk: Parent plan of care - Pre-feeding readiness - Oral feeding assessment: - Red flags for oral feeding	- 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 **Contact feeding therapist for formal feeding assessments if any Red Flags identified per pathway**
Nutrition and Growth: - Routine anthropometrics - Daily assessment of nutrition intake	- 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)
Parent Engagement and Caregiving Assessment	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
Discharge Readiness: - Evaluation of medical home - Parent educational needs - Developmental surveillance	- 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

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

Figure 1. Developmental care pathway.

areas of concern of the infant and family throughout the hospitalisation. A bundle of care is a group of structured evidence-based interventions that are provided together by the multidisciplinary team to improve patient outcomes. This bundle of care to support individualised developmental care includes both assessment of the infant and family across multiple domains and recommendations for tailored interventions based on the assessments. We review each domain below.

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Table 1. Key assumptions and definitions of the developmental care pathway for hospitalized infants with CHD

Inclusion Criteria	All inpatient infants witd congenital heart disease (CHD) ≤3 montds of age (or developmental equivalent). We acknowledge tdat infants witd acquired heart disease would also benefit from developmental care. However, we focused our review of literature and discussion for tdis patdway on infants witd CHD.
Pathway Target Audience	Interdisciplinary team members caring for infants with CHD, including, but not limited to physicians, bedside nurses, advanced practice nurses, psychologists, occupational therapists, physical therapists, speech language pathologists, registered dietitians, lactation consultants, pharmacists, child life specialists, music therapists, social workers, chaplains, developmental specialists, unit leaders, administrators, managers, case managers, parents, and family members.
Parents	For the purposes of this pathway, we will use the term "parents" to identify those individuals, biologically or non-biologically related to the infant, that assume the role of the infant's primary caregivers. We acknowledge that families extend beyond immediate parents and infants may be cared for by grandparents, siblings, and other supportive individuals. Key assumption is that parents are the primary caregivers for infants with CHD and need to be incorporated into all aspects of infant care.
Evidence for Pathway	We have incorporated all evidence currently available from within the CHD population. However, we acknowledge that where evidence does not yet exist from studies examining developmental care practices specifically in the CHD population, we have pulled from other at-risk infant populations and applied the evidence based on expert clinical experience to generate best practices. When we cite literature that is specific to the CHD population, we explicitly state this throughout the paper.
Individualized Nature of Care	We acknowledge that continuous assessment and reassessment is a key aspect to care. The developmental care pathway provides general guidance, but clinicians should tailor care to the unique needs of the family and bring in resources as needed. If at any point concerns arise in the care of infants with CHD, early engagement and consultation from a specialist (PT, OT, SLP, psychologist, etc.) should be incorporated into the plan of care, where resources are available.
Hemodynamic Stability for Developmental Care	We do not recommend a strict definition of "hemodynamic stability" as it varies tremendously from one patient to another. No matter how hemodynamically unstable an infant may be at any given time, there are always developmentally supportive interventions that can be incorporated into the care of the infant and family. Although concern for handling in a medically complex and hemodynamically tenuous newborn is justified, the risks must be balanced against the benefits of developmentally supportive care. The balance of pharmacologic and non-pharmacologic therapies may not always be driven by patient factors but rather the bias of individual providers, the time of day, and the acuity of other patients in a busy ICU. To decrease heterogeneity in care, ICUs should consider a shared baseline that describes a spectrum of clinical acuity and hemodynamic stability and corresponding individualized developmental care that would be both appropriate and inappropriate for providers and parents in those scenarios. The continuum of care for the infant needs to be reassessed frequently by the medical team to determine feasibility to safely increase developmental cares and parental involvement in the cares. We recommend that the interdisciplinary team works together to acknowledge which developmental care interventions are medically justified and reduce variability in care. Of prime importance is an interdisciplinary approach that supports continuous reassessment of the infant's capacity for varying degrees of developmental care interventions and incorporating the assessments and interventions in the daily evidence-based bundle of care as frequently as possible.

PT: Physical therapist, OT: Occupational therapist, SLP: speech language pathologist, ICU: intensive care unit.

Continuous behaviour state assessment

Assessment

Infant behaviour should be continuously observed (sometimes called cue-based care) to guide the infant's plan of care and to determine infant strengths and vulnerabilities. Infant behaviour is composed of five subsystems of functioning: autonomic, motor, state, attention/interaction, and self-regulation (Supplementary Table 2). These sub-systems exist simultaneously and mutually influence each other, occurring in continuous interaction with the environment based on the Synactive Theory of Development.[34] Infant functioning is described and understood in terms of organisation or competencies and disorganisation or vulnerabilities.[34]

Interventions

Consider opportunities to create a calm, nurturing, and welcoming environment.[6] Optimise opportunities to cluster and pace caregiving tasks based on infant behaviour to enhance the infant's emotional development of building trust and security.[21] Provide the infant with opportunities to respond, pausing after initial greeting, and facilitate behavioural responses that support the infant to self-soothe (e.g., bring their hands to mouth).[21]

Pain, withdrawal, sedation, and delirium assessment

Assessment

Infants with CHD face a variety of painful experiences during their hospitalisations. These unpleasant or unexpected sensory and emotional experiences during early development may lead to permanent alterations in brain processing and development.[35–38] Optimal pain management requires a multimodal approach. We recommend the use of objective pain assessment tools (Table 2) to avoid untreated pain or excessive analgesia.[37] Typically, acute postoperative pain is greatest in the first 48 hours with a progressive decline over the course of 7 days.[39]

The assessment and treatment of pain in children can reduce the risk and severity of delirium, a nonspecific disturbance of cognition and consciousness resulting from critical illness and ICU exposure.[40] Delirium affects 49% patients in paediatric cardiac ICUs, with 64% of those less than 1 year of age.[40] Delirium predisposes patients to long-term complications including decreased verbal and spatial memory and sustained attention, and impaired executive function.[40–42] Delirium is well-studied in paediatric populations, and validated screening instruments exist (Table 2) to enable early recognition.

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Table 2. Suggested instruments and clinical tools.

Category	Instrument	Instrument Citation	Instrument Description	Used or recommended in Infants with CHD
Developmental Assessment Measures	NICU Network Neurobehavioral Scale (NNNS)	Lester[160]	Examines both neurologic integrity as well as behavioural functioning and scores a full range of infant neurobehavioural performance that was intended to have broad applicability for detecting at-risk infants.	Hogan[161] Gakenheimer-Smith[162] Massaro[163] Lambert[164] Campbell[165]
	Newborn Behavioral Observations (NBO)	Nugent[166]	Infant-focused, family centred, relationship-based tool, designed to sensitise parents to their infant's competencies and individuality that fosters positive parent-infant interactions	Butler[20] Butler[167]
	Alberta Infant Motor Scale (AIMS)	Piper[168]	Focuses on motor patterns and movement	Fourdain[169] Long[170]
	Test of Infant Motor Performance (TIMP)	Campbell[171]	Measures postural and selective motor control of functional performance	Tripathi[172]
	Prechtl's Qualitative assessment of General Movements (GMA)	Einspieler[173]	Diagnostic tool for early detection of brain dysfunction	Tripathi[172] Huisenga[174]
	Newborn Individualized Developmental Care and Assessment Program	Als[175]	NIDCAP Observation is an assessment methodology that acknowledges the individualised, unique needs of each infant & family supports developing relationships. Four key elements of NIDCAP include the care of the infant, the care of the family, care of the healthcare team, care of the physical and social environments.	Miller[10] Kelso Damond[176] Butler[176] Peterson[4]
Parent Mental Health Screening	The PedsQL 2.0 Family Impact Module	Varni[177]	The Peds QL Family Impact Module is a parent self-report tool assessing the impact of paediatric chronic health conditions on parents and the family.	Tadros[178] Kaugars[179]
	Depression Anxiety Stress Scale (DASS)	Henry[180]	The DASS-21 is a self-report measure that assesses adult mental health symptoms in depression, anxiety, and stress.	Ware[181] Callahan[182] Blue[183]
	Pediatric Inventory for Parents	Streisand[184]	The Pediatric Inventory for Parents assesses levels of stress experienced by parents caring for a child with a chronic disease.	Choi[185] Kaugars[179] Vrijmoet-Wiersma[186]
	Edinburgh Postpartum Depression Scale (EPDS)	Cox[187]	The EPDS is a 10-item scale developed to identify women who may be experiencing postpartum depression.	Wu[188] Re[189] Solberg[190]
	Impact of Events Scale (IES-R)	Weiss[191]	The IES-R is a 22-item self-report measure assessing subjective distress caused by traumatic events.	Rychik[192]
	Psychosocial Assessment Tool (PAT)	Pai[193]	The PAT is a brief parent report of family psychosocial risk in families of children with health conditions.	Hearps[194]
Pain Assessment	N-PASS	Hall[37]	N-PASS assesses pain, agitation, and sedation level in critically ill infants with acute or on-going pain	Hummel[195]
	COMFORT Scale	Ambuel[196] Van Dijk[197] Smith[45]	COMFORT scale assesses pain in noncommunicative critically ill patients	Lisanti[152]
Delirium Screening	pCAM-ICU	Smith[198] Smith[199]	pCAM-ICU is a rapid screening tool that is highly validated and reliable in the assessment of delirium based upon arousal and content. Main features for delirium screening include acute change or fluctuating course of mental status, inattention, altered level of consciousness and disorganised thinking.	None.
	CAPD	Traube[200]	CAPD is a rapid and observational nursing screening utiliszed for the detection of delirium in the critical care setting. CPAD >9 sensitive and specific for delirium.	Staveski[42] Staveski[201]
Sedation	SBS	Curley[202]	SBS is a sedation assessment instrument in infants and young children supported on mechanical ventilation. The SBS is a 6-point scale that describes state behaviour on a scale of −3 to +2.	Lebet[203] Lincoln[204] Zuppa[44]

(*Continued*)

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Table 2. (*Continued*)

Category	Instrument	Instrument Citation	Instrument Description	Used or recommended in Infants with CHD
Withdraw	WAT-1	Franck[205]	WAT-1 describes opioid and benzodiazepine withdrawal symptoms in acutely ill infants and children. The WAT-1 is an 11-item, 12-point scale.	Franck[206] Lincoln[204]
Temperature Assessment	Skin temperature	Sinclair[207] Joseph[208] NANN[49]	Skin probes for continuous measurement are necessary when artificial heat sources are in use. Skin probe thermistors should be placed flat on the abdomen or flank and secured with a reflective probe cover.	None found
	Axillary temperature	Lefrant[209] Brozanski[54]	Common temperature site in infants used routinely with hands-on care. Axillary temperatures have reduced reliability when measured temperatures are outside of the normal range	None found
	Rectal temperature	Fonkalsrud[210]	Appropriate surrogate for core temperature, however, are not recommended for intermittent use in infants due to the risk of rectal perforation. Therefore, if rectal temperatures are necessary, continuous measurement is recommended with probes inserted no more than 2 centimeters.	None found
	Core temperatures	NANN[49]	Continuous core temperatures (oesophageal, nasopharynx, or bladder) should be obtained when possible; however, these methods can be difficult to obtain due to their invasive nature.	None found
Oral Feeding Assessments	Early Feeding Skills Assessment (EFS)	Thoyre[85]	A valid and reliable clinician reported assessment of infant feeding skills to help identify problem areas and target skills not yet developed.	Steward[121]
	Neonatal Oral Motor Assessment Tool (NOMAS)	Palmer[211]	Reliable tool to assess infant sucking patterns in pre-term and term infants.	None found
	Neonatal Eating Assessment Tool-Bottle Feeding (Neo-EAT-Bottle Feeding)	Pados[212]	Caregiver questionnaire used to measure symptoms of problematic feeding for infants birth to 7 months who are bottle feeding.	None found
	Neonatal Eating Outcome	Pineda[213]	Developmental feeding assessment for high-risk infants used to evaluate oral motor and feeding skills in preterm infants based on gestational age.	None found
Swallowing Studies	Videofluoroscopic Swallow Study (VFSS)	Pham[214]	A dynamic radiographic procedure used to evaluate the oral, pharyngeal, and upper oesophageal phase of a swallow.	Pham[214]
	Fiberoptic Endoscopic Evaluation of Swallowing (FEES)	Kwa[215]	A procedure that uses a flexible endoscope to observe the pharynx and larynx to evaluate for dysphagia. Usually performed by ear-nose-and-throat specialists with speech language pathologists.	Kwa[215]

Interventions

Ultimately, the goal is to prevent, reduce, or limit acute pain in the perioperative period by utilising a combination of pharmacologic and non-pharmacologic interventions.[43] Sedative medications are a mainstay therapy in the ICU to help patients tolerate the environment and medical/nursing interventions and to reduce anxiety. Sedation should be tailored to the patients' individual needs utilising goal-directed therapy.[44] Sedation levels and assessment for withdrawal should be examined using validated instruments (Table 2). Consideration should be paid to the total dosage and duration of sedation and analgesia medications due to the increased risk of morbidities (withdrawal, altered sleep, delirium, immobility, and potential neurotoxicity).[43] Specifically, judicious use or avoidance of benzodiazepines may reduce the likelihood of developing delirium.[45,46]

We recommend the incorporation of non-pharmacologic comfort measures into the care of CHD infants to prevent and manage pain and agitation in acute postoperative setting or with treatment of withdrawal and delirium (Table 3).[45] Non-pharmacologic comfort measures include a broad range of interventions, with varying degrees of evidence for each.[47,48] Our recommendation is to include as many as possible, based on the individualised infant response to the intervention and parental preferences.[47] Encouraging parents to provide non-pharmacologic measures increases parental engagement to provide comfort to their child.[47] Non-pharmacologic comfort measures should not replace adequate analgesia, but should be used in combination,[47] and may also be effective to treat withdrawal and delirium symptoms by normalising the environment.[46]

Assess physical and sensory environment: thermoregulation

Assessment

Although minimal research has studied thermoregulation in infants with CHD, the National Association of Neonatal Nurses developed general guidelines for temperature assessment in medically fragile newborns and infants (Table 2).[49] Infants with CHD,

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Table 3. Non-pharmacologic comfort interventions.

Non-pharmacologic comfort Intervention	Method of application/utilization	Evidence * = indicates evidence specifically generated within CHD population
Sucrose 24% oral solution	Often combined with non-nutritive sucking. Use for short duration procedural pain. Not for general comfort or agitation. Optimal dose not known, usually 2 ml or less. Mechanism: thought to work on endogenous opiate pathways or dopamine/acetylcholine.[48]	Reduced acute, short duration procedural pain including heel lance, venipuncture, intravenous (IV) cannulation and intramuscular (IM) injections in preterm and term infants.[48] Reduces behavioural pain responses and composite pain scale scores, less effect on physiological pain responses.[216] Beneficial effects of sucrose were less than with skin-to-skin care.[217] Evidence on reduction of pain/stress during other procedures such as arterial puncture, insertion of gastric tubes, bladder catheterisation, eye examinations, and *echocardiography is inconclusive.[218]
Non-nutritive sucking (NNS)	Often combined with the use of concentrated sucrose solutions or human milk. NNS can occur with pacifier or directly to the mother's empty breast.	Reduced behavioural distress (crying duration) and composite pain scores for brief, single painful stimulus such as heel lance, venipuncture, or immunisation in pre-term and term infants as well as older infants.[219]
Human Milk and Direct Breastfeeding	Mechanism of analgesic effect is thought to be release of cholecystokinin, a neuropeptide associated with analgesia.[48]	Reduced behavioural responses and composite pain scores from a single painful procedure including heel lance, venipuncture, or immunisation in preterm infants, term neonates, and older infants.[220-222] The effectiveness of breastfeeding or ingestion of human milk on pain is similar to the use of concentrated sucrose, and more effective than positioning, placebo, or no intervention.[220] Reduces crying time, heart rate, pain scores compared to oral sucrose, non-nutritive sucking, swaddling, and topical anaesthetics.[223] Expressed human milk alone may not provide the same analgesic effect as breastfeeding.[224]
Skin-to-skin (kangaroo) care (SSC)	Mechanism of analgesic effect is thought to be the release if cholecystokinin, a neuropeptide associated with analgesia, in response to the infant smelling mother's scent.[48] Most studies have used SSC for 10-15 minutes prior to the painful procedure.	Reduced physiological and behavioural distress to a single painful procedure such as heel lance, venipuncture, or immunisation in neonates.[225] Reduced pain responses to heel lance in preterm infants 28 to 32 weeks gestation.[226] *Reduced pain scores and calmer behavioural state, reduction in heart rate and respiratory rate during SSC. Effects on salivary cortisol were mixed.[152]
Massage	Mechanism: sensory saturation and reduction in pain signals.[48] Massage requires training to perform, and small studies have demonstrated beneficial immediate effects on hemodynamic parameters.[154]	Analgesic effects have been observed in response to venipuncture and heel lance[1], as well as decreased heart rate response to removal of adhesive electrodes.[227] *May reduce overall pain post-cardiac surgery.[154] Massage has been studied to reduce sympathetic activity, reduce infant stress response, improve behavioural state regulation, and promote parent–infant bonding and responsiveness.[228–230]
Facilitated tucking	Mechanism: sensory saturation leading to reduced pain signals.[48] Involves cradling the infant's limbs in a flexed position while side-lying or supine.	Reduced crying and pain responses to heel lance in preterm and term newborns.[48] Facilitated tucking has not been well studied outside of preterm infants.
Swaddling/containment	Swaddling, or wrapping the infant in a blanket, and hand containment, or use of one or two hands to define physical boundaries for an infant, may have analgesic effects by simulating an intrauterine environment.[48]	Swaddling has been reported to reduce crying time and pain scores related to a single painful stimulus such as heel lance, both with and without use of a pacifier, in preterm and term infants.[48] Swaddled infants tend to arouse less during sleep and sleep longer, so may promote comfort and reduce sleep interruptions.[231]
Music/distraction	Distraction technique	May help stabilise physiological parameters (heart rate, oxygen saturation) and reduce arousal from sleep in preterm infants, but has been shown to have conflicting results as an analgesic measure.[232] Distraction with a toy has been used in older infants with reduction in pain reactivity, although the quality of evidence was low.[219]
Holding/rocking	*Has been shown to be safe with infants with invasive lines after cardiac surgery.[148]	Has been reported to not reduce initial pain response and did not improve immediate pain regulation in response to a heel lance or venipuncture or immunisation in neonates and older infants, although the quality of evidence is low.[219]
Two caregiver support for caregiving	During infant care, offer parents the opportunity to support and soothe their infant to reduce the infant's stress and promote bonding and attachment.	*May reduce cardiopulmonary instability in the infant that results from stress responses.[6] If a parent is not available, another staff member should provide this support. Child life specialists have unique preparation to provide this support.
Human touch before, during, and after procedure	Before initiating infant care, provide gentle human touch to the infant's head and body, similar to containment.	Allows the infant to transition to the caregiving stimulus with less stress and startle response and may reduce behavioural and physiologic distress.[233]

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whether born premature or full-term, require close monitoring of temperature during hospitalisation due to risks of heat loss in the ICU / intraoperative environment and the associated interventions of critical illness.

Interventions

Infants receiving artificial heat sources in the pre or postoperative period should receive continuous temperature assessment while in use.[49,50] Newly born infants with CHD who are >34 weeks' gestation and not at risk for increased oxygen consumption should be admitted onto a pre-warmed radiant warmer/bed surface in servo control mode.[49,51] If there are concerns about the artificial heat reaching the infant because of sterile drapes or other procedures like echocardiograms, consider a thermal warming pad. Thermal warming pads may provide heat for up to two hours but may need to be replaced sooner depending on manufacturer guidelines. Place a single layer blanket in between the infant and the thermal warming pad. Incubators are helpful when infants with CHD are unable to maintain a body temperature of 36.5 °C axillary, unable to demonstrate adequate weight gain, are <34 weeks' gestation or <1500 g, or are from an outside hospital and previously maintained in an incubator.[49,52] Consider an incubator for infants ≥34 weeks' gestation who are demonstrating signs of increased oxygen consumption.[49,53]

Consider use of the following during patient transport: pre-warmed artificial heat source, power supply attached to artificial heat source, warm blankets, hat, pre-warming infant prior to transport (goal temperature 36.5 °C), and thermal warming pad.[49,54–57] When transitioning out of any artificial heat source into an open crib, infants should be dressed and bundled with a blanket(s) and demonstrate normothermia and weight gain for 2–3 days before discharge.[49,58] While maintaining continuous temperature monitoring, manually assess axillary temperature frequently until the infant's temperature is stable.[49,58] Evidence varies related to device mode (air versus servo control) during weaning.[49]

Assess physical and sensory environment: environmental sensory stimulation

Assessment

Infant behaviour should be continuously observed (Supplementary Table 2) to determine the infant's sensory experience and its influence on the infant and to provide opportunities for environmental modification. Interpretation of infant responses to sensory stimulation allows for direct attention to and response to demands from the physical and sensory environment that influence infant behavioural patterns.[7,34] Thus, all actions and reactions are dependent on the ability to interpret and respond to sensory information to support the infant's self-regulation and thresholds of coping.[21]

Interventions

Sensory interventions should aim to regulate the exposure to environmental stimuli, but not devoid the environment of all stimuli, with a goal of creating a home-like environment. We recommend the provision of low ambient light during the day and darkness at night, low sound levels, and gentle sensory input during care, including: four-handed care (involving two individuals in caregiving where one completes the care and one supports the infant), facilitated tucking, containment, massage, soft voices, and gentle touch. To support the auditory system, we support the recommendations of the American Academy of Pediatrics committee on environmental health:[59]

1. Incorporating a system of regular sound assessment in the ICU and within incubators. Ideally, a sound level exceeding 45 dB is avoided.
2. ICUs should develop and maintain a programme of sound reduction and management. This can include decreasing the sound levels in the entire unit, decreasing sound within the infant's bedside, reducing loud alarms and phone ringers, lowering voices to a soft whisper, reducing the sounds of machinery, running water, and closing lids/doors.[60]
3. Care practices should provide opportunities for the infant to hear parent voices live during parent–infant interaction, including book reading.[61,62] Earphones and other devices attached to the infant's ears for sound transmission should always be avoided.[60,63]

To support the visual system, remember that the ideal focal distance for term infants is 10–12 inches and gradually increases with time.[64] A parent's face is the most important visual input. Color perception does not fully develop until 2–3 months of age. Closely monitor infant reactions to determine if they are regulating appropriately and tolerating stimuli. High color-contrast toys and mobiles should only be used for short periods of time (approximately 10–15 minutes) based on infant cues for tolerance. Bright lights disrupt infant rest and sleep.[2] We recommend providing cycled lighting, which is low ambient light during daylight hours and darkness at night. This improves weight gain and increases sleep time in hospitalised infants.[63] When infants are in incubators, the incubators can be partially covered at night to support the development of the infant's circadian rhythm while allowing visualisation of the infant.

Smell and taste are powerful sensory inputs that develop prenatally and are important in the transition to postnatal feeding. In addition to the importance in recognition of the mother, smell and taste initiate metabolic pathways that promote digestion and metabolic control.[65] Young infants who are hospitalised and especially those on tube feedings should receive the taste and smell of mother's milk and smell of family while held skin-to-skin during feeding, even tube feedings. Providers should also be mindful of the taste and smell of hand cleaning materials, medications, materials placed on infant lips and face, and perfumes on staff.

The vestibular system begins to develop in the womb. Postnatally, the infant is strengthened and stimulated through movement and changes in position. Throughout infancy and toddlerhood, movements like rocking, swinging, rolling, crawling, walking, and running all provide input for a healthy vestibular system.[66] Given the potential for those movements to be limited in hospitalisation, maintaining changes in position and movement are important for continued development of the vestibular system, with interventions such as therapeutic positioning, range of motion, movement of the extremities or body, or therapeutic facilitation of the muscles.[21] Attention should also be paid to the tactile sensitivity of an infant and particularly passive touch (sensitivity to stimulation imposed on the skin).[21] The hospitalised infant is exposed to many tactile stimulations and often show higher sensitivity to tactile stimuli.[67] We recommend consideration of all objects touching the infant's skin and body. Allow for the availability of infant hands, face, and other areas of skin to remain as free from lines, tubing, and tape as possible so they can feel their own body, the skin of their parents, and soft materials/blankets.

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Developmental and motor supports

Assessment

Infants with CHD who undergo surgery in the first six months of life are at risk for delayed motor development as well as musculoskeletal impairments.[68] A developmental evaluation by a physical and/or occupational therapist integrates many aspects of a standardised assessment, including examination of environmental factors, motor function, neuromotor development, sensory processing, range of motion, reflex integrity, social interaction, and family needs.[69] A developmental evaluation is specifically tailored to respect the unique needs of a critically ill infant, minimising stress and monitoring physiologic state throughout.[70]

Interventions

We recommend a physical and/or occupational therapy consult upon admission as well as ongoing evaluation at regular intervals to ensure individualised developmental therapy supports are initiated early in the infant's hospitalisation.[71] These team members specialise in movement and posture, providing a unique opportunity to affect the shape of the musculoskeletal system and motor organisation of infants and concurrently supporting parents and caregivers to optimise infant neurodevelopment.[68]

We further recommend intentional therapeutic positioning of infants bundled with routine nursing care that includes head in midline, extremities flexed towards midline, and use of supports to provide boundaries and containment.[71] Providing boundaries to mimic the resistance in utero such as a swaddle or supports for positioning will allow dynamic activity to occur. This promotes a calm state and allows for improved self-regulation which can optimise cognitive and social-emotional outcomes.[72] Facilitated positioning throughout the hospitalisation promotes gross motor skills. Without proper positioning, abnormalities may occur in the musculoskeletal system such as retracted shoulders, hyperextension of the head and neck, plagiocephaly, and external rotation of the lower extremities.[71] Motor abnormalities are also observed such as poor head control, poor reaching skills, and resistance to postural changes.[6] Position of infant should be changed every 2 to 3 hours or with bundled nursing care times as appropriate. Positioning an infant in one position for an extended period can contribute to skeletal deformity, muscle shortening, and restricted mobility of joints.[73]

Consider early mobility which includes range of motion exercises (active, passive, and active assisted), massage, and out of bed experiences (holding, infant seat, swing, etc.).[74,75] Tummy time, or prone positioning, should be encouraged preoperatively and when prone precautions are cleared.[76,77] Prone positioning has multiple benefits, such as improving ventilation and decreasing work of breathing.[68] Research supports more timely attainment of gross motor skills for infants placed in prone positioning.[76,77] Tummy time progression, as well as plagiocephaly and torticollis prevention strategies can be demonstrated with parents even when infant mobility is restricted due to sternal precautions while hospitalised.[72]

Developmentally supportive feeding

Assessment

Breastfeeding assessment/use of human milk. We recommend parents experience the process of informed decision making for the use of human milk[78] using the Spatz 10 Step Model for Human Milk and Breastfeeding for Vulnerable Infants (Supplementary Table 3).[79] This model has been effectively implemented globally for infants requiring intensive care,[80] and in 2021 was adapted as the national model for human milk and breastfeeding in the United States by the Association of Women's Health Obstetric and Neonatal Nurses.[81] The model demonstrated improved human milk and breastfeeding outcomes exceeding national targets in several high-risk infant surgical groups.[82–84]

Pre-feeding readiness assessment. We recommend all infants with CHD receive a pre-feeding readiness assessment prior to introducing oral feeding during hospitalisation. An infant is ready to be fed orally when demonstrating the following conditions:

- Awake and alert state: Active engagement for efficient and safe oral feeding is highly dependent on the ability of the infant to achieve and maintain awake state.[85] Oral feeding efficiency improves in alert state compared to sleep state prior to oral feeding in stable preterm infants.[86]
- Demonstrating feeding cues with established non-nutritive suck on a pacifier: The infant must achieve and maintain autonomic and state organisation to maintain stability in increasingly complex motor tasks such as non-nutritive sucking. We recommend attention to stress cues during engagement in non-nutritive suck, which may include increased respiratory rate, arching, munching, and pulling off or away from pacifier.[87,88]
- Maintain physiologic stability with attention to level of respiratory support: Infants with tachypnoea may have challenges regulating a coordinated suck/swallow/breathe sequence. Limited evidence exists on feeding safety on non-invasive positive pressure respiratory support, with currently no research exclusive to the full-term cardiac infant.[89] Without sufficient guidelines for feeding infants on respiratory support, careful consideration of the infant's clinical picture is needed for smaller bolus oral feeding when on stable respiratory support.[90]

We recommend the Readiness section of the early feeding skills assessment be administered by a feeding therapist to objectively determine if the infant can demonstrate appropriate motor state and feeding cues prior to offering breast or bottle.[85]

Oral feeding assessment. We recommended utilising a cue-based feeding assessment, with continuous evaluation of infant behavioural state, infant cues to engage and disengage from feeding, oral motor function for latching, sucking and milk extraction, and regulation of swallowing and breathing.[91–93] Further oral feeding assessment includes response to feeding supports, haemodynamic and respiratory stamina and stability with feeding activity, and sustaining endurance for adequate oral intake to maintain growth and development.[86] Infants with CHD are at risk for tachypnoea, tachycardia, and decreased oxygen saturations during oral feedings, resulting in difficulties maintaining appropriate and safe suck/swallow/breath coordination during oral feeds, as well as have a higher prevalence of gastroesophageal reflux in comparison to those without CHD.[94,95] This necessitates continuous screening and evaluation for swallowing difficulty/aspiration risk and gastroesophageal reflux. Oxygen desaturations, increased work of breathing, and coughing/choking during feeds are overt signs of swallowing difficulties, placing infant at high risk for aspiration.[94] Common symptoms of gastroesophageal reflux include discomfort, irritability, excessive crying, back arching, feeding refusal, and/or frequent emesis.[96]

To date, no standardised objective feeding assessments specific to the unique needs of infants with CHD have been validated;

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however, assessments specific to preterm newborns exist and may have applicability with infants who have CHD.[95,97,98] Standardized assessments and algorithms evaluate feeding readiness, oral motor function, swallowing skills, and respiratory regulation to determine the infant's challenges for appropriate feeding and to guide intervention (Table 2).[85,99,100]

"Red Flags" during oral feeding. Red flags are signs to discontinue oral feeding or to consider feeding modifications or additional supports. Continued feeding when red flags are present can result in negative oral feeding experiences and ultimately oral aversion.

- Behavioural state and subsystem changes (Supplementary Table 2)
- Clinical signs of dysphagia: milk dribbling from the mouth, coughing during feeding, wet breath sounds, milk residual in oral cavity, fatigue, gulping, multiple swallows, pulling off the nipple, desaturations, cyanosis[94]
- Signs of feeding intolerance or gastroesophageal reflux: discomfort, irritability, excessive crying, vomiting, back arching, feeding refusal, mouthing, stridor[101]

Interventions

Breastfeeding/use of human milk. Follow the Spatz 10 Step Model for human milk and breastfeeding for vulnerable infants (Supplementary Table 3) to support parents in their use of human milk and/or breastfeeding.[79]

Pre-feeding readiness interventions. Oral care with colostrum has known benefits in premature infants, including decreased inflammatory response in postsurgical infants, stimulation of the infant's immune system, decreased risk of infection, and faster attainment to full oral feeding.[102] We recommend administering fresh colostrum via a saturated sterile cotton swab (0.2 ml total) on the tongue, gums, and inner cheeks and repeating every 3–4 hours if the infant is tolerating well.[102–104] Even while intubated, oral care, and stimulation with colostrum/breast milk is beneficial in newborn infants[105] with a decreased incidence of thrush and ventilator-associated pulmonary infections in infants after cardiothoracic surgery.[106]

Oral stimulation includes non-nutritive sucking and offering a pacifier dipped in expressed human milk or formula. A combination of oral stimulation may improve readiness for initiation of oral feeding, attainment of total oral nutrition, reduce time to full oral feeding, and reduce length of stay following cardiac surgery.[87,107,108]

Cue-based feeding. We recommend use of infant cue-based feeding as the standard oral feeding intervention for infants with CHD. This approach emphasises the quality of the feeding experience over the volume consumed. Cue-based feeding intervention involves observing an infant's subsystem signs of organisation to initiate and advance oral feeding while understanding stress signs or subsystem disorganisation to alter oral feeding techniques and provide additional support for the infant and parents (Supplementary Table 2). Research demonstrates that cue-based feeding reduces length of stay and improves weight gain in preterm infants.[92]

Individualised feeding plans. We recommend use of individualised feeding plans that are attentive to the infant's unique developmental and physiologic needs in line with family-centered care. Individualised feeding plans are associated with improved oral feeding outcomes[109,110] and should be frequently reevaluated by the feeding team with interdisciplinary collaboration based on the infant and family's unique needs. Example feeding plan interventions may include:

- Prioritisation of feeding the infant at the breast if that is the parent's goal.
- Infants should be prepared for direct breastfeeding through skin-to-skin care and non-nutritive experience at the breast.
- Modification of the rate of milk flow from a bottle nipple, which may improve physiologic stability during bottle feeding in term and preterm infants.[111,112]
- Side-lying positioning stabilises oxygen saturation during oral feeding, improve chest wall movement by decreasing the effects of gravity on rib cage expansion. This position may be beneficial for slowing bolus flow by decreasing hydrostatic pressure in the bottle compared to upright positioning.[113]
- Co-regulation/paced feeding provides regular pauses or breaks for breathing during an oral feed to allow for improved minute ventilation and decreased respiratory effort.[91]

Oral aversion prevention and intervention. Prevention of oral feeding aversion and compromised feeding is imperative for successful oral feeding and influenced by care practices during hospitalisation for infants with CHD.[114] To reduce risk of prolonged feeding challenges, both early exposure to feeding opportunities and early identification of infant vulnerabilities during feeding, gastrointestinal issues and swallowing disorders is imperative.[115,116] Interventions that support prevention of oral aversion include:

- Early identification of infant stress during feeding: Stressful feeding experiences can result in establishment of altered neural pathways especially during the initial stages of oral feeding trials which can lead to negative consequences on feeding skill development and desire to feed orally.[93]
- Early identification of gastrointestinal issues: Infants with CHD are at increased risk of feeding and swallowing disorders and gastrointestinal complications.[97,98,117] Diagnostic assessments in collaboration with a paediatric gastroenterologist can be beneficial to assess potential underlying mechanisms which may contribute to feeding challenges.[117]
- Early management of swallowing disorders: Infants with CHD are at high risk for swallowing difficulties and should be clinically evaluated by a healthcare professional specialising in dysphagia using diagnostic studies (Table 2).

Nutrition and growth

Infants with CHD are known to be at risk for poor growth,[118–122] which negatively influences neurodevelopment.[123,124] Infants with CHD may experience growth failure secondary to a variety of factors including suboptimal energy intake, oral aversion, early satiety, increased metabolic demands, and gastrointestinal disturbances impairing motility and/or absorption.

Assessment

Close assessment of growth is imperative to monitor the adequacy of nutrition intake. Routine anthropometric assessments should include daily measures of weight and at least weekly measurement of head circumference and length and consideration of weight-for-length metrics.[125–127] Anthropometrics are vital to assist in weight-adjusting nutrition provisions to maintain adequate growth velocity and to identify early concerns for growth failure. Daily intake of calories, proteins, lipids, and macro- and micro-nutrients should

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be closely monitored and adjusted based on individualised needs.[128–131] Registered dietitians are essential members of the interdisciplinary team who collaborate to individualise recommendations to optimise nutrition support, monitor growth of infants during hospitalisations, and provide support for feeding intolerance.[132,133]

Interventions

We recommend the use of clinical nutrition pathways as a standardised approach to nutrition considering the positive outcomes demonstrated in infants with CHD.[131,132,134,135] Specifically, clinical nutrition pathways for infants with CHD have (1) shortened the time to achieve goal calories,[136,137] (2) increased the percent of patients meeting their calorie and protein goals,[138] (3) decreased the incidence of necrotising enterocolitis,[139] (4) decreased the duration of postoperative parenteral nutrition,[136,137] (4) decreased hospital length of stay,[129,139] and (5) improved weight-for-age Z-score change over hospital length of stay.[99,133,138] Despite variation in content across published pathways,[140] standardised nutrition pathways minimise variability of nutrition care between providers within institutions.

Institutional pathways for both implementing feeding and nutrition are helpful. Key components in a pathway should include the safety of preoperative enteral feeding, use of parenteral and enteral nutrition in the postoperative period, frequent anthropometric measurements, avoidance of ad lib oral feeding without clearly defined volume and caloric goals, and consultation with a registered dietitian. Following cardiac surgery, infants often require parenteral and enteral nutrition until clinical status and postoperative dysphagia improves and the infant is demonstrating pre-feeding readiness.[133,140] While infant cue-based feeding is an integral component to developmental care, infants in the postoperative period that are ad lib feeding should ideally have defined volume and calorie goals to prevent suboptimal nutrition intake. Infants experiencing difficulties meeting nutrition goals should be supplemented with enteral tube feedings to prevent undernutrition. Enteral nutrition may also be indicated in infants with vocal cord dysfunction or gastrointestinal difficulties.[133,141,142]

Parent engagement/caregiving

Assessment

An underlying assumption of this pathway is that parents are the primary caregivers for their infants (Table 1). Unfortunately, infants are often separated from their parents, which contributes to parental stress arising from parental role alteration.[28] Parental role alteration is a perceived stressor that has repeatedly been found in the cardiac ICU setting to uniquely contribute to both anxiety and depressive symptoms in parents.[143–145] We recommend that the interdisciplinary team regularly review parent participation at the bedside to determine how to best support families in the care of their child.

Interventions

We recommend that parents be incorporated into all aspects of care, including but not limited to decision making for the plan of care, medical and developmental rounds, emergent and non-emergent medical procedures, comfort measures, and routine infant care such as feeding, diaper changing, dressing, positioning, and holding.[143–145] We also recommend removing any organisational barriers for parent presence. Parents should be encouraged and supported to provide direct care to their infants during hospitalisation, including any of the non-pharmacologic comfort measures described in this pathway (Table 3). We recommend supporting parent–infant interactions to promote comfort and reduce stress for infants and their parents. One specific measure that can be uniquely provided by parents is skin-to-skin care, or kangaroo care, which occurs when an infant dressed only in a diaper is held on a parent's bare chest. Parents participating in skin-to-skin care report positive social-emotional responses, decreased perceived stress, increased parent–infant attachment, decreased post-partum depression, and increase breast milk production.[146,147] Evidence-based standards and procedures for holding and skin-to-skin care are carefully reported and described.[148,149] Research demonstrates that skin-to-skin care in infants with CHD in the pre- and post-operative periods is safe and beneficial.[150–152] We recommend that centres caring for infants with CHD develop evidence-based holding guidelines and procedures for safe transfer and parental holding opportunities to promote parental bonding and holistic care.[5] Reevaluation of holding or skin-to-skin care readiness is recommended to occur daily on rounds. If the infant is very ill and should remain in the bed, parents and caregiving staff are recommended to provide positive sustained touch.[5,153,154]

Discharge readiness

Assessment

Comprehensive discharge planning for infants with CHD includes individualised content regarding the developmental and psychosocial needs of infants and their families. Discharge readiness assessment includes ongoing evaluation of the medical home during the inpatient hospitalisation and assessment of parent educational and resource needs.[155] This includes daily evaluation of the family (social support, resources, and coping strategies) during the ICU stay and as the infant is de-intensified. Parents may have educational or language barriers, experience emotional struggles, and complex family systems impacting their processing of discharge information and safe transition home. Parents require comprehensive information prior to discharge including, but not limited to, infant medical care (such as infant cardiopulmonary resuscitation, placement and management of supplemental tube for medications and feedings, home equipment orientation, and other medical needs such as oxygen, and special formula instructions), infant safety and caregiving (safe sleep, bathing, monitoring weight, and feeding), and supports for neurodevelopment including referrals to early intervention services, anticipatory guidance on the infant's developmental opportunities at home, and connection with outpatient developmental services.[156]

Interventions

We recommend incorporating the developmental and psychosocial needs of the infant and family into the discharge planning process. An integral part of the discharge readiness plan is ensuring a consistent and smooth transition plan of care across service lines (e.g., cardiac ICU to acute care unit to home), utilising available resources and key interdisciplinary team members. As the infant recovers, providers can gradually remove positioning devices to model safe sleep guidelines. Parents or other family caregivers should be provided a comfortable space to room-in with their infant prior to discharge.[157] Rooming-in would ideally be offered as early and as often as possible to provide parents ongoing contact with their child, opportunities to increase bonding with their child,

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as well as learn, practice, and become confident in the skills required to care for a medically complex infant after discharge.

All follow-up appointments including developmental follow-up and early intervention should be scheduled prior to discharge. Discharge planning should include arranging timely follow-up appointments with primary care, cardiology and other specialist teams, therapists, nutrition, and social work, as needed.[158] Comprehensive neurodevelopmental follow-up is critical to the ongoing evaluation following discharge of infants with CHD and can include cardiac, post-intensive care, or other neurodevelopmental follow-up team.[13] For all infants with a supplemental feeding tube, we recommend close follow-up by a registered dietitian and feeding therapist to closely monitor growth and weight-adjust feeding regimens. Research has demonstrated that despite referral by practitioners for early intervention, only about half of high-risk infants with CHD receive early intervention services post-discharge at the time of outpatient neurodevelopmental evaluation and many never received early intervention.[159] Discharge education and paperwork should clearly outline the developmental care plan, referral to early intervention, and contact information for the neurodevelopmental follow-up team.

III. Continue bundle of care daily until discharge

Repeat formal developmental and psychosocial screening prior to discharge

As described in previous sections, the components of the developmental care bundle should be continued throughout the infant's hospitalisation and individualised based on the changing needs of the infant and family. We further recommend repeating a developmental assessment of the infant as well as psychosocial screening of parents (Table 2) prior to discharge to ensure that the family is connected with the appropriate resources post-hospitalisation.

Discussion and conclusions

Neurodevelopmental concerns are highly prevalent in infants with CHD.[13] After thoroughly reviewing current literature and forming expert and stakeholder consensus, the Cardiac Newborn Neuroprotective Network, a Special Interest Group of the Cardiac Neurodevelopmental Outcome Collaborative, generated an evidence-based developmental care pathway for hospitalised infants with CHD. The pathway includes standardised developmental assessment and parent mental health screening, along with the implementation of a daily developmental care bundle, which incorporates individualised assessments and interventions to tailor care to the needs of infants with CHD and their families. Hospitals caring for infants with CHD are encouraged to adopt this developmental care pathway and track predetermined metrics and outcomes using a quality improvement framework. Many metrics could be followed based on the assessments and instruments outlined in Table 2. We encourage any hospital, centre, or inpatient unit adopting this pathway to closely examine whether documentation fields are available for all developmental care practices and ensure that fields are created where needed in the electronic health record.[11] Future work is recommended to generate both short- and long-term neurodevelopmental and psychosocial outcomes of this pathway that would greatly add to the body of literature on developmental care for infants with CHD. We acknowledge that where research was lacking in CHD, we applied literature from other populations such as prematurely born or critically ill infants. Continued evaluation of developmentally supportive care interventions through implementation and dissemination of high-quality research and quality improvement investigations are crucial to develop evidence to support best practices in this vulnerable population of infants and their families.

Supplementary material. To view supplementary material for this article, please visit https://doi.org/10.1017/S1047951123000525

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