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Optimizing Quality of Life in Children with Complex Congenital Heart Disease

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Abstract

Purpose of Review Individuals with congenital heart disease (CHD) can experience long-term morbidities related to physical, neurodevelopmental, and psychosocial functioning. These long-term sequelae are more likely to occur for patients who meet the high-risk criteria and are associated with diminished health related quality of life (HRQOL). Understanding how to mitigate risk or intervene to improve physical, neurodevelopmental, and psychosocial outcomes for patients with CHD is critical for improving HRQOL.

Recent Findings Instruments measuring HRQOL are available and widely used in children with CHD. Lower HRQOL is associated with greater disease complexity and medical care utilization, lower self-perception and competency, more behavioral and emotional difficulties, and greater educational impairment. Interventions like family-centered neurodevelopmental care, early intervention, psychological and behavioral services, physical activity, educational services, and family support have been shown to positively impact physical, neurodevelopmental, and psychosocial outcomes for patients with CHD, but it is unclear what interventions in these domains will specifically improve HRQOL.

Summary There is a critical need for research focused on interventions to improve neurodevelopmental, psychosocial, and physical functioning in children with CHD. Intervention research needs to be high quality, use appropriate instruments, and should examine the impact of these interventions on HRQOL in both the short- and long-term.

Keywords Congenital heart disease · Quality of life · Health related quality of life · Neurodevelopmental outcomes · Psychosocial functioning · Intervention

Introduction

Congenital heart disease (CHD) is the most common congenital malformation, impacting nearly 1% of live births worldwide [1]. A third of babies born with CHD will have complex CHD that requires surgical or catheter-based intervention within the first year of life [2]. CHD survival rates have improved dramatically in the last few decades [3], with long-term survival (> 20 years) now estimated at 80% for children with complex CHD [4]. With improving survival rates, the field has shifted to focus on reducing CHD related morbidity. Individuals with CHD, especially those who require surgical intervention in infancy, can experience long-term physical, neurodevelopmental, and psychosocial sequelae [5–10] which are strongly associated with diminished quality of life (QOL) [11, 12].

Despite recognition of the long-term impacts of these physical, neurodevelopmental, and psychosocial morbidities, little research has focused on interventions in the CHD population to mitigate these challenges to improve QOL for patients with CHD [13, 14]. This review examines research looking at the effectiveness of treatments designed to improve QOL that address physical functioning, neurodevelopmental, and/or psychosocial symptomatology in patients with CHD or other chronic illnesses.

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Defining Quality of Life

QOL is a multidimensional construct that describes a child's ability to function in a variety of contexts (e.g., at school, with peers, family life) and derive satisfaction from doing so [15–17]. Three domains are included in QOL: 1) physical health status and physical functioning; 2) psychological status; and 3) social functioning [15–17]. Health related quality of life (HRQOL) offers a more specific description of QOL for individuals with a chronic illness and can be defined as the influence of a specific illness, medical therapy, or health services policy on one's ability to function and feel satisfaction from physical, psychological, and social contexts [18]. Within this review, we will use HRQOL for ease.

Measuring Quality of Life for Patients with CHD

Measuring HRQOL is a critical component of the evaluation of long-term outcomes for patients with CHD as it provides a comprehensive assessment of an individual's health status, and may result in identification of physical, functional, and/or psychosocial difficulties for which interventions could be implemented [11]. Ongoing assessment of HRQOL over time offers the opportunity for patients, parents, and health care providers to monitor changes in status and evaluate the impact of any therapies or interventions that may impact HRQOL [19]. Despite the potential benefits of measuring HRQOL, assessment in pediatric populations is challenging as children's capabilities vary significantly based on age and developmental capacity. Varying levels of CHD severity, treatment approaches, and outcomes further complicate HRQOL assessment with the pediatric CHD population [11]. Historically, measurement of HRQOL in patients with CHD has been limited, with only one published study identified as measuring patient's perceived HRQOL between 1980 and 2000 [20], though the number of studies including HRQOL has been steadily increasing since 2000 [21].

When measuring HRQOL, both general and disease-specific instruments are available for the pediatric CHD population [22–28]. Generic HRQOL instruments allow for comparison of HRQOL outcomes across chronic disease groups or between chronic disease groups and healthy controls, while disease-specific HRQOL instruments are more comprehensive and better able to identify differences between sub-groups within a disease category [11]. A comprehensive review of currently available HRQOL measures for cardiac patients is available in previously published work by Marino and colleagues [11, 29]. Ideally, HRQOL measurements should assess a wide age range of patients, have both patient self- and parent/guardian proxy-reporting, and be administered easily and quickly.

HRQOL Scores in Patients with CHD

Findings from past research on the HRQOL of children and adolescents with CHD have been variable, with some studies reporting worse HRQOL and others finding similar or better HRQOL scores for patients with CHD compared to healthy controls. This variability is thought to be the result of differences in the domains of HRQOL being studied, the appropriateness of the HRQOL instrument(s) chosen to address the research question, biopsychosocial factors unique to the children and adolescents being assessed, and study-based limitations that result in underpowered analyses and/or reduce the generalizability of any findings [11].

Larger studies and systematic reviews assessing HRQOL outcomes have shown that children and adolescents with CHD have similar HRQOL scores to children with other pediatric chronic illnesses, but worse HRQOL scores compared to similar aged healthy peers [30, 31]. Despite the perception that CHD primarily has physical effects on functioning, prior research has shown that the greatest negative impact on HRQOL arises from issues in psychosocial and educational functioning [32]. Past research has also looked at HRQOL in patients with CHD by diagnosis and procedural groups, which is well summarized by Marino and colleagues [29]. Within the pediatric CHD population, patient-reported HRQOL decreases as disease complexity increases [31–36]. Specifically, children and adolescents with mild CHD not requiring any surgical or catheter-based interventions report the best HRQOL, followed by those with repaired biventricular CHD, while patients with single ventricle CHD report the worst HRQOL scores [31, 33, 35]. That HRQOL decreases as disease severity increases was also found in a large, multi-center study assessing HRQOL using a disease specific instrument by Marino and Wray [33, 34]. However, they also observed examples of single ventricle patients that had HRQOL scores as high as patients with aortic stenosis who had not undergone intervention and aortic stenosis patients with HRQOL scores as low as the average single ventricle patient, suggesting that there may be resilience and depressant factors that influence an individual's HRQOL over time [33]. Identifying resilience and depressant factors may allow for prevention and intervention efforts to protect or improve HRQOL.

Looking at a patient's unique medical history to understand what complications they have experienced and their health care utilization over time may provide a more nuanced understanding of HRQOL for patients with CHD [36]. For example, O'Connor and colleagues [36] utilized latent class analysis to look for group differences in HRQOL based on patient's cardiac medical

history. They found four distinct CHD complexity groups, and greater CHD complexity was associated with greater burden of illness and lower patient- and parent-reported HRQOL [36]. There are numerous, well documented surgical and perioperative factors (e.g., perioperative seizures, neurologic injury, prolonged hospitalization, mechanical support, cardiopulmonary resuscitation, heart transplantation) that can negatively impact neurodevelopmental outcomes including HRQOL [6, 7]. Lower HRQOL has also been associated with greater medical care utilization as measured by number of cardiac surgeries, cardiac-related hospital admissions, and doctor visits in the last year [33]. Similarly, behavioral, emotional, and other mental health factors can have a significant impact on HRQOL in patients with CHD. Lower HRQOL was associated with poorer patient self-perception and competency and increased behavioral and emotional problems in the pediatric cardiac population (33). Ernst and colleagues [37] found that half of the variance in HRQOL scores for patients with CHD was accounted for by factors like educational impairment, poor self-esteem, anxiety, and post-traumatic stress symptoms of both patients and their parents. Interventions that aim to reduce health care utilization, improve behavioral and social-emotional functioning, and treatment of mental health symptoms may result in improved HRQOL for patients with CHD.

Interventions that may Preserve or Improve Quality of Life

Individuals with CHD are at increased risk for differences in development, academic, and psychosocial functioning. Despite the risk of poor physical, neurodevelopmental, and/or psychosocial outcomes in individuals with CHD being well documented, understanding of how to mitigate those risks in individuals with CHD is still limited [38]. The primary aim of this review will be to present research related to interventions that could help preserve or restore physical functioning, neurodevelopment, and/or psychosocial wellness to promote and protect HRQOL in children and adolescents with CHD. We will consider interventions focused on the surgical and perioperative period, social and family context, and development and academic functioning. Many of the difficulties faced by children and adolescents with CHD are also described in other medical populations, so we also review interventions that have been effective in addressing neurodevelopmental and psychosocial concerns in other medical groups when CHD-specific literature is unavailable. Table 1 summarizes interventions described below.

Individualized Family-Centered Neurodevelopmental Care

Individualized family-centered neurodevelopmental care practices aim to minimize the mismatch between what the developing brain needs and the hospital environment by observing infant behavior and making modifications to the environment and/or caregiving to meet the needs of the infant [38]. Neurodevelopmental care is recognized as the best practice for medically fragile infants (e.g., premature and/or required neonatal surgical intervention), but implementation in pediatric cardiac intensive care units (ICU) is limited compared to neonatal ICUs [67]. There is an evidence-based developmental care program, Neonatal Individualized Developmental Care and Assessment Program (NIDCAP), which has been shown to reduce length of stay and improve physiological functioning, long-term neurodevelopment, parent confidence, and family satisfaction among premature infants [39–42]. Despite recent recognition of the importance of implementing neurodevelopmental care practices with the CHD population [38], there are no studies looking at the efficacy of NIDCAP or another comprehensive neurodevelopmental care intervention program in the pediatric cardiac ICU setting or with CHD patients. Individual components of neurodevelopmental care like skin-to-skin contact, developmental care rounds, cue-based care, family support, and education for providers, have been associated with improved developmental outcomes for patients with CHD and may improve HRQOL as well. [43, 44, 68–73].

To make implementation of neurodevelopmental care easier and to reduce variation in care practices, the Cardiac Newborn Neuroprotective Network, a special interest group of the Cardiac Neurodevelopmental Outcome Collaborative (CNOC), outlined an evidence-based developmental care pathway for infants hospitalized with CHD [67]. The neurodevelopmental care pathway includes recommendations for standardized developmental assessment, monitoring of parental mental health, and implementation of a daily developmental care bundle. The working group acknowledges that research to support these neurodevelopmental care interventions within the CHD population is limited but did highlight cardiac specific research related to benefits of skin-to-skin holding [43], reduced postoperative pain through infant massage [44], and reduced cardiopulmonary instability with two-person caregiving [67]. Evidence from other high-risk populations is cited for interventions where cardiac-specific research is unavailable. A comprehensive review of recommended interventions can be found in the published developmental care pathway [67]. Briefly, neurodevelopmental care intervention recommendations include: 1) monitoring of infant

Table 1 Interventions for individuals with CHD and their families

Approach	Description	Findings
Family Centered Neurodevelopmental Care	Care- and environment-based interventions designed to minimize the mismatch between the PCICU environment and what the developing brain needs	• Evidence based program (NIDCAP) for premature infants in NICU – reduces length of stay; improves physiological function, long-term developmental outcomes, parental confidence, and family satisfaction [39–42] • One hour of skin-to-skin care for infants with CHD during pre- and post-operative period resulted in – decreased infant pain scores; calmer behavioral states during skin-to-skin; reduced heart rate and respiratory rate; increased systolic blood pressure; reduced cortisol levels after skin-to-skin for infants that had high baseline cortisol [43] • 30 min of daily postoperative massage for infants with CHD compared to 30 min of daily quiet time – daily massage associated with lower daily pain scores and lower average daily heart and respiratory rates [44] • Interventions are likely to impact HRQOL, but has not been directly studied in individuals with CHD
Early Intervention & Rehabilitative Therapies	Early Intervention is a federal grant program in the United States that provides free or low-cost developmental services for infants and toddlers who meet criteria for delayed development. Outpatient rehabilitative services like physical therapy, occupational therapy, speech therapy can also be accessed through insurance	• High-quality and high-frequency early childhood developmental services are effective in other high-risk populations [45, 46] • Physical therapy in early postoperative period for infants and toddlers with CHD – physical therapy was started on average five days after surgery; all patients demonstrated reduced gross motor functioning; postoperative physical therapy resulted in improved gross motor abilities by the time of discharge [47] • 10-week program that targeted two gross motor skills every two weeks via 4–6 play-based activities that parents were asked to do with their infant for 20 min per day – development of participants progressed at the expected rate or an increased rate to catch up with developmental expectations; parents reported positive impact on family life from the intervention [48] • General utilization of early intervention services remains low in patients with CHD [49] • Interventions are likely to impact HRQOL, but has not been directly studied in individuals with CHD

Table 1 (continued)

Approach	Description	Findings
Psychological & Behavioral Interventions	Evidence-based interventions such as parent management training, cognitive behavioral therapy, acceptance and commitment therapy, trauma-focused therapy, and mindfulness-based interventions that address areas of concern like behavioral difficulties, anxiety, depression, posttraumatic stress, attention-deficit/hyperactivity disorder, procedural anxiety, coping with medical illness	• Few children with CHD participate in psychological evaluation and treatment [50] • Six-week mindfulness training that included yoga, meditation, cognitive restructuring, and group support for adolescents with CHD or cardiac device compared with group support only – both groups resulted in a decline in illness-related stress; use of coping skills was associated with lower levels of depression; participants with higher baseline anxiety/depression scores had improved scores after intervention [51] • Two educational workshops for mothers of children with CHD that focused on general developmental challenges and CHD-specific concerns, and one individual follow-up session – improvements in maternal mental health and family functioning; no specific impacts on child related outcomes, but children were perceived as sick less often and missed fewer days of school [52, 53] • Expansion of intervention above to include CHD patients and siblings in a one-day workshop and individual follow-up – outcomes for intervention group were not different than those who received care as usual [54] • Compared treatment group which provided information and coping skills training to treatment as usual (information only) – treatment group were more cooperative and less upset in the hospital; better adjusted after discharge; better school functioning; and functional health status improved faster; treatment group caregivers also reported greater confidence in their ability to care for their children in the hospital and at home [55]
Physical Activity	Exercise training and other activities that promote movement and physical activity like camp	• Exercise training improves exercise capacity, physical activity, motor skills, and muscular function [56] • Impact of exercise training on HRQOL is mixed with some studies finding improved HRQOL regardless of whether physical fitness improved [57–61], others finding no change [62, 63], and others depending on parent- vs patient-report HRQOL [64] • Summer camps for children with CHD can positively impact physical functioning as well as self-perceptions, self-esteem, and general behavior [65]
Educational Interventions	Educational advocacy	• Educational advocates can help ensure that children with CHD receive all appropriate school-based services and accommodations to optimize educational attainment and HRQOL • Limited research in this area
Family Support	Access to support, resources, education, and psychosocial intervention for parents of who have received a prenatal CHD diagnosis and/or parents of children with CHD	• Interventions have been varied in their approach and have included palliative care and family-centered nursing care – reduced maternal anxiety; more positive reframing; increased communication scores; better family relationship scores; better parental satisfaction [66] • Limited research in this area

PCICU Pediatric cardiac intensive care unit, *NIDCAP* Newborn Individualized Developmental Care and Assessment Program, *NICU* Neonatal intensive care unit, *CHD* Congenital heart disease, *HRQOL* Health related quality of life

behavioral state with clustering of care based on infant needs; 2) prioritizing non-pharmacologic approaches to pain management when possible; 3) managing environmental stimuli with awareness of lights, sounds, and touch; 4) development and motor supports through proper positioning, passive range of motion, and prone positioning; 5) feeding interventions to prevent oral aversion, providing nutrition by mouth once appropriate, and supporting the use of human milk; 6) promoting parental presence through touch, holding, and participation in care; and 7) preparation for the eventual transition home.

Early Intervention

Neurobehavioral abnormalities have been identified pre- and post-operatively for infants with CHD who require surgical intervention in the first year of life [6, 7], establishing the need for early rehabilitative interventions like physical therapy, occupational therapy, and speech or feeding therapy. Early Intervention (EI) services provide comprehensive developmental services with the goal of preventing, delaying, or reducing the developmental impact of risk factors for children from birth to age three [74]. In the United States, EI is a federal grant program that is managed at the state level to provide free or low-cost developmental services for infants and toddlers who meet criteria (e.g., documentation of developmental delay, 1.5 standard deviations below the mean for age), which also varies by state.

EI to support developmental milestone attainment is particularly important, as gross motor ability is an early predictor of HRQOL, executive functioning, and mood [75]. Many children with CHD need rehabilitative therapies after surgical intervention or prolonged hospitalization, but EI services remain underutilized by eligible cardiac patients [74]. Though not well studied in children with CHD, past research has established that high-quality, high-frequency early childhood developmental services are effective in other high-risk patient populations like very low birthweight infants [45, 46]. In infants and toddlers with CHD, physical therapy started in the early postoperative period has been shown to promote gross motor recovery [47], and rehabilitation delivered through a 10-week program of parent-led developmental activities has also been shown to help children with CHD increase rates of developmental progress to meet age-appropriate levels [48]. Although EI services are beneficial, utilization rates remain low for all eligible children, including those with CHD [49].

No studies have investigated the impact of EI on HRQOL with cardiac patients, but optimizing developmental outcome and functional status is likely to improve HRQOL in turn. This idea is supported by decades worth of research with other high-risk populations who received prenatal and infancy home visits by nurses, which were shown to improve cognitive, academic, behavioral, and sociodemographic outcomes for children in these programs [76]. Identification of eligible individuals with CHD and referral to appropriate services is likely an easy intervention to implement.

Evidence-Based Psychological & Behavioral Interventions

Individuals with CHD have a higher prevalence of emotional, behavioral, and social difficulties than their heart healthy peers [77]. Children with single ventricle anatomy have been found to have a 65% lifetime prevalence of having a psychiatric disorder, with a 5 times higher lifetime rate of anxiety disorders and 6 times higher lifetime rate of attention-deficit/hyperactivity disorder (ADHD) than the general population [78]. Despite high rates of mental health concerns, few children and adolescents with CHD participate in psychological assessment or treatment [50]. Interventions (e.g., parent management training, cognitive behavioral therapy, acceptance and commitment therapy, trauma-focused therapy, mindfulness-based interventions) addressing areas of concern commonly reported by individuals with CHD (e.g., behavior concerns, anxiety, depression, posttraumatic stress, ADHD, procedural anxiety, coping with medical illness) have been developed and established as effective with non-CHD populations [38], but CHD-specific research is still lacking.

A recent systematic review on psychological interventions for individuals with CHD only identified nine unique interventions targeting children and adolescents with CHD or their mothers [14]. Of the CHD-specific interventions that have been studied, common intervention components include psychoeducation, supportive counseling, relaxation skill training, mindfulness-based stress reduction, and problem-solving skill development. Adolescents with CHD reported a decline in stress after attending six weeks of mindfulness training, which included yoga, meditation, cognitive restructuring and group support [51]. An intervention targeting mothers of children with CHD reported improvements in maternal mental health and family functioning after providing two educational workshops on how to address general developmental challenges and CHD-specific concerns, having mothers observe their child engage in exercise, and one individual follow up session [52, 53]. Unfortunately, an expansion of this intervention to include CHD patients themselves did not show differences in emotional and behavioral concerns at follow-up [54]. Finally, a psychoeducation and coping skills intervention was found to be effective in reducing symptoms of maladjustment post-surgery for patients with CHD [55]. The limited data available for review highlights the urgent need for psychological

intervention research in children and adolescents with CHD. It will be important to consider how to leverage technology to provide education and interventions in modalities that are more accessible to patients and their families (e.g., telehealth, video conferencing, social media).

Physical Activity & Exercise Capacity

Overall, individuals with CHD have lower levels of daily physical activity and reduced levels of fitness compared to healthy peers [79–82]. The benefits of regular exercise are well documented for the general population, but physical activity and fitness are also important for individuals with CHD as activity and fitness level are associated with future outcomes [83–86]. In 2013, the American Heart Association [87] recommended regular physical activity for children and adults with CHD, as exercise intolerance or a sedentary lifestyle may put children with CHD at additional risk of developing comorbidities including obesity, diabetes, and symptoms of anxiety and depression [88]. In a recent review paper that included 3,256 patients with CHD, exercise training was shown to improve exercise capacity, physical activity, motoric skills, muscular function, and QOL [56]. The impact of exercise training on HRQOL was mixed across studies, with some finding improved HRQOL regardless of whether physical fitness improved [57–61], while others noted no change in HRQOL [62, 63], though this also varied by parent- versus patient-reported HRQOL [64]. Though the research is limited, summer camps for individuals with CHD have been shown to positively impact self-perceptions of physical functioning, self-esteem, and general behavior [65].

Education Related Interventions

Neurodevelopmental impairment is linked to poor educational outcomes for children with CHD, which can limit final educational attainment, employment, lifelong earnings, and HRQOL [6, 7]. Specifically, individuals with cCHD perform worse than norms on measures of intellectual and executive functioning, with notable levels of impairment in the area of metacognition [89]. School competency and school-related QOL is also lower in individuals with cCHD [89]. Utilization of special education services is high among students with CHD [90], but schools do not always recognize the challenges some patients with CHD face, or implement recommended academic supports from hospital-administered neuropsychological assessments [91]. Effective advocacy to ensure that children with CHD receive all appropriate school-based services and accommodations has the potential to improve educational attainment and HRQOL long-term.

School-liaison programs, or hospital-based educational advocates, can bridge the gap between the medical team and school. This type of programing is the standard of care in pediatric cancer and has been shown to be effective in promoting access to services and is associated with parental satisfaction [92]. While not the standard of care within pediatric cardiology, past research supports the benefit of a school-liaison program for cardiac patients. In a cohort of 61 patients, only 13 (21%) had educational plans prior to review by the school-liaison program. New or expanded educational plans were needed by 58 (95%) of patients, and the school-liaison program was able to accomplish this for 56 out of the 58 patients (97%) [92]. Further research will be needed to understand the impact of appropriate educational services on long-term neurodevelopmental outcomes and HRQOL.

Family Support

A recent systematic review found that over 80% of parents of children with CHD report clinically significant symptoms of post-traumatic stress, 30–80% report severe psychological distress, and 25–50% report symptoms of depression and/or anxiety [93]. Parental mental health is a strong predictor of child development outcomes, even more so than medical variables [94, 95], highlighting how intervention focused on parental adaptation may also positively impact child neurodevelopmental and HRQOL outcomes [66]. While there is increasing recognition of the importance of supporting parental mental health and family functioning for families of children with CHD, published research has not established evidence related to the most effective type of treatment, timing of treatment, or mode of delivery [66].

Two systematic reviews [14, 96] found seven unique intervention studies for parents of children with CHD. Across these studies, the therapeutic approach of parent focused interventions varied widely (e.g., education and parenting skills training, parent-infant interaction and bonding, early pediatric palliative care). Tested interventions were successful in reducing maternal anxiety and improving maternal coping, mother-infant attachment, parenting confidence, satisfaction with care, and infant cognitive development at 6 months [96]. Results were mixed for maternal depression and infant feeding, and there was no evidence that interventions improved parent, infant, or family HRQOL. There has also been qualitative work looking at parent preferences for psychosocial intervention, which found that parents want direct management of parent mental health symptoms, peer support provided by other experienced parents, education on how to effectively communicate with medical teams and advocate for their child's needs, and education about how to partner in their child's medical and developmental care [97].

Future Directions

Advancements in HRQOL measurement through the creation of reliable, valid, and generalizable measures has allowed a more thorough understanding of HRQOL-related outcomes in patients with CHD. Despite this, there continues to be a dearth of literature exploring the relationships between HRQOL and neurodevelopmental, psychosocial, and physical morbidity factors [29]. Better characterization of these relationships will help identify specific factors that may be improved through modification of current care and/or the development of targeted interventions. High quality intervention research using appropriate HRQOL instruments is needed across neurodevelopmental, psychosocial, and physical domains for patients with CHD. Outcomes should include both the intervention target (e.g., physical, psychological, social, education attainment) and HRQOL for the most comprehensive understanding of the impact of the intervention. Utilizing outcome measures recommended by the International Consortium for Health Outcomes Measurement (ICHOM) CHD working group would allow for easier comparison of intervention effects and outcomes across studies [98]. It is also important that intervention research allows for both short- and long-term follow-up to understand the effectiveness of interventions over time. Careful consideration should be given to the timing of and duration of any studied intervention as these two factors may significantly impact the effectiveness of any given intervention.

Conclusions

CHD-related morbidities have been well documented, but there has been little focus on ways to mitigate poor outcomes and HRQOL. Neurodevelopmental, psychosocial, and physical functioning related intervention research with CHD patients is still limited, but there are promising data to support the potentially positive impact of targeted interventions. It is critical to investigate the effectiveness of existing evidence-based interventions with cardiac patients (e.g., cognitive behavioral therapy for anxiety) and identify where and when cardiac-specific interventions need to be modified from other pediatric populations or developed. Routine measurement of HRQOL from patient and parent perspectives will be an important component to stratify which patients may benefit from intervention and whether interventions are effective in the short- and long-term. Effective interventions have the potential to profoundly impact neurodevelopmental, psychosocial, and physical outcomes and HRQOL of individuals with CHD across the lifespan.

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Data Availability No datasets were generated or analysed during the current study.

Declarations

Competing Interests The authors declare no competing interests.

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