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Pediatric Heart Conditions: What Do Occupational Therapists Need to Know?

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Comments

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Pediatric heart care is in a new and remarkable era. Mortality rates have sharply decreased because of life-saving medical advances. Optimizing the quality and function of those lives saved is the new goal. Occupational therapists must be aware of the opportunities this exciting time brings to the profession. The shifting focus of the U.S. health care system toward providing evidence-based, client-centered, quality-driven care means occupational therapists need to examine their roles in high-quality, value-based, population-specific care for those diagnosed with pediatric heart conditions (Leland et al., 2015).

Defining Pediatric Heart Conditions

Congenital Heart Disease

Congenital heart disease (CHD) is the most diagnosed congenital anomaly occurring in approximately 1 out of every 110 live births. CHD has a substantial (30%) genetic component (Ko, 2015), but the cause remains speculative with epigenetic factors a strong consideration (Vecoli et al., 2014). One quarter of those diagnosed are considered critical and will need immediate surgery within hours or days of birth (American Heart Association [AHA], 2019). Most importantly, the families of those diagnosed potentially face a lifetime of coping with chronic illness and uncertainty.

Over 90% of children born with CHD will live into adulthood (Khairy et al., 2010). Improved survival rates, however, have brought to light increased potential for neurological deficits and developmental delays. The etiology remains unclear but suspected causes range from prenatal brain dysmaturation and hypoxia and pre and intraoperative perfusion and injury to exposure to noxious medications and the environment (Wernovsky & Licht, 2016). Abnormal fetal brain development; neurological events, such as stroke and seizures; and structural brain abnormalities in childhood appear to result in delayed motor, cognitive, and social skills. Questions continue to arise regarding the adverse effects of this chronic disease on happiness, ease of participation in personal and social contexts, and life transitions (Mellion et al., 2014).

In 2012, the AHA issued a ground-breaking scientific statement as a call to action for stakeholders in pediatric cardiology. The AHA and the American Academy of Pediatrics combined to review literature outlining the sequelae of CHD deficits and delays, classified based on level of evidence; build an algorithm to determine those most at risk; and recommend practice guidelines to optimize neurodevelopmental outcomes. The following conclusion was released:

Children with CHD are at increased risk of developmental disorder or disabilities or developmental delay. Periodic developmental surveillance, screening, evaluation, and reevaluation throughout childhood may enhance identification of significant deficits, allowing for appropriate therapies and education to enhance later academic, behavioral, psychosocial, and adaptive functioning. (Marino et al., 2012, p. 1143)

Acquired Heart Disease

Pediatric cardiomyopathies (PCMs) are a severe and burdensome form of heart failure and the most common cause of sudden cardiac arrest in children. Approximately 30,000 children in the US are affected, and the rates are rising (Lipshultz et al., 2019). The etiology is mainly unknown, but possible causes include viral illness, chemotherapy, genetic factors, or part of an underlying metabolic or neuromuscular disorder (Wilkinson et al., 2010). Of all of the children diagnosed with PCM, 40% will go on to need a heart transplant or will die. The mortality rate of PCM is higher than the combined deaths of all childhood cancers (Children's Cardiomyopathy Foundation, 2019).

Sudden onset PCMs present in a particularly frightening and intense way for children who have no idea it is coming. Pulmonary, renal, hepatic, gastrointestinal, and musculoskeletal impairment can occur. The decision for life-saving and invasive intervention can transpire swiftly. Management with medication is the first line of defense, but conditions can quickly decline to the need for extracorporeal life support ventricular assist devices (VADs) and listing for heart transplantation (Yuan, 2018).

As is the case with CHD, recent advancements have improved survival rates for children with PCMs. However, acquired heart disease, chronic heart failure, and acute decompensated heart failure result in months to years of impairment (AHA, 2019). Pediatric heart failure management is in a period of rapid growth. New pulsatile and continuous-flow extracorporeal VADs are used to maintain left, right, or biventricular heart function and are now a staple in pediatric cardiac intensive care units. A long wait for heart transplantation while paralyzed, sedated, and on life support is no longer the norm. A new trend in managing late-stage pediatric heart failure is to insert small implantable VADs, which are commonly used in adult end-stage heart failure. These devices allow children the opportunity for time and function, either to wait for transplant or to prolong life if they are not transplant candidates. However, it is uncharted territory as to how these medical devices; surgical interventions; and intrusive interventions, such as cardiopulmonary bypass and extracorporeal membrane oxygenation (ECMO), affect the developing body and brain (Kindel & Everitt, 2016).

From Surviving to Thriving

Innovative heart catheterization techniques, medical management protocols, surgical procedures, and mechanical circulatory support have improved the survival rate of children affected by heart disease during childhood (Burki & Adachi, 2017). Infant and child survival rates are at an all-time high and there are now more adults living with pediatric-diagnosed heart conditions. With transition to new occupational and life roles, there is growing concern for cognitive, motor, behavioral, and adaptive capacity problems. A review of recent literature supports the mounting evidence that areas of concern exist, many of which are within occupational therapy's scope of practice (see Figure 1).

Motor and Developmental Concerns

Both the AHA and the International Society of Heart and Lung Transplant (ISHLT) have issued statements and guidelines directed at the management of children with pediatric heart conditions. The AHA presented formal guidelines for developmental screening, evaluation, and continued surveillance for those born with CHD, with a strong emphasis on the need for continued monitoring throughout their childhood years, as deficits can persist and change with age (Marino et al., 2012). Both the AHA and the ISHLT statements have direct implications for domains that are within occupational therapy's scope of practice, including development, cognition, and transition through life stages (Kirk et al., 2014). Per these recommendations, some hospital systems are now implementing multidisciplinary neurodevelopmental assessment groups and programs that span acute care to outpatient service delivery (Lisanti et al., 2016; Lisanti et al., 2019).

Referral to therapy services, including occupational therapy, is a key component of the AHA and ISHLT's recommendations; however, there is no known literature of occupational therapy's participation in this type of program. Imms (2004) provided the only identified occupational therapy contribution in literature, somewhat ahead of current times, calling for occupational therapy's participation in comprehensive programs that "promote optimal occupational performance" (p. 161). Occupational therapy textbooks and practice guidelines have minimal to no information on complex

pediatric heart defects, the impact of heart failure on neurodevelopment, or how complex cardiac disease affects children as they age (Clark & Kingsley, 2013; Kramer, 2018; O'Brien & Kuhanek, 2019). Since academic coursework follows the information provided in occupational therapy textbooks and practice guidelines, a reasonable conclusion is that current academic programs include little instruction to students beyond typical pediatric heart defects seen in neonatal intensive care units.

Figure 1
Pediatric heart conditions and related lifespan deficits

Infant
Feeding problems (Hill et al., 2014)
Speech/language delays (Hövels-Gürich et al., 2008)
Motor delays (Majnemer et al., 2006)
State regulation problems (Torowicz et al., 2010)
Preschool
Fine motor and adaptive skill delays (Brosig et al., 2017)
Attention/behavior problems (McCusker et al., 2007)
Sensorimotor delays (McCusker et al., 2007)
Academic readiness delays (verbal/nonverbal reasoning, social reasoning, language, and number skill delays) (McCusker et al., 2007)
Higher prevalence of ADHD and 5 times higher risk for autism (Tsao et al., 2017)
School-Aged
Deficits in academic achievement, fine motor function, visual-spatial skills, working memory, hypothesis generating and testing, sustained attention, and higher-order language skills (Bellinger et al., 2003)
Executive functioning, inhibitory control, planning, cognitive flexibility, working memory, executive attention, abstract problem solving, and inferential learning (Cassidy et al., 2015)
Significantly lower health -related quality of life (Mellion et al., 2014)
Increased propensity for obesity and poor exercise tolerance (Pinto et al., 2007)
Adolescent
Mathematic, executive functioning, and visua-l-spatial deficits from white matter injury (Rollins et al., 2014)
Increased risk of internalizing problems like anxiety and depression and of externalizing behaviors like hyperactivity or aggression (Karsdorp et al., 2006)
Chronic feelings of loneliness are associated with worsened perceived health in adolescents with CHD (Vanhalst et al., 2013)
Deficits in perceptual reasoning, working memory visual perception, visuomotor integration, executive, and motor skills (Schaefer et al., 2013)
Potential for worsening heart failure, surgery, and orthotopic heart transplant
Adult
Lower academic and occupation levels, preference for familiar setting, deficits in body image, and denial of disease (Daliento et al., 2005).
Increased risk of mental health problems and emotional distress, especially anxiety and depression (Jackson, Leslie et al., 2018)
Sub-optimal living conditions, relationships, occupational level, and income (Opid et al., 2015)
Barriers to cardiology follow up, lack of knowledge of cardiac condition or risk factors, and gaps in care (Harrison et al., 2011)
IQ within average; academic up to 2 SD below mean for single ventricle physiology (Wernovsky et al., 2000)
Executive functioning impairments, but memory intact (Daliento et al., 2005)

Those that care for a child with a heart condition are aware of the toll that the illness has on the interruption of normal development during a child's formative years, which often necessitates skilled intervention. Parents of children diagnosed with heart defects at birth note delays and deficits that impact typical childhood roles and occupations (Farr et al., 2018). Per the *Morbidity and Mortality Weekly Report*, nearly 60% of the children with diagnosed pediatric heart conditions have special health care needs, inclusive of physical or speech therapy (Chen et al., 2018).

Referrals to developmental specialists, including occupational therapy, occur as a result of neurodevelopmental evaluations, pediatrician visits, postsurgical events, or after acute-care hospital admissions. Recommendations for therapeutic interventions through early childhood intervention programs, home health therapies, and outpatient therapy services are made when deficits are identified through developmental screenings or comprehensive developmental assessments (Brosig et al., 2014). When neurological events or an acute decline in function occur from life-saving interventions or prolonged hospitalizations, a more comprehensive rehabilitation approach is taken. From personal experience in the following settings, referral examples include:

- infants to early childhood intervention programs or home-based occupational therapy for global developmental delays, poor ability to self-regulate and calm, tactile and vestibular sensitivities, and positional deformities affecting motor skill development from prolonged hospitalizations;
- toddlers and preschoolers to home health or outpatient occupational therapy for sensorimotor, feeding, and school-readiness deficits;
- school-aged children for school-based or outpatient occupational therapy for fine motor, coordination, and visual-motor processing delays; and
- those who experience neurological trauma, stroke, or have extensive rehabilitation needs after prolonged hospitalization to postacute rehabilitation settings in which they receive occupational therapy services.

While referrals are made for different reasons and the scope of deficits are different, all are children with heart conditions at different points in their life paths. Whether problems are acute or chronic, referrals are made as a result of an underlying cardiac-based diagnosis. The diagnosis does not go away, and the problems often shift and change as the child ages.

Heart Failure-Induced Brain Injury and Cognition

When the heart cannot effectively pump oxygenated blood to body systems, then normal function is interrupted to all organs, including the brain. Hsu and Pearson (2009) identify typical somatic signs in children as “edema, respiratory distress, growth failure, and exercise intolerance” (p. 64). Progression of heart failure leads to pulmonary congestion and end-organ failure of the kidneys and liver. Deleterious effects on bodily organs are easy to detect through medical testing and functional observations; however, that is often not the case with brain changes. There is a new shift to focus on both acute and chronic injury that occurs to the brain (Havakuk et al., 2017).

Like the AHA, the ISHLT issued guidelines in 2014 for the management of pediatric heart failure, the first document to address heart failure in children. The comprehensive summary, regarding end-stage heart disease in children, identified needed areas of assessment and intervention domains that included: (a) depression and psychological, (b) cognitive and psychosocial, and (c) exercise and functional activity performance. Like the AHA statement on neurodevelopmental outcomes, this pressed

the medical community to recognize that children with heart failure were at risk for physical, neurological, and psychosocial deficits as well (Kirk et al., 2014).

Children and adolescents with heart failure are at risk for cognitive deficits that affect participation in age-appropriate physical, social, academic, and occupation-based activities, and structural brain irregularities are seen in both congenital and acquired heart failure populations (Menteer et al., 2010; Rollins et al., 2014). Heart-failure induced brain injury is linked to autonomic, motor, emotion, personality, and mood disruption as well as the higher-order cognitive skills of executive function (Havakuk et al., 2017). Those brain disruptions present a host of potential neurodevelopmental problems when combined with a developing brain and body. Impairment in executive function skills also present potential problems when adolescents are growing into their adult roles. Working executive function skills are important for cognitive reserve, resiliency, and life-skill management (Cassidy et al., 2015).

Lifespan Care

Deficits and delays do not disappear as an individual with a pediatric heart condition diagnosis gets older, and it is important to transition care to address adult-based challenges. Adolescence is a period of rapid physical, cognitive, emotional, and social change where individuals begin to seek their own identity and sense of self in preparation for adulthood (Christie & Viner, 2005). It is an important time to recognize responsibility for managing future medical care and decisions. However, transition difficulties are common and result in gaps in care and increased hospitalizations (Uzark et al., 2015).

Many medical and physical factors are contributory, but compromise to the brain is a factor in cognitive functions essential for managing life transitions (Marelli et al., 2016), with anxiety and depression as potential issues (Pike et al., 2018). Executive function is particularly at risk, and deficits are nearly twice as high for those with CHD compared to controls (Cassidy et al., 2015). Executive functions are necessary for adolescents and young adults to tap into essential resiliency factors like adaptive coping skills (Jackson, Gerardo, et al., 2018; Jackson, Leslie, et al., 2018).

Transition into adulthood is already a complex phenomenon for teenagers. The addition of a chronic disease process makes that navigation more difficult. Understanding medications and why they are needed, navigating the intricacies of the health care system, and managing the emotional consequences of progressive disease are often barriers to effective transition to adult care. Sable et al. (2011) also notes that typical risky adolescent behaviors, such as unhealthy lifestyle choices, misunderstanding physical limitations, and misperception of body symptoms, may result in outcomes that are life-changing. Struggles to adapt to traditional adult roles and decisions, such as advanced academia, occupational choice and retention, decisions regarding partner choice and reproduction, and independent living also occur (Daliento et al., 2005; Opić et al., 2015). Cognitive impairment, including executive function disorders and real-world functional cognition problems, impact these important decision-making processes.

Provision of education through written materials or didactic teaching is not enough. Occupational therapists are trained to identify cognition and executive function deficits that impact an individual's ability to care for themselves independently. This population needs a client-centered and holistic intervention strategy to ensure successful transition through life roles.

Impact on the Family

Pediatric heart conditions impact the entire family. A life-changing chronic diagnosis has implications for social, cultural, and familial domain interruption. It is difficult for families to navigate

the complexities of medical decision-making and person and emotional factors. Parents identify initial diagnosis, options for termination, potential challenges of their child, social implications of having a child with a chronic illness, inter-parent factors, and maladaptive coping issues as stressors (Jackson, Higgens, et al., 2018). Without support, they are left to navigate each life stage and new environment independently.

The Role of Occupational Therapy

A Knowledge-to-Action framework is a systematic approach to guide evidence-based program development in health care. Knowledge creation is the first step and involves inquiry, synthesis, and identification of potential algorithms (Straus et al., 2013). In this case, the above literature inquiry reveals that pediatric heart conditions negatively impact body systems and functional outcomes well into the adult years. Also discussed, occupational therapy literature inquiry reveals sparse to no information on therapeutic guidelines. Thus, questions arise as to how to address this population's needs in a holistic way. Is occupational therapy the answer to maximize self-care capacity, participation in meaningful activity, and effective lifespan care?

Some authors have adapted adult cardiac rehabilitation protocols to fit the pediatric population (Tikkanen et al., 2012). A recent literature review of pediatric cardiac rehabilitation studies reveals that all had exercise- and activity-based interventions, none addressed cognition, and scant few addressed developmental or physical considerations (Rogers & Harris, 2019). People who live with pediatric heart conditions have rehabilitation needs other than an activity-only adult cardiac rehabilitation model (Akamagwuna & Badaly, 2019).

Occupational therapy provides a needed bridge between generalized adult-based cardiac rehabilitation strategies and individualized strategies to promote successful and progressive transition through life stages. Tailoring individual physical and cognitive needs, addressing development and next-stage needs, and encouraging adaptive behaviors like resiliency and self-advocacy is the new age of pediatric cardiac rehabilitation, and occupational therapy can lead the way.

Primary Domains

Development and motor skills. Chronic illness impacts physical growth, developmental skills, and functional activity tolerance. Physical development and motor skills are building blocks for participation in exercise and functional activity (Rogers & Harris, 2019). The occupational therapist should assess strength, range of motion, coordination, fine and gross motor skills, and functional activity endurance to implement individualized plans that address the impact of acute and chronic illness on functional status.

Functional cognition. Heart failure-induced brain injury impacts cognitive processes needed to plan and direct goal-oriented behaviors (Wolf et al., 2019). Cognition and executive function skills are building blocks for academic success, management of self-care skills related to heart failure, and transition to adult care. The occupational therapist should assess cognition, person factors, and using performance-based assessments to implement individualized plans that address the impact of acute and chronic illness on functional cognition status.

Life stage and transition skills. Chronic illness, neurodevelopmental delays, and cognition deficits impact an individual's ability to transition successfully to the next life stage. Managing transitions is a dynamic and complicated process. The occupational therapist should use client-centered strategies to set goals, develop plans, and build processes to make transitions successful and meaningful.

Caregiver and child support, engagement, and participation. Pediatric heart conditions impact a family's ability to manage stress, make decisions, and plan for the future. Engagement and participation in life is an important outcome measure. The occupational therapist should assess individual barriers, supports, and aspirations to implement individualized plans geared to support their full participation in life.

Secondary Domains

The impact of chronic illness on childhood development necessitated the addition of four other domains. First, the impact of medical trauma on participation, function, and independence is necessary to recognize. Second, the ability to adapt to changes in body, mind, and functional status is essential. Children and adolescents with heart conditions look, act, and want to participate in life like their peers. However, they have special needs, scars, and considerations that are not visible. Third, developing resiliency to face current and future medical challenges is an essential skill for those who face uncertainties in health and condition. Last, developing self-advocacy and self-management skills is imperative to understand, own, and manage a life-long heart diagnosis.

Transactional Process Approach

The complex interaction between occupations, client-factors, performance skills and patterns, and context and environment that occurs in chronic pediatric illness is vital for future and current occupational therapists to recognize. There is not a one-size-fits-all approach. King et al. (2018) presents a transactional framework for pediatric rehabilitation that moves away from a traditional, unidirectional medical model approach that attempts to "fix" whatever problems arise. Instead, it shifts to "meaningful situated and cumulative experiences" (p. 1830) to guide a child to develop the capacity to adapt to challenging life events, develop strategies to overcome problems, and build self-advocacy and resilience skills.

The four tenets of this approach are (a) adaptive outcomes occur as a result of interactions between a person and what is happening to them in the context of setting, time, or interaction; (b) adaptive development happens when a person sees what they are capable of and realizes their potential; (c) a person can achieve positive outcomes in many different ways, not just through the normal trajectory of development or goal-attainment; and (d) there are temporary periods in a person's life that will bring challenge, adversity, and times of growth. This model provides an interesting viewpoint when addressing chronic and progressive pediatric heart failure. Teaching children and their families how to adapt, overcome, and plan is an invaluable skill when addressing adversities of health.

The Path Forward

In conclusion, occupational therapy has great potential to positively impact the lives affected by pediatric heart conditions in new and innovative ways. Modifying adult cardiac rehabilitation models to fit pediatric patients is not enough to meet their complex needs. Identification of domains and a transactional pediatric theoretical framework is a first step in developing practice algorithms. Next steps include the involvement of patient and family stakeholders, the formation of multi-disciplinary teams, and the development of evidence-based practice guidelines grounded in the promotion of adaptation, resiliency, and self-advocacy.

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