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Review

Strategies to Overcome Barriers to Physical Activity Participation in Children and Adults Living With Congenital Heart Disease: A Narrative Review

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ABSTRACT

Physical activity participation is critical for optimal physical, psychological, and cognitive health in children and adults living with congenital heart disease (CHD). Majority of the general population are not sufficiently active, and with the added psychological, physical, and socioeconomic barriers faced by individuals with CHD, it is unsurprising

RÉSUMÉ

L'activité physique est essentielle à une santé cognitive, psychologique et physique optimale chez les enfants et les adultes atteints d'une cardiopathie congénitale (CC). La majorité de la population générale n'est pas suffisamment active et compte tenu des obstacles socio-économiques, physiques et psychologiques auxquels sont également

Congenital heart disease (CHD) refers to structural cardiac abnormalities that are present at birth. Between 2010 and 2017, approximately 9-11 in every 1000 live births were affected by CHD.[1–3] Advances in paediatric cardiology and medical care have resulted in increased life expectancy—more than 90% of children born with CHD are now expected to live into adulthood.[4–6] As the number of adults with CHD rises, clinical attention has shifted from solely focusing on reducing mortality to improving quality of life due to complex late morbidity emerging as a major problem for this population.

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Incorporating physical activity counselling into routine clinical care is crucial for improved long-term outcomes, as individuals with CHD are at high risk for reduced physical activity, poor exercise capacity, poor cognitive function, and obesity, which has important medical and psychosocial implications.[7–13] In the scientific literature, the term "exercise" is generally considered a subcategory of physical activity that is purposeful, planned, and focuses on maintaining or improving a component of physical fitness.[14] Throughout this review, the term "physical activity" will be used. This encompasses exercise as well as any bodily movement requiring energy expenditure.

Historically, the advice given to individuals living with CHD was to restrict physical activity due to concerns regarding its safety and the perceived need to protect these children.[11] However, accumulating evidence suggests that participation in regular physical activity can improve aerobic capacity, body composition, muscular fitness, and quality of life in the cardiac population.[15–17] Although the evidence

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that many people living with CHD do not meet the recommendations for physical activity either. The aim of this review is to outline lifelong physical activity barriers faced by individuals living with CHD and provide age-appropriate strategies that can be used to ensure the development of long-term positive physical activity behaviours. Barriers to physical activity include safety fears, lack of encouragement, low exercise self-efficacy, body image concerns, limited education, socioeconomic status, reduced access to resources, and cardiac diagnosis and severity. These barriers are multifaceted and often begin in early childhood and continue to develop well into adulthood. Therefore, it is important for children to participate in physical activity from early stages of life as it has been shown to improve cardiorespiratory fitness, muscular endurance, and quality of life. Current literature demonstrates that participation in physical activity and higher intensity exercise after appropriate screening is safe and should be encouraged rather than dissuaded in people born with a congenital heart condition.

confrontées les personnes atteintes d'une CC, il n'est pas surprenant que celles-ci soient nombreuses à ne pas respecter non plus les recommandations en matière d'activité physique. L'objet de cette analyse est de décrire les obstacles à l'activité physique que rencontrent tout au long de leur vie les personnes atteintes d'une CC et de proposer des stratégies adaptées à l'âge qui peuvent être utilisées pour promouvoir l'adoption durable de saines habitudes en matière d'activité physique. Les obstacles en question comprennent la peur du danger, l'absence d'encouragement, un faible sentiment d'auto-efficacité, une mauvaise image de soi, un faible niveau d'études, le statut socio-économique, l'accès limité aux ressources et le diagnostic de cardiopathie ou la gravité de la cardiopathie. Ces obstacles, qui comportent de multiples facettes, trouvent souvent leur origine dans la petite enfance et se perpétuent jusqu'à l'âge adulte. Il est donc important pour les enfants de s'adonner très tôt à l'activité physique. Il a en effet été montré que l'activité physique améliore la capacité cardiorespiratoire, l'endurance musculaire et la qualité de vie. Les données publiées indiquent par ailleurs que l'activité physique en général et les exercices à haute intensité — après une évaluation adéquate — sont sûrs et doivent être encouragés plutôt que découragés chez les personnes nées avec une cardiopathie congénitale.

regarding the general population and heart failure patients demonstrates an array of benefits including long-term reductions in the development of chronic disease, cardiovascular disease, and all-cause mortality,[18–21] physical activity is particularly important for those with CHD to improve skeletal muscle function, muscle mass, and exercise capacity.[22–26] In the Fontan cohort specifically, improvements in the lower limb skeletal muscle pump can improve pulsatile flow of the Fontan circulation, encouraging improved cardiac output during exercise.[16,23] One measure of exercise capacity is VO_2 peak, which is the maximal amount of oxygen the body consumes at peak exercise.

The Super-Fontan phenotype describes individuals with a single ventricle circulation who achieved normal exercise performance (>80% predicted VO_2 peak) and have higher exercise self-efficacy.[27,28] The Super-Fontan phenotype in adulthood is positively associated with childhood daily activity.[29] Although awareness of the benefits of physical activity continues to grow, its uptake is still low. Literature shows significant variability regarding the activity levels of individuals with CHD compared with their healthy peers. However, often both groups are not sufficiently active.[30–32] Globally, close to 70% of adults with CHD failed to meet the World Health Organization physical activity recommendations.[33] However, there is large variation due to geographical location, socioeconomic status, and education level.[33]

The obstacles to physical activity participation faced by the adult CHD community often arise in childhood and are continually impactful in adulthood, similar to the general population, but this cohort also face CHD-specific barriers.[34,35] The barriers to activity in children and adults have previously been explored separately, but there is limited discussion surrounding the effect of childhood inactivity on adult behaviour patterns in the population with CHD with accompanying strategies to overcome these for future generations. The barriers to physical activity and the proposed solutions discussed in this article are shown in Figure 1. This narrative review aims to highlight lifelong barriers to physical activity in the population with CHD and provide age-appropriate strategies to assist in overcoming them.

Barriers

A multitude of factors contribute to reduced levels of physical activity in the general population, including age, lifestyle, and socioeconomic status.[36–38] Often the barriers that influence physical activity are established in childhood and continue to be influential into adulthood. Majority of the general population are insufficiently active,[39] and when combined with the physical and psychological limitations experienced by individuals living with CHD, it becomes clear why many do not achieve the recommended physical activity guidelines. Although practical guidelines have been developed,[25,40–42] additional resources are required to determine optimal exercise prescription to help physicians and health practitioners encourage adherence and alleviate fears in individuals living with CHD and their families.

Safety fears and lack of encouragement and support

Previously, limited understanding regarding the safety and benefits of physical activity for individuals with CHD led to activity restrictions imposed by physicians, overprotective parents, and a lack of encouragement and support towards activity during childhood, adolescence, and adulthood.[34,35,43] Historically, individuals living with CHD were advised against participating in regular exercise, due to concerns regarding the worsening of cardiac function and the potential for sudden cardiac death. However, these fears were not based on a comprehensive understanding of the actual risks of moderate to vigorous activity or the long-term health benefits of regular physical activity. In 2000, exercise was proposed as a viable way for patients with CHD to improve quality of life.[44] The past 2 decades have seen extensive research into the safety and efficacy of physical activity for individuals living with CHD

<table>
<tr><th></th><th>BARRIERS</th><th>CHILDHOOD STRATEGIES</th><th>ADULT STRATEGIES</th></tr>
<tr><td rowspan="2">Family & Support Network</td><td rowspan="2">• Overprotection by parents and support network.
• Patients and parents unsure where to find advice.
• Inactivity accepted as normal.</td><td>• Providing opportunities for outdoor, game-based play to enhance FMS development.
• Reduce restrictive language regarding physical activity.</td><td>• Community and support groups to share experiences with.</td></tr>
<tr><td colspan="2">• Family and friend based physical activity (going for walks/ bike rides together).
• Consistent encouragement and support from friends, family and others to be physically active.</td></tr>
<tr><td rowspan="2">Healthcare System</td><td rowspan="2">• Physical activity not a distinct part of the medical curriculum.
• Unclear, restrictive or contradictory advice.
• Attitude of cardiologist influences self-efficacy.
• Restricted access to cardiac rehabilitation services.
• Limited time during appointments to adequately educate on physical activity.
• Lack of randomised controlled trials.</td><td>• Providing parents with specific, clear physical activity advice and resources to get information.</td><td>• Motivational interviewing by clinicians and other health providers.</td></tr>
<tr><td colspan="2">• Education regarding safety and importance of physical activity.
• Discuss seasonally appropriate activities.
• Use of positive language regarding physical activity.
• Development of Level I evidence (Randomised Controlled Trials).
• Realistic goal setting.
• Incorporating allied health professionals as part of routine model of care.
• Enhancing referral pathways to alleviate burden on physicians.</td></tr>
<tr><td rowspan="2">Individual</td><td rowspan="2">• Low exercise self-efficacy .
• Feelings of exclusion/ isolation from peers and family.
• Condition related anxiety.
• Body image and self-consciousness.
• Preferencing sedentary activities.
• Lack of foundational movement skill development.
• Neurocognitive delays.
• Reduced education levels.</td><td>• Building foundational movement skills from a young age.
• Participating in sport and physical activity at school.
• Outdoor play activities with friends.</td><td>• Participate in physical activity with friends and family.
• Reducing negative body language talk, utilising guided imagery and exposure therapy.</td></tr>
<tr><td colspan="2">• Attempting different activities to find ones that are enjoyable to increase exercise self-efficacy.
• Seeking psychological assistance to combat anxiety and body image concerns.</td></tr>
<tr><td rowspan="2">Environmental</td><td rowspan="2">• Reduced access to safe, suitable and adapted facilities.
• Restricted access to resources in rural areas.
• Lack of age-appropriate rehabilitation options.
• Seasonal variability.
• COVID-19.
• Technological advances = increased screen time.</td><td>• Creating fun ways to be active at home (obstacle courses/ dance routines).
• Age and condition appropriate options.</td><td>• Exercise practiced at home.</td></tr>
<tr><td colspan="2">• Development of low-cost resources.
• Utilising parks and outdoor play areas.
• Reductions in recreational screen time.
• Telehealth programs reduce the need for travel.</td></tr>
</table>

Figure 1. Categorized barriers (Family & Support, Healthcare System, Individual, and Environmental) to physical activity for individuals living with congenital heart disease and accompanying strategies to overcome these, separated into childhood and adulthood strategies where appropriate. FMS, foundational movement skills.

for improved cardiovascular and psychosocial outcomes,[25,45] but there is still a lack of level I evidence to prescribe specific and individualized physical activity for this population.

Today, cardiopulmonary exercise testing (CPET) is used primarily to assess a patient's capacity to respond to the haemodynamic demands of exercise. CPETs are also useful in the identification of disease progression, determining needs for surgery or added therapy, transplant assessments, specific exercise prescription, and assessment of the impact of therapeutic interventions.[46] Today, although there are no congenital defects that result in complete physical activity restriction, parental concerns stemming from fear of condition worsening can lead to a mismatch between physician recommendations and parental restriction.[42,47] One study found that, regardless of willingness to provide advice, only 13% of general practice clinicians in Scotland correctly described the physical activity guidelines.[48] It is not unsurprising that physicians may feel uncomfortable prescribing specific physical activity according to the recommendations, when only 13% of medical degrees in the United States include physical activity education in the curriculum,[49] with similar deficiencies in education shown in other affluent countries including Canada, Australia, and the United Kingdom.[50–52]

It has been consistently demonstrated that individuals provided with restrictive, ambiguous, or contradictory advice are more likely to question their own exercise capabilities and have reduced levels of activity compared with those encouraged and given specific advice from physicians.[34,47,53–56] Exercise self-efficacy is defined as one's beliefs about their ability to successfully engage in physical activity.[57] Overprotection by parents and others in caregiving roles (eg, teachers) have resulted in feelings of exclusion and isolation from peers as well as reductions in self-esteem and poor development of self-efficacy.[58–60] Contrastingly, some children choose to exclude themselves from physically active tasks due to physical limitations and low exercise self-efficacy.[61] When asked about perceptions of exercise and physical activity, 14% of parents of children with CHD were unsure regarding the safety of exercise, 1% felt it was unsafe, and 15% of parents had unanswered questions about their child's activity.[62] Furthermore, this study highlighted the infrequency of advice related to physical activity given to patients and their parents, with 71% having never received any advice, and of those who were given advice, 50% reported that it was inconsistent between appointments.[41] Today, although data supporting the safety of physical activity have grown and community awareness has improved, there is still a need for more level I and II evidence regarding moderate to vigorous physical activity in the population with CHD.

Psychosocial

Despite the known benefits of physical activity, people living with CHD face an assortment of psychosocial barriers to its performance. These include, but are not limited to, anxiety about their cardiac condition, low self-esteem, body image concerns, and limited social support. Exercise self-efficacy is one of the most consistent determinants of exercise participation in the CHD cohort.[63,64] Early life discouragement, exercise restrictions, and exclusion from activity often result in low exercise self-efficacy, leading to the prioritization of alternate endeavours, which often require lower physical exertion.[34] Cardiologist's attitude towards physical activity is shown to be directly related to exercise self-efficacy in adolescents.[63,65,66]

The prevalence of neurocognitive delays and dysfunction is much higher in the population with CHD compared with the general population.[67,68] Barriers to physical activity participation in the presence of intellectual disability and neurocognitive deficits include preferencing inactive lifestyles, lack of adapted spaces and inclusion, lack of support, reduced motivation levels, and general acceptance of inactive lifestyles by family and friends.[69,70] Children with CHD have reported barriers to include poor body image and low self-esteem—especially when scar exposure, cyanosis, and breathlessness may be experienced.[43,59,71,72] Canadian and Swedish children feared unwanted questions related to scars and chose alternate activities to avoid exposure.[34,59] Patients with cyanotic heart disease are also at greater risk of developing clubbed digits, whereas some genetic syndromes (Di George syndrome/Noonan syndrome) may result in dysmorphic faces.

The experiences of youth living with CHD vary widely; cultural and social misrepresentations of heart conditions are rife.[72] Children with CHD are often conflicted with the desire to be considered "normal," but, at the same time, having people understand that their heart condition does affect them and their abilities to participate.[72,73] It is important to recognize the varied personal experiences of children and adults with CHD and their perceptions towards physical activity and the world around them, which are often influenced by their upbringing and attitudes towards their heart condition. Parents of children with CHD are also at higher risk of developing anxiety and depression as they are often so consumed with caring duties that their own psychological needs are neglected.[74–76]

Socioeconomic

Generally, individuals from lower socioeconomic status areas have lower levels of physical activity than those in higher socioeconomic status areas.[77,78] In the Fontan cohort, no serial CPET data from individuals that lived in remote or very remote areas of Australia exist, highlighting a reduction in access to care and a reduced capacity to screen for safe activity participation.[79] Data retrieved from the Australia and New Zealand Fontan Registry identified that the mean total health care system cost incurred from birth to 18 years of age in the Fontan population is estimated to be AUD$390,601 with 164 days in hospital.[80] The average out-of-pocket costs for American families with children undergoing surgery for severe CHD in their first year of life is USD$3000; however, this ranges from USD$50 to USD$18,167.[81] Similarly, the Canadian population with CHD also face high costs with the mean annual cost being approximately CAD$20,000 for children and between CAD$19,000 and CAD$22,000 for adults.[82] The financial burden placed on families who have a child living with CHD cannot be underestimated. In addition to the growing cost of living, families, especially those with children who have moderate and complex CHD, are faced with the expense that comes with ongoing care. The growing number of adults with CHD due to advances in medical care have resulted in a shift in the proportion of expenses linked to hospitalizations and care. This is specifically shown in the Canadian population with adults accounting for 38.2% of the costs in 2004 and 45.8% of the costs in 2013.[82]

Another challenge faced by families are excessive days missed from work and job loss due to excessive, unexpected caring duties that can be required to care for a child with CHD.[83] The term "expense" was linked not only to financial aspects but also to the well-being of the family unit.[83] An area that is not as well researched is access to cardiac rehabilitation based on health cover, whereby 13% of Americans noted was the reason they could not access this service.[84]

Evidence suggests that individuals with CHD have higher odds of not obtaining a university degree, not completing secondary education, and not completing vocational training compared with their non-CHD peers.[85] Often lower education levels result in decreased physical activity participation in the general population.[86] Overall, in developed countries, high costs, limited resources, and disruptions to the family unit are major socioeconomic factors that limit exercise participation in individuals living with CHD.

Cardiac diagnosis, symptoms, and physical ability

It is reasonable to assume that condition severity would be the major contributing factor to reduced physical activity participation in people who have CHD. Potential cardiovascular risks associated with physical activity in the CHD cohort include arrhythmias, inability to increase cardiac output, myocardial ischemia, heart failure exacerbation, aortic dissection, and sudden cardiac death.[87] Diagnostic tools to assist with mitigating these complications include completing a CPET and transthoracic echocardiography, which are often included in standard clinical care and are recommended for safe and appropriate exercise prescription.

Across the globe, it seems that individuals living with CHD are frequently limited by physical symptoms, fatigue, and low energy although many report that they would participate if given specific advice on how to do so safely.[34,35,88] Symptoms of breathlessness, hypotension, arrhythmia, and cyanosis when participating in physical activity (although not necessarily related to cardiac diagnosis or lesion) have been shown to be barriers towards participation.[34,43,87,89] In the Fontan cohort specifically, direct measures of activity were found to be unrelated to medical history.[90] Blanchard et al.[91] concluded that in Canadian children, CHD diagnosis was in fact strongly associated with fitness, but others have shown that exercise self-efficacy is a much more important predictor of activity compared with diagnosis and disease severity.[63,64,91]

Among the Canadian paediatric cohort, deconditioning is often misinterpreted as condition-related, which can result in reduced activity participation throughout the lifespan.[72,91] This perception can exacerbate habitual physical inactivity that begins in childhood and continues throughout adulthood.

Environmental factors

Participation in physical activity can be significantly hindered by numerous environmental barriers, which can impact not only the general population but also people living with CHD. Lack of access to safe and suitable exercise facilities including parks, green spaces, and bike paths, and inclement weather, unsafe neighbourhoods, and lack of transport can all impede physical activity engagement.[34,84,92] Adolescents and young adults attending cardiac rehabilitation expressed feeling incongruent among a setting of older patients,[92] highlighting the need for age- and condition-specific exercise services. In the non-CHD cohort, adherence to exercise programmes was increased in the intervention groups with similar aged participants regardless of gender due to perceptions of group cohesion.[93,94] Seasonal variability is another important factor to consider when encouraging individuals to participate in activity.[95] Advances in technology have increased the amount of time available for children to watch TV and play videogames, especially when the home environment does not offer play opportunities.[11] Reductions in neighbourhood safety have also influenced children's activity levels.[96]

COVID-19

The global COVID-19 pandemic had negative impacts on physical activity participation due to lockdowns and isolation periods worldwide. A review of 150 studies across 26 countries found consistent declines in physical activity participation in children, as well as increased screen time and other sedentary behaviours.[97] Studies have confirmed that COVID-19 resulted in reduced physical activity participation in Canadian children living with CHD.[98,99]

It appears that there has been an increase in TV viewing that has continued after the lifting of pandemic restrictions, which is exacerbated in lower level income families.[100] Children whose parents were able to facilitate alternate activities including community and school sport were less likely to maintain high screen time viewing after COVID-19.[100] The high levels to which studies have reported screen time during the pandemic have not been sustained, although remain slightly higher than prepandemic levels.

Overcoming Barriers

Healthcare system

Given the significant impact of physical activity on overall health and quality of life, it is crucial for health systems to prioritize the delivery of current information on its safety for people living with CHD. As exercise at a submaximal level is shown to be safe in most children,[5,8,45,101] improved education surrounding the importance of leading a physically active lifestyle from a young age should be prioritized to reassure families of the benefits of physical activity not only for exercise capacity and muscle strength but also for long-term development and quality of life.[17,24,45,88,102] Patient-specific physical activity prescription should be discussed throughout follow-up consultations to ensure that patients are aware of their own capabilities and limitations that will vary according to their physiological grade and symptoms.[25,103] Ensuring that age- and condition-appropriate options are available is critical to ensure that younger congenital patients do not feel out of place in a cardiac rehab setting with older patients.[92]

As time restraints are a major barrier for physicians to prescribe adequate physical activity advice, enhanced referral pathways and implementing e-referral systems to physical activity/exercise and/or cardiac rehabilitation services could alleviate this issue.[104,105] When resources allow, incorporating allied health professionals can facilitate effective physical activity prescription and adherence. However, for this to be possible, increased awareness and understanding of physical activity among health care professionals and educators is also essential.[106−109]

Health systems and low-cost resources should be developed that facilitate access to exercise professionals as part of the model of care, with a high focus on promotion rather than restriction.[107] Simply providing patients with written physical activity forms is shown to reduce anxiety, increase confidence, and increase physical activity levels in the population with CHD.[108−110] An example of how to provide patients with specific physical activity advice is provided in Figure 2.[110]

Children

Childhood physical activity participation is heavily reliant on parental encouragement and organization.[111] In children with CHD, promoting physical activity can seem daunting for parents who view their children as fragile and are not necessarily confident in completing physical activity themselves.[11,43] Although parents in the United States and Canada often recognize the need for interventions at the family level, necessary tools and information are lacking to assist the promotion of healthy lifestyles for themselves and their children.[59,96] Improvements surrounding education and exercise safety in schools and among health practitioners are also vital.

Parental participation in physical activity can improve parents' ability to perform caregiving duties and can enhance children's quality of life, psychological health, and physical health.[59] Recommendations for competitive sport that are based on haemodynamic, electrophysiological, and functional parameters have been developed alongside general guidelines for specific CHD diagnosis.[25,41] However, these materials are designed for medical professionals and are based on limited data. Developing thorough, patient friendly information on the safety, benefits, and appropriate types of physical activity is crucial to engage this population in healthy long-term habits.

Foundational movement skill development. Foundational movement skills (FMS) include locomotor, object control, and stability skills as well as other skills (eg, swimming strokes and cycling) that are required to adequately participate in physical activity.[112] The development of FMS is a predictor of long-term physical activity adherence in children. Competency in FMS is associated with health benefits, greater physical activity engagement, improved cardiorespiratory fitness, increased self-esteem, and reduced risk of developing obesity across the globe.[59,113,114] Children with higher motor control proficiency are much more likely to participate in moderate to vigorous physical activity than those who had performed worse.[115,116]

Congenital Heart Disease Physical Activity Prescription

Name: ____

Date: _______________ **Congenital Heart Defect:** ____________________________________

Barriers Identified	Likes	Dislikes

Intensity of physical activity recommended		Tick Box
Low Intensity	Steady heart rate but moving around (eg. Strolling, light housework)	☐
Moderate Intensity	Increased heart rate and break a sweat. You can talk but not sing (jogging, swimming, dancing)	☐
Vigorous Intensity	Difficulty talking (running, fast swimming, boxing, spin class)	☐
Amount of Time Recommended		
30 minutes per day OR 150 minutes per week		☐
Other		☐

Types of Physical Activity		Circle Appropriate		
Aerobic	Walking, running, swimming, skipping, kickboxing, cycling.	**OK**	**AVOID**	**OTHER**
		Comment:		
Resistance	Strength training, weightlifting (banded, dumbbells, body weight, barbell)	**OK**	**AVOID**	**OTHER**
		Comment:		
Specific Activities to Avoid		**Circle Appropriate**		
High Impact Risk	Martial arts, Rugby, Boxing	**OK**	**AVOID**	**OTHER**
High Cuts risk	Rock Climbing	**OK**	**AVOID**	**OTHER**

Weekly Planner
Plan when you will do activity each week.

Figure 2. Exercise prescription tool for utilization during clinical appointments with physicians and allied health professionals. Adapted from Lyle and Hartman[110] (http://creativecommons.org/licenses/by/4.0/). Changes made include the top row to identify barriers, likes, and dislikes; descriptions of intensity levels; examples of aerobic and resistance exercises; and weekly exercise planning space.

Physical literacy is another important factor in lifelong physical activity participation and involves building the skills, knowledge, and behaviour patterns, which result in confidence in participating in physical activity in the long term.[117] Providing developmentally appropriate programmes run by trained staff to enhance FMS development in a school and community environment is essential for young children.[118] Structured physical activity is classified as deliberate practice performed under supervision and with the guidance of an adult trainer.[119] Parents and schools should aim to provide opportunities for outdoor play activities where possible as these are associated with increased moderate to vigorous physical activity levels and are crucial in the development of fundamental movement skills,[120–123] which are closely associated with long-term maintenance and adherence of activity.[124] Interventions targeting school age children with duration greater than 1 year may be more effective for long-term physical activity participation.[125,126] Further studies on pre-school and school-aged children with longer follow-up are required to determine optimal strategies to encourage lifelong physical activity adherence, but current evidence shows that game-based play incorporating specific and developmentally appropriate activities from a young age improves FMS.

Increasing education on safety and appropriate type of physical activity. There is often a mismatch between parental concerns and physician recommendations in relation to exercise recommendations impacting cardiac safety in the population with CHD.[47] It seems that there is no correlation between the level of overprotectiveness provided by parents and the severity of their child's CHD diagnosis; however, many children (including those with simple heart murmurs) are found to have activity restrictions advised by their doctor.[43]

Further, educational materials should be provided to parents, schools, and teachers who are involved in the care of children with CHD to assist with enabling positive physical activity behaviours and developing exercise self-efficacy, while promoting inclusivity.[127] Teacher encouragement towards participation in physical activity during recess is shown to increase exercise self-efficacy and physical activity in healthy primary school–aged children.[127] Physicians and health care providers should consider seasonally appropriate activities to ensure that access to the recommended activity is available and adhered to in the long term.[95]

Family-based physical activity interventions. Participation in physical activity is more likely when a patient's chosen activity matches their physical ability and personal interests. Promotion of activity should be based around the child's exercise self-efficacy, activities they are interested in, and the ability of parents/siblings to provide support.[34,66] Clinicians and allied health professionals in activity promotion roles should provide support for barriers that may be faced in relation to activity.[66] Proven methods used to increase children's physical activity in the general population include goal setting and reinforcement, education to increase knowledge of physical activity, and changes to the family psychosocial environment.[128] One study found that regular exercise practiced from home may be an effective way to counteract reduced activity and increased body mass index for young patients living with CHD.[129] Goal setting and family planning can be a particularly useful strategy to increase physical activity by planning in a calendar or workbook: where, when, how, and what physical activity will be undertaken that week.[108,130,131] Children with increased support and encouragement from parents and siblings are more likely to be physically active,[35,111,132] as they often mirror parents and older siblings.[34,111] Hence, it is crucial for family members to model and encourage positive health behaviours to further engage children with CHD with long-term participation patterns.[34,35,111,133] Outdoor play in the general population is shown to increase physical literacy and habitual physical activity levels.[120,121,134] Each intervention should cater to the needs of the family and combine goal-setting techniques with reinforcement to increase motivation.[130,133]

Setting attainable activity goals and developing action plans to achieve these goals are critical, and these should be established based on availability of resources, the child's interest, and the family's ability to provide adequate support and encouragement.

Reducing recreational screen time. The increase in screen time among children has almost doubled in the last 2 decades and has been linked to reduced health outcomes.[135–138] Reducing recreational screen time can lead to an increase in physical activity engagement in children.[139] Effective strategies to reduce screen time include electronic TV monitoring devices, removing televisions from children's bedrooms, and utilizing contingent feedback systems—TV time is earned when positive health behaviours are engaged in.[140] Applying rules and time limits to daily screen time can also assist in reducing sedentary time and may provide more opportunities for active play. Although reducing screen time can be challenging for many families, efforts must be made to find alternative activities to screen-based tasks that can increase physical activity and exercise participation and reduce health risks for children.

Adults

Childhood and adolescence are key periods for establishing lifelong physical activity habits.[141] Adults with CHD who have positive physical activity experiences as children are more likely to develop positive attitudes towards activity and participate as adults.[34] Canadian adults now participating in activity reported minimal restrictions as children.[35]

Models of counselling for health behaviour change. A model often used while trying to increase physical activity participation is the self-determination theory. This theory focuses on the notion that humans have 3 basic psychological needs: autonomy, relatedness, and competence.[142] It also highlights the distinction between intrinsic and extrinsic motivation and how increased autonomy is associated with internalized motivation, which is crucial for behaviour change.[142] Self-efficacy is one of the core constructs of the social cognitive theory[143] and may be one of the keys to improving physical activity participation in the CHD cohort. To obtain mastery, another core construct of the social cognitive theory, activities within the capabilities of the patient should be encouraged including taking rests when required and participating in activities they are interested in.[144] Slow exercise progression in accordance with the guidelines and advice from the treating cardiologist should be followed to ensure safe and continual adherence.[145]

Motivational interviewing. Motivational interviewing techniques should be used by physicians and allied health practitioners to identify personal motivations and commitment to a specific goal in a safe environment, free from judgement.[146] It is important to note that motivational interviewing, when applied as a behavioural change technique on its own, is not always effective and often requires multiple sessions and accompanying physical activity prescription to be useful.[147–149] Although treating physicians may not have adequate time to engage in motivational interviewing, allied health professionals such as exercise physiologists should use this when appropriate. Utilization of motivational interviewing allows patients to verbalize their goals and identify what is important to them. This can also allow the health provider to understand which stage of change the patient is currently in and adjust recommendations accordingly.

Tailored approaches to conversation should be implemented depending on the level of importance of exercise, how ready they are to begin, and how confident they are in their own success.[150] A psychological intervention incorporating motivational interviewing is shown to increase physical activity in patients with CHD.[147] For patients in the precontemplation and contemplation stage, strategies should focus on cognitive aspects associated with behaviour change and education on the benefits of activity along with the negative impacts of inactivity and sedentary behaviour.[150,151] Interventions that focus on realistic goal setting, social support, and feedback appear to have the most beneficial outcomes for physical activity behaviour change.[148]

Education—exercise is safe!. Multiple studies have investigated the effects of exercise in people living with CHD and found no reports of serious adverse events that were directly related to exercise testing or training, albeit in highly selected cohorts where participants were clinically stable at the time of intervention.[8,16,101,152,153] Important considerations are ventricular function, coronary lesions, coarctation/dilation of the aorta, outflow tract obstruction, valvular function, severe cyanosis, pulmonary hypertension, and arrhythmias.[25] As evidence continues to demonstrate physical activity for this population as safe when appropriately prescribed, tools based on the current recommendations should be developed to assist treating physicians with prescribing exercise efficiently and thoroughly during consultations, alongside psychological service referrals to assist with anxiety and body image concerns.

Access to resources. As it is only recent that the focus has shifted to exercise prescription and promotion rather than restriction,[107] relevant resources are lacking. For many individuals, reduced access to resources is a barrier to completing physical activity. With the closure of gyms and other fitness facilities during the COVID-19 lockdown period, the use of public spaces for sport and physical activity increased by 5.2% from 2019 to 2021. Australian participation statistics show that physical activity participation in adults overall is currently higher than that before the lockdown period.[154] Although the pandemic resulted in negative impacts on physical and mental health, it created opportunities to develop at-home exercise routines and advance the use of telehealth programmes for medical treatment. Virtual physical activity became one of the top 20 activities during the pandemic with an estimated 935,000 people using online platforms to complete activity. Stay-at-home orders during the pandemic eliminated many outdoor play opportunities for children and their families, while also increasing screen time.[155,156]

A positive outcome that occurred as a result of the COVID-19 pandemic and lockdowns is the development and increasing use of telehealth programmes and online exercise interventions.[157] Telehealth has also been used as an alternative to in-person consults[158] and as a way to provide information and education to families with children living with CHD after surgery, which has been found to reduce loss to follow-up and the care burden for parents.[159] The pandemic provided an opportunity for the development of at-home interventions due to the closure of gyms and limitations on group activities. Physicians and health educators can use these online resources for their patients who may not have adequate access to traditional physical activity facilities.[157]

Body image. It is understandable that individuals with CHD, particularly those who have undergone cardiac surgery, may struggle with a poor body image and low self-esteem. This can result in avoidance of activities that may involve scar exposure.[72] Surgeons and health practitioners are encouraged to discuss scar healing and expectations after cardiac surgeries to mentally prepare patients and their families for what is to come.[160,161] Disruptions to "normal" development in childhood and adolescence, sometimes resulting in smaller stature, can lead to lower self-esteem in children with CHD.[162] To improve body image and self-esteem, individuals should be encouraged to participate in activities they enjoy with people they feel supported by. This may involve seeking out supportive environments and communities, such as support groups where shared experiences are discussed.[163] Seeking professional support from a therapist or counsellor can be beneficial in addressing negative body image and low self-esteem, where tools and strategies can be provided to assist with confidence building. Strategies that can be useful in reducing poor body image are changing negative body language, using guided imagery, and exposure therapy.[164] By prioritizing self-care and seeking support, individuals with CHD can learn to embrace their scars and feel more comfortable participating in activities where their scars may be visible to others.

Conclusions

Physical activity promotion from childhood with the support of physicians, health systems, family, and teachers is critical for building healthy habits and encouraging long-term adherence. The importance of developing physical literacy from a young age cannot be underestimated, especially among those living with CHD. Providing clear and specific patient-centred advice that focuses on promotion, rather than restriction of activity, can improve exercise self-efficacy, habitual physical activity, and thereby quality of life in people living with CHD. Empowering patients by providing concise education and access to support networks will assist in overcoming the barriers they face when trying to participate in physical activity.

Ethics Statement

Not applicable.

Patient Consent

The authors confirm that patient consent is not applicable to this article. This review article did not require consent from patients.

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