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Fostering Development in Children With Congenital Heart Disease

Birth to Three

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Children with complex congenital heart defects often show delays and deficits in cognitive, language, motor, and social-emotional functioning. As such, the American Academy of Pediatrics and the American Heart Associated recommend ongoing monitoring and support of development. In conjunction with the formal therapeutic supports frequently recommended for young children with CHD, caregivers are instrumental in providing an enriching environment to enhance development in the hospital, at home, and in early childhood settings. In this article, we review the common developmental sequelae associated with CHD, underlying causes, and ways in which parents, family members, and professional caregivers can support development for children with CHD from birth to three years old. **Key words:** *congenital heart defects, congenital heart disease, developmental support, early child development, parent guidance*

OVER TWO million children are living with congenital heart defects (CHD) in the United States and nearly one in four of these individuals have complex CHD requiring intervention in infancy (Centers for Disease Control, 2022). Generally, CHD is defined as a structural abnormality of the heart and (or) great vessels that is present at birth (Liu et al., 2019). Advances in the diagnosis and management of complex CHD have significantly improved the rates of survival. However, the risk of associated developmental deficits and delays remain high across different domains of development, including cognitive, language, motor, feeding, behavioral, and psychosocial development (Bellinger et al., 2009; Gaynor et al., 2015; Marino et al., 2012; Mussatto et al., 2014; Ryan et al., 2019; Snookes et al., 2010; Triedman & Newburger, 2016; Wernovsky, 2006; Wernovsky & Licht, 2016). While many developmental delays and deficits associated with CHD are mild, there is a wide range of outcomes ranging from slight concern to more profound developmental disability across domains.

There are many underlying risk factors accounting for developmental delays in children with CHD, starting in the perinatal

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period (Donofrio & Massaro, 2010; Wernovsky & Licht, 2016). Brain development, metabolism, and cerebral blood flow are affected in utero among infants with critical CHD with smaller fetal brain volumes and delays in brain maturation noted at birth compared to healthy newborns (Donofrio & Massaro, 2010; Licht et al., 2009; Limperopoulos et al., 2010; Miller et al., 2007). After birth, management of complex CHD requires hospitalization and surgical intervention in infancy. In addition to developmental delays associated with extended hospitalization, infants with CHD are at an increased risk of experiencing negative neurologic events in the pre-, peri-, and postoperative periods, such as seizure, cardiac arrest, and stroke (Chen et al., 2009; Chock, Reddy, Bernstein, Madan, 2006; Ryan et al., 2019). As a result, children with complex CHD are at risk for a range of developmental sequelae beginning in infancy and spanning across the lifespan (Butler et al., 2022, 2019; Donofrio & Massaro, 2010; Gaynor et al., 2015; Jerrell, Shuler, Tripathi, Black, Park, 2015; Massaro, El-Dib, Glass, Aly, 2008). Many newborns with CHD are easily overwhelmed by social and sensory stimulation, difficult to console, and challenged in maintaining in state organization. They also show delays in motor skills and oral feeding (Butler et al., 2019; Massaro et al., 2011; Owen et al., 2014; Ryan et al., 2019). The difficulties in the newborn period contribute to the risks of poor feeding, decreased attention, delayed motor milestones, suboptimal autonomic regulation, behavior problems, and specific cognitive challenges in infancy and toddlerhood (Gaynor et al., 2015; Majnemer et al., 2009; Ryan et al., 2019). School age children with CHD are more likely to show deficits in learning, attention, social skills, executive functioning and memory, organization, and motor functioning, often requiring additional supports in school (Gerstle, Beebe, Drotar, Cassedy, Marino, 2016; Miatton, De Wolf, François, Thiery, Vingerhoets, 2007; Ryan et al., 2019; Shillingford et al., 2008). These concerns can persist throughout adolescence and adulthood with support required for executive functioning, attention, memory, learning, social/emotional skills, and transitioning to independence in adulthood (Cassidy, White, DeMaso, Newburger, Bellinger, 2016; Karsdorp, Everaerd, Kindt, Mulder, 2007; Luyckx, Goossens, Van Damme, Moons, 2011; Lyon, Kuehl, McCarter, 2006; Ryan et al., 2019; Schaefer et al., 2013).

Given the known long-term risk of neurodevelopmental challenges for children with CHD, the American Heart Association (AHA) recommends regular surveillance, screening, and evaluation of neurodevelopment in the pediatric CHD population beginning early in infancy (Marino et al., 2012). Young children with complex CHD also require developmental support through formal therapeutic services such as physical therapy (PT), occupational therapy (OT), feeding therapy, developmental education, speech and language therapy services, and support for parent coping in the newborn period and early infancy (Butler, Huyler, Kaza, Rachwal, 2017; Butler et al., 2019; Lisanti et al., 2019). These services are often provided while inpatient in the hospital, but they are also often required in the home environment after hospital discharge. Programs such as Early Intervention (EI), Head Start, and Early Head Start have been shown to improve children's long-term outcomes in multiple domains (Anderson et al., 2003; Blauw-Hospers, de Graaf-peters, Dirks, Bos, Hadders-Algra, 2007; Landa, 2018; McCormick et al., 2006; Puthussery, Chutiyami, Tseng, Kilby, Kapadia, 2018). In the United States, EI services are publicly funded programs, which provide home based services for free or at reduced cost for any child who is eligible and are available in every state and territory (see www.cdc.gov/ncbdd for more information).

This article was created with a multidisciplinary team of professionals and a parent of a young child with CHD. We review the common developmental concerns and challenges for children with CHD from birth to three years of age along with therapeutic

options and recommendations for families and providers. We focus on concerns and supports across developmental domains, including motor, speech and language, cognitive, feeding, social, emotional, sleep, and behavioral development. In addition, we address concerns for increased health-related stress, anxiety, and depression for children with CHD and their families. Across each area, we highlight common causes and presentations of delay as well as specific recommendations to support development.

Caregivers that are helpful in support of development include family members, inpatient and outpatient therapy teams such as speech and language therapy, occupational therapy, physical therapy, a developmental specialist and music therapy, along with other opportunities such as structured playgroups and early intervention services. Recommendations provided in this manuscript complement rather than replace formal therapeutic supports. The developmental recommendations are beneficial for all young children with CHD regardless of whether or not a development concern is identified professionally. Table 1 provides an overview of common challenges and recommendations to support development for each domain.

MOTOR SYSTEM

Motor delays and disabilities are relatively common among infants and toddlers with CHD (Brandlistuen et al., 2010; Freier et al., 2004; Gaynor et al., 2015; Majnemer et al., 2006; Miatton, De Wolf, François, Thiery, Vingerhoets, 2006; Newburger et al., 2012; Ryan et al., 2019; Sarajuuri et al., 2010; Snookes et al., 2010). Some of these concerns occur because infants with CHD often have limited opportunities to develop their fine and gross motor skills that are routinely available to healthier infants. When infants have CHD, they frequently experience weakness and fatigue associated with their illness and may not have the energy nor motor tone required for motor exploration. Infants with CHD also are frequently restricted in their movements before and after cardiac surgery given their need for medical interventions and hemodynamic concerns making it difficult to receive early and regular movement. Sternal precautions following surgery to protect the healing chest incision may vary in timeframe from 0 to 6 weeks across institutions (Clifton, Cruz, Patel, Cahalin, Moore, 2020; Uzark et al., 2022). These precautions typically include restrictions in lifting, pulling to sit, and tummy time. Limited strength and opportunities for gross motor movement can lead to muscle weakness, decreased head control, difficulty achieving and crossing midline, and poor balance and coordination.

Children with CHD may also demonstrate altered muscle tone, typically lower tone and strength, which can lead to delayed attainment of gross motor skills such as rolling, sitting, crawling, supporting weight, walking, and running. They often show asymmetrical gait, difficulties with high-level balance and coordination, and reduced core strength. Furthermore, static positioning postoperatively can lead to cervical rotation preferences, torticollis (difficulty turning head to one side), and plagiocephaly (head flattening) further impacting development and gross motor skills (Brandlistuen et al., 2010; Donofrio & Massaro, 2010; Freier et al., 2004; Gaynor et al., 2015; Newburger et al., 2012; Ryan et al., 2019; Sarajuuri et al., 2010).

To support motor skill development, young children with CHD often require physical therapy and occupational therapy, which generally occur through inpatient care, EI, preschool, and outpatient clinics. In addition, there are many activities that facilitate the practice of motor skills that families and providers can incorporate at home and in early childhood settings to enhance motor development (Blauw-Hospers et al., 2007; Hughes, Redsell, Glazebrook, 2016; Morgan et al., 2016; Riethmuller, Jones, Okely, 2009; Stieber et al., 2012; Vanderveen, Bassler, Robertson, Kirpalani, 2009).

Table 1. Developmental Concerns and Recommendations for Young Children With CHD

Area	Main Challenges	Recommendations
Gross motor	• Head control • Balance, coordination, and strength • High and low motor tone • Asymmetry • Delayed mastery of gross motor milestones	• Tummy time while being held in prone position and on a flat surface • Lying on both sides and looking in both directions • Hanging toys to reach for, grasp, and kick • Supported sitting • Ball play (rolling, throwing, kicking) • Navigating play structures with support
Fine motor	• Tight, fisted grip with thumb tightly in grasp • Asymmetrical use of hands • Decreased strength and dexterity • Sensory sensitivity	• Offer objects to feel with hand and fingers • Gently move thumb from grasp • Support bringing hands to midline and mouth • Present objects at midline • Build, stack, and string blocks • Use play dough, clay, and sand
Language	• Hearing loss • Reduced oral-motor coordination • Reduced exposure to language • Delayed mastery of language milestones	• Imitate cooing and facial expressions • Use speech that is clear and simple for your child to copy • Read and point out pictures in a book • Sing simple songs with hand movements and nursery rhymes
Cognitive	• Reduced energy and exploration • Decreased reaction to environment • Reduced fine motor skills impact the acquisition and demonstration of cognitive skills • Delayed mastery of cognitive and problem-solving skills	• Provide toys to feel and explore • Use mirrors • Hide toys and help find them • Play imitation games • Reduce screen time
Feeding & nutrition	• Slow growth and weight gain • Need for additional calories • Tire quickly • Reflux, gagging, choking, aspiration • Oral aversions	• High-calorie diet (milk, formula, or breast milk) • Supplemental tube feedings • Consistent schedule • Feeding/mealtimes should be positive • Oral muscle activities: straws, bubbles, pacifiers • Games with food: touching/smearing, smell
Social, emotional, and behavioral	• Attachment • Decreased social engagement, including eye contact, facial expressions, imitation • Difficulty with soothing and regulation • Easily overwhelmed	• Provide soothing and reduced stimulation if needed • Talk to your infant all the time • Read, or sing to child • Participation in play groups • Use visual schedules

(*continues*)

Table 1. Developmental Concerns and Recommendations for Young Children With CHD (*Continued*)

Area	Main Challenges	Recommendations
	• Hyperactivity and inattention\ • Maladaptive social behaviors, such as hitting, biting, and throwing	• Use positive discipline strategies such as praise to promote wanted behavior and ignoring and time-outs for unwanted behaviors
Child coping	• Separation from caregivers • Anxiety related to hospital and medical professionals	• Cluster care and bring child to treatment room for procedures • Encourage medical play • Develop social stories for medical appointments and procedures • Read children's books related to medical procedures
Parent coping	• Concerns with child health and development • Trauma and grief related to child's illness • Anxiety about future procedures • Stressors related to finances, transportation, balancing care for other children, work, appointments • Symptoms of concern: avoidance, restlessness, fatigue, irritability, worry, angry outbursts, guilt	• Basic self-care: eating healthy, regular meals, good sleep, taking time for oneself • Connecting with other parents of children with CHD • Connect with regional and national support group • Talking to a trained mental health professional

Tummy time is helpful in promoting core strengthening and head control, and recommended to begin as early as possible, even in the newborn period. For infants following cardiac surgery, this should be discussed with the medical team (Clifton et al., 2020; Uzark et al., 2022). Caregivers can start to introduce tummy time early postoperatively by holding the infant in the prone position on the caregiver's chest while in a seated position, progressing to a reclined seated position. When medically ready, caregivers can support infants to practice tummy time on a flat surface by slowly rolling infants from back to belly. When on their belly, support the infant to lay with their arms tucked under their chest and their legs tucked under their body.

In addition, it is important to offer a flat unobstructed surface to practice moving. A soft surface on the ground with toys which hang over head, such as a play mat, can provide babies with an opportunity reach, grasp, and kick. This is helpful in practicing gross motor skills. Caregivers can assist infants to bring their hands together at midline, reach for toys, roll to their sides and stomach, and support the infant in sitting. Side-lying play is a way to first achieve hands to midline and facilitate reaching and kicking without the impacts of gravity that are present in the supine position. Holding the infant in a supported sitting position allows for visual exploration of their environment while engaging their proximal and core muscles to work on head and postural control.

Toddlers and preschoolers benefit from toys that encourage motor skills such as pushing, pulling, kicking, jumping off and over, and riding. Caregivers can arrange for motor play at playgrounds or in the home by supporting children to navigate stairs, climb over play structures or furniture, and to roll, throw, catch, and kick balls. Additionally,

social games with movement and imitation offer engaging ways to develop motor skills, such as imitating the way animals walk, having dance parties, playing "Simon Says," or setting up obstacle courses with opportunities to crawl, jump, run, climb, and balance.

Fine motor development is also often delayed among infants and toddlers with complex CHD (Donofrio & Massaro, 2010; Gaynor et al., 2015; Limperopoulos et al., 2002; Majnemer et al., 2009; Ryan et al., 2019; Uzark, Spicer, Beebe, 2009). Infants with CHD may have trouble fully opening their hands and extending their thumbs. Instead, they may keep their hands in a fisted posture much longer than other infants their age and are less likely to spontaneously explore objects. Once they begin using their hands, young children with CHD often continue to present with fine motor delays, including slow transition to a pincer grasp, difficulty with tasks such as reaching, holding, and transferring objects, and asymmetry with early hand preference and limited bilateral integration (Majnemer et al., 2009; Sarajuuri et al., 2010).

There are numerous strategies that are effective in promoting early fine motor development in home, hospital, and early childhood settings (Duff & Charles, 2004; Lobo, Galloway, Heathcock, 2015; Morgan et al., 2016; van Hof, van der Kamp, Savelsbergh, 2002). Caregivers can provide plentiful opportunities, even in young infants, to hold and manipulate objects that vary in shape, size, weight, and texture to promote individual finger movements. Presenting objects in midline and providing toys to grasp with both hands at once provides the child with opportunities to cross midline, use hands symmetrically, and transfer objects from one hand to another. As an infant's fine motor skills develop, caregivers can start to introduce activities that require more refined fine motor movements such as building with blocks, using Play-Doh or putty, painting, stringing beads, and drawing or writing. Across each of these activities, caregivers can scaffold support as needed to reduce frustration, improve confidence, increase independent exploration, and increase enjoyment in participating in fine motor tasks.

SPEECH AND LANGUAGE DEVELOPMENT

Young children with CHD are at increased risk of experiencing speech and language delay and disability (Marino et al., 2012; Miatton et al., 2006; Mussatto et al., 2014; Ryan et al., 2019; Uzark et al., 2009). Potential concerns include reduced use of facial expressions, eye contact and gestures, delays in meeting language milestones, poor speech-motor coordination, and impaired articulation. Several factors can contribute to early language delays for children with CHD. For example, infants in hospital settings typically experience reduced opportunities for language exposure and practice (Caskey, Stephens, Tucker, Vohr, 2011). Additionally, some infants with CHD experience medical complications that can affect their ability to understand and produce verbal language, including cognitive-related language impairment secondary to neurologic injury, hearing loss, visual impairment, and vocal cord paralysis (Grasty et al., 2018; Ryan et al., 2019; Sachdeva et al., 2007). Current standards recommend that all children with CHD receive an audiology and vision evaluation to determine if they have appropriate hearing sensitivity and vision, respectively (Marino et al., 2012). Furthermore, interventions may need adaptation to accommodate any sensory limitations that may affect the ways in which a child can interact with the environment.

Caregivers are in an ideal position to encourage positive language development starting in early infancy and even during hospitalization. In fact, while infants benefit from increased exposure to adult language

in the hospital setting, they benefit most from hearing their family speaking regularly from early in the newborn period (Caskey et al., 2011). For family members who cannot be at the bedside, recordings of their voice talking, reading, or singing can be played for the child. Caregivers are encouraged to talk to their child as frequently as possible, narrating what they are seeing and doing, describing the child's own actions, carrying on back and forth "conversations" with infants, alternating between listening to and imitating sounds and facial expressions and responding to infant sounds as if they are meaningful (Topping, Dekhinet, Zeedyk, 2013). Reading to children regularly, beginning in early infancy, is recommended. Reading books and singing songs provides a rich and enjoyable language experience for young children. With infants, simple colorful books are recommended, and books with repeated lines and rhymes are excellent for toddlers and preschoolers.

Imitation is a foundational building block of learning and language development (Hanika & Boyer, 2019). Caregivers can provide opportunities to model and practice imitation skills through social interaction and play. For example, holding their infant 6–10 inches from their face, caregivers can model imitation by mimicking the noises, cooing, babbling, laughter, and facial expressions of their child. They also can make facial expressions (e.g., smiling, sticking out their tongue) and sounds (e.g., cooing with vowels, babbling with simple consonant–vowel sequences) for their child to imitate.

As infants grow to toddlers, caregivers can further encourage language development by using language that is clear, simple, and consistent, and acknowledging and expanding on all of a child's attempts to communicate. Caregivers often become skilled at meeting their child's needs even when the child is not communicating in clear, complex ways. As a child's language develops, it is important for caregivers to purposefully create opportunities for communication (e.g., providing choices for snack time, play time) time to respond to the adult's communication. Caregivers can introduce more complex language by repeating and then expanding on what their children say. For example, if a child says "truck" the caregiver could respond and say "big truck!" or "fast truck!" Asking questions can be a difficult way to encourage young children to talk, as questions will not allow for continuation of the conversation or interaction. For example, questions such as "What does the cow say?" or "What is that?" may show a child's knowledge, but do not support the next conversational turn from the adult. If a child is very quiet or delayed, using "forced choice" questions (e.g., "A or B?") may be more helpful than yes/no questions, as they require the child to say (i.e., practice) a more specific vocabulary word (e.g., "Should we read a book or color?"). In general, however, it is best to keep test-like questioning to a minimum, and instead, provide "out loud" narration of the day in the form of labeling objects and actions, commenting, describing, and wondering to get more response and interactive communication (e.g., "Wow, look at that bird! Tweet tweet!" "Oh no, my cereal spilled!"). Songs and rhymes are also excellent for promoting language and early sound awareness that eventually develop into the phonological processing that underlies more complex language skills such as independent reading and writing. Using "fill in" opportunities in verbal games, book sharing, and songs is also a wonderful way to support a young child's language, as the adult takes the burden of the message, leaving out just a word or two at the end for the child to complete (e.g., "Ready, set…," "Wheels on the bus go round and …," "Brown Bear Brown Bear, what do you see? I see a red bird looking at…") (Dunst, Meter, Hamby, 2011; Justice & Pullen, 2003). In addition, many children benefit from seeing and using sign language and pictures to support their understanding of language and ability to communicate, and such supports can reduce communicative frustration.

COGNITIVE DEVELOPMENT

As with other domains of development, early cognition can be compromised in children with CHD (Bellinger, Bernstein, Kirkwood, Rappaport, Newburger, 2003; Butler et al., 2019; Dittrich et al., 2003; Gaynor et al., 2015; Marino et al., 2012; McCusker et al., 2007; Miatton et al., 2006; Ryan et al., 2019; Snookes et al., 2010). In addition to neurological injury in the perinatal period and innate infant characteristics (e.g., genetic conditions, extra cardiac anomalies), several factors can impact early cognitive development for children with CHD. During the stage of cognitive development classically characterized by sensorimotor exploration and learning, infants with CHD often have reduced energy and less ability to explore the world using their senses. They may experience increased exposure to painful procedures and prolonged periods of intubation and sedation. Infants with CHD often demonstrate decreased reaction to people, objects, and activity in their environment and thus delays in achievement of early cognitive milestones such visual tracking and object permanence are noted. In addition, fine motor delays limit sensorimotor and thus independent exploration of the environment in infancy. Cognitive challenges often persist as children become toddlers and then preschoolers with particular difficulties with visual spatial skills (Bellinger et al., 2003; Marino et al., 2012).

Caregivers are instrumental in providing an enriching environment to support the development of cognitive skills for infants and young children with CHD across settings (Britto et al., 2017; Butler et al., 2017; McCusker et al., 2010; Poehlmann & Fiese, 2001; Smith, Landry, Swank, 2006). For example, caregivers can provide frequent developmental stimulation and play opportunities for infants such as opportunities to look at moving objects, faces, mirrors, and pictures which allows for children to explore and learn about their world. Additionally, caregivers can engage infants by touching and talking to them, reading books and showing pictures as well as providing opportunities to swat, reach, and grasp objects. It is also important to provide toys of different textures and sounds to feel and explore. At the same time, it is critical that while presenting objects, caregivers read infant behavior to identify when infants are prepared to learn and explore and when they might be overstimulated and need a calming break or less stimulation. In infants, behaviors such as looking away from the caregiver, color changes, and hiccupping, coughing, or sneezing may be a sign of stress and indicate that the infant needs a break before re-engaging.

Cause and effect toys help children to develop curiosity and an understanding of their world as well as their place as an agent within it. For example, rattles, bells, or other objects that can be manipulated to make noise encourage the understanding of relationships among people, objects, and actions. Games such as peek-a-boo and hiding toys under blankets reinforce object and people permanence and supports early precursors of problem solving.

Toddlers and preschoolers benefit from opportunities for more complex types of play that promote social engagement, pretend play skills, problem solving, and visual spatial skills. Activities to promote cognitive development include playing with pegboards, shape sorters, and puzzles, replicating blocks in different designs, finding objects hidden in sand or rice, and matching games. Caregivers can model and participate in pretend play activities using props with dolls, action figures, and stuffed animals to act out scenes (e.g., feeding, playing at the park, taking a bath). Screen time should be limited and avoided for children under two years of age (Brown, Council on Communications and Media, 2011).

FEEDING AND NUTRITION

Adequate nutrition is critical for development as it is required for appropriate growth

and development of muscles, bones, and the brain. However, many risk factors place young children with CHD at risk of experiencing impaired acquisition of nutrition, slow growth, and difficulty with oral feeding skills (Daymont, Neal, Prosnitz, Cohen, 2013; Jadcherla, Vijayapal, Leuthner, 2009; Kurtz, Chowdhury, Woodard, Strelow, Zyblewski, 2019; Maurer et al., 2011; Medoff-Cooper & Ravishankar, 2013; Steltzer, Rudd, Pick, 2005). Infants with CHD may tire quickly and not have enough energy to engage in typical oral feeding. They frequently have low oral muscle tone, struggle to coordinate sucking, swallowing, and breathing, and experience temporary or permanent vocal cord paralysis which can affect the safety of swallowing (Einarson & Arthur, 2003; Kohr et al., 2003). Aspiration and difficulty swallowing can lead to respiratory complications, requiring monitoring respiratory status. Children with CHD often require fluid restrictions, tube feedings, or specialized formulas or thickened feeds, all which can limit their opportunity to practice typical oral feeding. Some young children experience aspiration, gagging, choking, and vomiting, which affects exploration of new textures or tastes. Additionally, poor postural control and disruptions to feeding schedules influence developmentally appropriate feeding practices, and impact sleep.

Regardless of what a child eats, and even if a child is exclusively tube-fed or on an altered diet, caregivers can help promote healthy habits and emotions around food and eating. Even when in the hospital, parents play a central role in their child's care, and infants benefit from feeding with their parents, family members, and professional caregivers in a calm and comforting environment. Adults can support an infant's postural control during feeding, ideally by physically holding the infant. If possible, infants benefit from holding or closeness with family during feedings. Special positioning, such as sidelying or supportive seating, may be recommended by the medical team to optimize feeding. Infants are more likely to engage when caregivers are attentive to their infant's cues (of hunger, stress, discomfort and comfort) and feeding is based on these child-directed cues. Caregivers should pause or cease feeding when an infant is distressed, disengaged, or overwhelmed. When there are restrictions to oral feeding, infants and young children can often continue to practice oral stimulation and feeding skills by sucking their own hand, a caregiver's finger, or a pacifier, often with tastes of expressed breastmilk or formula for positive oral experiences.

Many young children with CHD continue to demonstrate disrupted feeding patterns throughout childhood (Maurer et al., 2011). Feeding challenges during the toddler and preschool years can include reduced oral intake, slow growth, oral aversion, picky eating, and strong preferences for certain flavors or textures. Healthy habits can be encouraged among young children by working to ensure that mealtimes are social, fun and free from pressure. Encourage inclusion of children in mealtimes, even if they have a reduced ability to eat by mouth. Participation in family meals models eating, social skills and also promotes language development. Provide opportunities to feel successful during meals including praise for efforts and progress. Providing food on a tray supports independence in feeding and fine motor skills of manipulating small objects. Introducing foods slowly with at least one preferred food is helpful. As children are ready for new foods, adults can "link" foods by introducing new foods that are similar to ones already in a child's repertoire. Food play also can help to address food aversions, as children explore foods through touch, taste, and smell. Caregivers can encourage healthy feeding and nutrition by helping children to develop the physical and motor skills necessary for eating by mouth. Oral motor skills for spoon feeding or chewing may develop later in children with CHD due to inexperience or oral aversion. Activities such as using straws, chewing practice, and blowing bubbles can provide positive oral

motor experiences and practice with different oral movements. Caregivers can help to promote independent eating by encouraging young children to hold the spoon using hand-over-hand support as needed. Even if tube-fed, provide children with opportunities to practice using utensils, such as using utensils to cut Play-Doh, dig in sand, and transfer objects from one container to another.

SLEEP

Sleep is critical for brain development, overall growth and physical development (Davis, Parker, Montgomery, 2004). Establishing appropriate patterns of sleep and awakening is an important accomplishment of infancy and toddlerhood. The National Sleep Foundation (Hirshkowitz et al., 2015) and the American Academy of Sleep Medicine (Paruthi et al., 2016) have released consensus statements on recommended total hours of sleep for young children, though variations in sleep patterns exist (Sadeh, 2004). Early sleep challenges are associated with later social–emotional, behavioral, and executive functioning difficulties (Bernier, Carlson, Bordeleau, Carrier, 2010; Mindell, Leichman, DuMond, Sadeh, 2017).

Sleep problems are prominent in infants and toddlers with CHD. These include receiving fewer hours of sleep at night, sleeping too much during the day, difficulties falling asleep and frequent night-time awakenings (Sadhwani et al., 2023). Young children with CHD are also more likely to sleep in their parent's bedroom compared to a normative sample. The etiology of these sleep concerns is often multifactorial. In addition to typical causes of sleep concerns in early childhood, young children with CHD have additional factors impacting sleep that are physiological in nature, including reduced cardiac functioning, oxygen desaturation leading to increased sleep-disordered breathing, and reduced endurance. While there are cultural reasons families may choose to co-sleep, families of young children with CHD may also be influenced by factors related to increased parental vigilance and concern about the child's medical condition.

Establishing good sleep hygiene is key to managing sleep challenges. It is critical that caregivers develop a consistent regular bedtime routine, including setting aside time to prepare for sleeping and activities to transition from awake and alert to calming. Consider maintaining sleep routines and schedules for consistency at night and during the day. Caregivers should ensure that the physical environment is supportive of sleep including a quiet, dark room with the temperature regulated. There exists a variety of behavioral and responsive practices to support families in sleep hygiene for their child. From this range of practices families can choose to implement those that work best for them and their child. Sleep interventions can be provided by a specialist and several sleep programs provide step by step guidance to help caregivers navigate sleep concerns (Galland & Mitchell, 2010). It is recommended that families speak to their EI providers, neurodevelopmental specialists or pediatricians for guidance around the best strategy for themselves and their child.

Along with sleep hygiene is the importance of "safe sleep." Sudden unexpected infant death (SUID) remains the third leading cause of infant mortality in the United States (Centers for Disease Control and Prevention, 2022). SUID is a term that includes sudden infant death (SIDs), infant accidental suffocation and strangulation in bed, and all other unknown causes of death for infants younger than 1 year. Infants with medical complications such as preterm birth, cardiorespiratory disorders, low birthweight, and neurological concerns are at higher risk for SIDS (Moon & Carlin, 2022; Moon, Darnell, Goodstein, 2016). The American Academy of Pediatrics (AAP) created guidelines for safe sleep in order to reduce the incidence of SIDS (Moon et al., 2016). The recommendations for safe sleep include: supine positioning on a flat firm sleep surface, removal of all

soft objects such as stuffed animals and loose bedding away from the infant's sleep area, and the use of a pacifier without a blanket or soft toy attached. Other recommendations such as encouraging breastfeeding and limiting exposure to smoke, alcohol and illicit drugs were also included (Moon et al., 2016). Many of these safe sleep recommendations are different from the sleep environment an infant experiences in the hospital when they are critically ill. Hospital providers should teach, model and encourage safe sleep practices prior to discharge. Once home, families should discuss with their medical providers their child's risk of SUIDS and how to closely follow the AAP guidelines to prevent SUIDS.

SOCIAL, EMOTIONAL, AND BEHAVIORAL DEVELOPMENT

Young children with CHD often experience prolonged hospitalizations with exposure to frequent stressors placing them at an increased risk of disrupted social, emotional, and behavioral development (Brandlistuen et al., 2010, 2011; Butler et al., 2019; Majnemer et al., 2009; Ryan et al., 2019). Hospitalized infants are exposed to patterns of both under- and overstimulation with reduced opportunities for physical closeness and positive interactions with caregivers (Butler et al., 2017; Lisanti et al., 2019; Sood et al., 2016). In addition, as children grow, caregivers often struggle to provide social interaction while also keeping their child safe from new illness and at times report they must restrict their interactions outside of the family.

It is not surprising that young infants often show difficulties with maintaining state regulation that interferes with their ability to self-regulate and socially engage with their caregivers. Ongoing behavioral concerns include reduced frustration tolerance, difficulty with self-regulation, hyperactivity, and inattention which often persist throughout childhood (Majnemer et al., 2009; Miatton et al., 2007; O'Reilly et al., 2013; Ryan et al., 2019; Shillingford et al., 2008). Additionally, communication challenges, including both reduced comprehension of what is being said or asked, and reduced ability to expressively communicate, can increase a child's frustration and exacerbate behavioral problems.

Beginning in early infancy, caregivers can help to support state regulation and encourage healthy social, emotional, and behavioral development in young children with CHD (Butler et al., 2017; Lisanti et al., 2019; McCusker et al., 2010). Infants display cues when they are feeling stressed and caregivers can learn to identify these cues and support the infant. Common signs of stress in infants include color changes, variable breathing and heart rate, wide eyes and adverted gaze, splaying fingers, negative facial expressions (e.g., wrinkling forehead), crying, hiccupping, and sneezing. Caregivers can respond to such cues with soothing and reduced stimulation (Als, 1999; Lisanti et al., 2019). When calm and alert, offer infants opportunities for increased stimulation and social interaction, such as looking and listening while caregivers speak, reading to them and singing. Infants require attention, patience, and lots of face-to-face time, which can help develop the capacity for self-control and resilience (Bernier, Carlson, Whipple, 2010; Sanders & Mazzucchelli, 2013). Remembering that newborns best focus on objects 6–10 inches away, hold young infants near your face while engaging with them.

Caregivers can continue to promote curiosity and self-regulation by providing a consistent schedule and offering empathetic, responsive, and sensitive care (Bernier et al., 2010; Sanders & Mazzucchelli, 2013). Encourage opportunities to engage in activities that inspire social interaction with other children and adults, including imitation games with adults and peers. Inviting a child to accompany family during errands and participate in structured playdates, developmental play groups, and music classes increases social interaction with modeled behavior. Caregivers can further promote the development of healthy social,

emotional, and behavioral skills through modeling the behaviors they want to see in their children. Play is an excellent medium to help with modeling and facilitating social interaction and self-regulation. As children get older, adults should emphasize social, emotional, and behavioral competencies. Once children develop language, they can begin to identify and name their emotions. Positive behavioral strategies can help to encourage positive behaviors and reduce unwanted behaviors (Dishion et al., 2008). For example, family and professional caregivers who use rewards, visual supports, specific labeled praise, differential attention, and logical consequences help children learn the implications of their actions.

HEALTH-RELATED STRESS, ANXIETY, AND DEPRESSION

Although medical care is lifesaving for children with CHD, the required surgeries, hospitalizations, and other treatments can be distressing or even traumatizing for patients and their families (Boat et al., 2020). Children with chronic health conditions are at substantially elevated risk of mental health problems, including anxiety, mood, and behavioral disorders (Adams et al., 2019). In addition, caring for a chronically ill child imposes long-term stressors for the family including anxiety, depression, and traumatic stress (Boat & Amin, 2017; van Oers et al., 2014). Mental health problems in this growing population pose a high cost to individuals, families, communities, and society.

Professionals should proactively address both the physical *and* emotional health challenges for both patients and families that are inherent within childhood chronic illness (Boat & Amin, 2017; Pickles et al., 2020; Sood, Kenowitz, Goldberg, Butler, 2023). Although some level of stress and discomfort during medical procedures is unavoidable, family and professional caregivers can reduce fear and create positive associations with medical environments (Butler et al., 2017; Lisanti et al., 2019). Young children benefit from opportunities to engage in medical play with families and professional caregivers (Li et al., 2016). Furthermore, social stories can help children prepare for routine medical checkups and procedures and manage the child's expectations. Caregivers provide necessary support for a child at any age with their presence during hospitalizations and procedures. Providing access to comfort items, such as pacifiers, blankets, stuffed animals, and other familiar items from home can be reassuring in the hospital. Child Life is an invaluable resource before, during, and after procedures to comfort, distract, entertain, and support coping for patients. Whenever possible, provide choices for a child so that they can maintain a sense of control (Lerwick, 2016). For example, children could help pack their bag for overnight stays, choose which arm to use for their blood pressure cuff, and decide what color bandage they want. Books also can help children to predict and understand their medical experiences. Some good choices include *Franklin Goes to the Hospital* by Paulette Bourgeois, *Curious George Goes to the Hospital* by Margret and H.A. Rey, *Matty's Heart* by Jean Clabough, *Zip-Line,* by David Humphreys and *Daniel Visits the Hospital* by Alexandara Cassel Schwartz.

Parental mental health is a major component of child and family well-being. Parents and families of children with CHD are at high risk of stress, anxiety, depression, and post-traumatic stress disorder (PTSD) (Biber et al., 2019; Bishop et al., 2019; Helfricht et al., 2008; Uzark & Jones, 2003). Family members may display symptoms at any point during their child's medical journey from the prenatal period onward. Symptoms of concerns with well-being can include avoidance, restlessness, intrusive thoughts or nightmares, excessive fatigue, problems concentrating, irritability, incessant worrying, angry outbursts, reduced interest, a sense of detachment, and feelings of hopelessness and guilt. Physical manifestations of stress can include poor sleep,

changes in appetite and weight, tense muscles, and pain.

Medical and therapeutic professionals are encouraged to proactively discuss family emotional health and wellness early on (Demianczyk et al., 2022; McWhorter et al., 2022; Sood et al., 2023). For many families, understanding that their concerns and feelings are normal and that it is safe to discuss feelings with trusted health care professionals is sufficient to promote emotional health and wellness, while other families could benefit from professional mental health care and the support of a trained mental health professional to manage symptoms of anxiety, depression, or PTSD. In addition, parents and family members often find connecting with other families of children with CHD and engagement with regional and national support groups (such as Mended Little Hearts, Sisters by Heart, and Conquering CHD) helpful in processing the reality of having a child with CHD.

DISCUSSION

Children with complex CHD are at risk for long-term developmental delays and concerns across all areas of development (Bellinger et al., 2009; Cassidy et al., 2016; Gaynor et al., 2015; Marino et al., 2012; Ryan et al., 2019; Snookes et al., 2010; Wernovsky, 2006). Ongoing developmental monitoring provided by licensed professionals and formal therapeutic interventions (Marino et al., 2012) are recommended for all young children with complex CHD. In addition, EI early in infancy is recommended to prevent delays and is suggested to begin even before concerns are noted. To fully optimize development, parents, family members and caregivers are recognized and supported as crucial facilitators of development from birth onward.

It is important for family members, professional caregivers and therapists to be aware of the common developmental concerns for young children with CHD in order to support the development of foundational developmental skills. In this article, we provided an overview of the literature describing developmental concerns often associated with complex CHD such as delays in motor, language, cognitive, feeding, sleep and difficulty with state regulation impacting daily living skills, behavior, attention, feeding, and coping concerns for family and child. We highlighted activities and interventions for parents, families and professional caregivers to help support development across domains in the hospital, home, and early childhood settings. By working together, families and professional caregivers can optimize development for young children with CHD by providing an enriching environment and ongoing developmental supports across all settings.

While there is a great deal of information regarding long-term outcomes for children with CHD (Marino et al., 2012), limited research exists on the impact of developmental interventions to support enhancement of long-term outcomes. Current literature advocates for early developmental intervention for children with CHD and their families (Cassidy et al., 2021; Lisanti et al., 2023; Ware et al., 2020); however, the specific developmental therapies, timing of implementation, and frequency necessary to impact long-term outcomes are unclear. Future research should investigate the potential relationship of caregiver engagement and developmental stimulation implemented early in infancy on the quality of life for children with CHD. This would help provide additional evidence to strongly support the early provision of developmental intervention by families and caregivers.

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