



Original Article

# Perceptions of Healthy Lifestyles Among Children With Complex Heart Disease and Their Caregivers

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## ABSTRACT

**Background:** Children with complex heart problems may be at higher risk for sedentary lifestyle morbidities than their healthy peers. This project examined perceptions, barriers, and supports that influence healthy active lifestyles among children with complex heart problems and their caregivers, to enable effective health and quality-of-life interventions.

**Methods:** Inductive thematic analysis was conducted of semi-structured guided discussions from 6 focus groups (young child [n = 2]; older child [n = 4]; parents of young child [n = 4]; parents of older child [n = 4]; pediatric cardiologist [n = 5]; pediatric cardiac nurse [n = 5]) and individual interviews with 7 parents, 5 parent/child dyads, 2 adults with complex heart problems, 6 pediatric cardiologists, 3 pediatric cardiac nurses, 4 pediatric cardiology mental health professionals, and 14 recreation professionals.

**Results:** Four interrelated themes were identified: (i) "It takes a village"—coordinated and collaborative interdisciplinary support; (ii) clear healthy lifestyle communication among children, families, and professionals is critically important; (iii) Creating supportive environments by building professional expertise; (iv) inspiring healthy

## RÉSUMÉ

**Contexte :** Les enfants atteints d'un trouble cardiaque complexe pourraient être exposés à un risque plus élevé d'états morbides associés à la sédentarité que leurs pairs en bonne santé. Notre projet visait à étudier auprès d'enfants atteints d'un trouble cardiaque complexe et de leurs aidants les perceptions, les obstacles et les mesures de soutien qui influent sur l'adoption d'un mode de vie actif sain, afin de mettre en place des interventions efficaces pour améliorer la santé et la qualité de vie de ces patients.

**Méthodologie :** Nous avons mené une analyse thématique inductive comprenant des discussions dirigées semi-structurées auprès de six groupes (jeunes enfants [n = 2]; enfants plus âgés [n = 4]; parents de jeunes enfants [n = 4]; parents d'enfants plus âgés [n = 4]; cardiologues-pédiatres [n = 5]; infirmières en cardiologie pédiatrique [n = 5]) et des entrevues individuelles auprès de 7 parents, 5 dyades parent-enfant, 2 adultes atteints d'un trouble cardiaque complexe, 6 cardiologues-pédiatres, 3 infirmières en cardiologie pédiatrique, 4 professionnels de la santé mentale en cardiologie pédiatrique et 14 professionnels du loisir.

Children born with complex heart problems (CHPs) are those diagnosed with serious hemodynamic disturbances, arrhythmias, or cardiomyopathies, which are often associated with hypoxia, congestive heart failure, and metabolic acidosis prior

to treatment.<sup>1,2</sup> Research indicates that these children have an increased risk for secondary morbidities affecting their physical and mental health.<sup>3,4</sup> For all children, including those with cardiac diagnoses, their physical and mental health and quality of life are intimately connected to physical activity, healthy eating, and mental well-being, known collectively as healthy active living.<sup>5,6</sup>

Physically active play is essential for normal childhood growth and development.<sup>7</sup> It also decreases long-term atherosclerosis risk, increases endurance, strength, and flexibility,<sup>8</sup> reduces sedentary lifestyle health risks (eg, diabetes, obesity), helps maintain a healthy body weight,<sup>9</sup> and improves self-efficacy, self-esteem, and academic performance.<sup>10,11</sup> Children with CHPs are typically less active than their

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**Ethics Statement:** This study was approved by the Research Ethics Boards at The Hospital for Sick Children (SickKids), and the Children's Hospital of Eastern Ontario.

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See page 862 for disclosure information.

lifestyles in the children's own environments. All groups identified a need to improve knowledge about childhood heart conditions among education and recreation professionals and to encourage effective communication between healthcare professionals and families. Participants indicated that these changes would support families, educators, and recreation professionals in engaging children with heart problems in healthy lifestyles in home, school, and community settings.

**Conclusions:** Important healthy lifestyle barriers were identified within individuals and in their interactions. There is a profound need to enhance knowledge of childhood heart conditions and improve interactions among key stakeholders—children and families, educators, and recreation and healthcare professionals.

peers<sup>12</sup> and often have motor skill delays.<sup>13</sup> Inactive childhoods and motor skill deficits triple the risk of sedentary lifestyles over the long term.<sup>14</sup> Inactive lifestyles among children with CHPs have historically been linked to disease-specific determinants, such as reduced cardiorespiratory capacity.<sup>15</sup> However, recent research suggests a relatively weak association between severity of congenital heart disease and physical activity participation.<sup>12,16</sup> These results suggest that children with heart problems may experience healthy lifestyle limitations unrelated to their cardiorespiratory physiology.

Compounding the health risks associated with sedentary lifestyles and chronic illness in children are concerns regarding growth failure, obesity, and physical activity—related injury risk.<sup>3,17</sup> Children with CHPs often are fed energy-dense food in infancy to enable proper growth and provide sufficient calories for the increased energy expended secondary to the disease.<sup>17</sup> Even with nutritional supplementation, the growth of these children is often much slower than that of their peers.<sup>3</sup> After the heart function is improved, these habits and developed tastes for energy-dense food leave these children at higher risk for overweight and obesity in adolescence.<sup>18</sup>

Previous investigations of the biopsychosocial factors that affect healthy active lifestyles among children with cardiac problems are limited, and they have been conducted separately among patients, families, or healthcare providers. As a result, the data focus on individualistic discourses to the exclusion of the very interactive processes that underlie the adoption of a healthy active lifestyle. Previous studies have identified both limited self-efficacy and parental anxiety as important factors associated with participation.<sup>19–23</sup> In addition, many cardiologists restrict the physical activity of children with CHPs to some degree,<sup>24</sup> and confusion can arise because reports of activity restrictions have been found to differ among parents, cardiologists, and the child's medical record.<sup>25</sup> These findings and clinical experience suggest that there are many more factors that impact the healthy lifestyle habits of these children.

**Résultats :** Nous avons dégagé quatre thèmes interreliés : i) « il faut tout un village » — soutien interdisciplinaire coordonné et axé sur la collaboration; ii) communication claire de ce qu'est un mode de vie sain entre enfants, familles et professionnels (élément d'une importance cruciale); iii) création de milieux favorables par le développement des expertises professionnelles; iv) stimulation de l'adoption d'un mode de vie sain dans les milieux que fréquentent les enfants. Tous les groupes interrogés ont signalé la nécessité d'améliorer les connaissances des professionnels de l'éducation et du loisir quant aux problèmes cardiaques de l'enfance et d'encourager une communication efficace entre les professionnels de la santé et les familles. Les participants ont indiqué que de tels changements aideraient les familles, les enseignants et les professionnels du loisir à donner aux enfants atteints d'un trouble cardiaque la chance d'adopter un mode de vie sain à la maison, à l'école et dans la communauté.

**Conclusions :** Des obstacles importants à l'adoption d'un mode de vie sain ont été cernés à l'échelle individuelle et sur le plan des interactions. Il existe un besoin profond de rehausser les connaissances en matière de troubles cardiaques de l'enfance et d'améliorer les interactions entre les principaux intervenants — les enfants et leurs familles, les enseignants et les professionnels de la santé et du loisir.

Clarifying information about appropriate nutrition and exercise has been shown to increase healthy behaviours.<sup>26</sup> Based on data indicating that children with heart problems are less active than their peers, a proactive approach to the promotion of active lifestyles at every clinical encounter is recommended,<sup>27</sup> although this method is not yet widely established in practice. To better understand the complex relationships among the biopsychosocial factors impacting the healthy active lifestyles of children with CHPs, this study sought to explore the perceptions of children with CHPs, their parents, healthcare professionals, and recreation professionals in regard to the issues, supports, and resources that influence their ability to achieve healthy active lifestyles for these children.

## Methods

### Participants

Purposive sampling was used to recruit boys and girls with a diverse range of cardiac diagnoses, parents of children with CHPs, healthcare professionals caring for pediatric cardiac patients, and community recreation professionals. Eligible participants who met the inclusion/exclusion criteria (Table 1) were recruited to participate in focus-group discussions or individual interviews. This study was approved by the Research Ethics Boards at The Hospital for Sick Children (SickKids), Toronto, Ontario, Canada, and the Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada.

Children with CHPs, parents of children with CHPs, and healthcare professionals were recruited through the pediatric cardiology clinics at the Children's Hospital of Eastern Ontario (Ottawa, Ontario, Canada), and family and professional networks. Children were required to be cleared to participate in physical activity and have a stable health status (ie, not be acutely ill), as determined by the responsible cardiologist. Children with significant developmental delays

**Table 1. Recruitment criteria for participants**

Participants	Criteria
Children with complex heart problems	<ul style="list-style-type: none"> <li>Have a heart condition requiring ongoing follow-up</li> <li>Be able to verbally answer questions and express opinions in English</li> <li>Be between 4 and 17 years of age</li> <li>Be able to provide informed consent or assent to participate</li> </ul>
Parents	<ul style="list-style-type: none"> <li>Have a child with a heart condition requiring ongoing follow-up</li> <li>Be able to provide informed consent to participate</li> <li>Be able to verbally answer questions and express opinions in English</li> </ul>
Healthcare professionals	<ul style="list-style-type: none"> <li>Have professional experience working with children with heart problems requiring ongoing care, as a physician, nurse, dietician, social worker, or other healthcare professional</li> <li>Be able to provide informed consent to participate</li> <li>Be able to verbally answer questions and express opinions in English</li> </ul>
Recreation professionals	<ul style="list-style-type: none"> <li>Have professional experience working with children in a community physical activity, recreation, or sport setting</li> <li>Be able to provide informed consent to participate</li> <li>Be able to verbally answer questions and express opinions in English</li> </ul>

impacting their physical activity participation were excluded from this research. Community recreation professionals were recruited through Variety Village, an inclusive sport training and fitness centre (Toronto, Ontario, Canada) and the City of Toronto Division of Parks, Forestry, and Recreation (Toronto, Ontario, Canada). Recruitment measures utilized for this study include flyers posted in patient areas, and information distributed through professional and community support networks (eg, KidPACES, Helping Hearts).

Families/healthcare professionals/recreation professionals who expressed interest in the study were contacted by telephone by a member of the research team who determined eligibility and whether the participant could attend a focus group. Individuals unable to attend the appropriate focus group were offered the opportunity to contribute their perspectives during an individual interview, either in person or by telephone. When participants arrived for the interview or focus-group session, the researcher obtained informed consent/assent for participation, as appropriate to the age of the participant. All children were informed of the study in the presence of their parents and were required to give written consent or verbal assent prior to participation. All adult participants provided written informed consent.

### Data collection: interviews and focus groups

This exploratory study employed an inductive qualitative design using focus-group discussions and semi-structured interviews. An inductive approach was used to analyze the qualitative data in order to directly obtain the study participants' unique perceptions on "healthy active living" without imposing preconceived ideas, categories, or responses based on theoretical perspectives or previous research.<sup>28</sup> Participation in a

focus group required 60 to 90 minutes, and an interview required 30 to 60 minutes. For the focus groups/interviews with children, the length of the discussions, wording of questions, and activities conducted varied, depending on the age of the children. Separate focus groups were held for young children, adolescents, parents of young children, parents of adolescents, pediatric cardiologists, and pediatric cardiology nurses. Focus groups were conducted until data saturation was achieved, ie, "the point in data collection and analysis when new information produces little or no change to the codebook."<sup>29</sup>

The initial activity for each focus group, including those with children, was a group discussion of the "rules" for the group, so that everyone could participate and enjoy the discussion. Having the group members identify the rules, with prompting from the researchers as needed, emphasized to the participants the importance of treating everyone's comments with respect and keeping the discussions confidential. Each focus group began and ended with an explanation from the researcher that what was said and who was present should be considered confidential, with participants encouraged to maintain that confidentiality.

A semi-structured guide was designed for the focus-group/interview discussions, based on the study objectives and existing scientific evidence (Table 2). Based on the literature surrounding healthy lifestyle behaviours, the key factors for consideration were identified as the participant's understanding of "healthy active lifestyle," perceived barriers and facilitators, knowledge of existing resources, concerns about adopting healthy lifestyle behaviours, and perceptions of how existing supports could be improved. Questions were then developed to probe each of these factors, with the wording adjusted to suit each stakeholder group (children, parents, healthcare and recreation professionals). The draft questions were then pilot tested for comprehension with 3 to 5 children and their parents. Members of the research team reviewed the question wording for healthcare and recreation professionals. Broad and open-ended questions were prioritized, to enable participants to discuss the concept of "healthy active living" from their own perspectives. Prompts to encourage further discussion identified physical activity, healthy eating, and injury prevention—these topics reflect the scope of the funding agency. The guide included questions about how children, parents, and professionals perceived healthy active lifestyles, the existing resources they used, resources they would like to have, and perceptions of the role of professionals in promoting healthy active lifestyles. Specific questions regarding barriers and facilitators to physical activity were added because of the existing evidence that children with cardiac diagnoses are less active than their peers. The interview questions were reviewed and approved by the research team and all collaborating organizations. Craft activities and stories were used to facilitate the discussions with young children. The focus groups and interviews were digitally recorded, and the recordings were transcribed for data management using NVivo qualitative research software (Version 12, QSR International).

### Data analyses

All transcription of the study audio tapes took place at the Children's Hospital of Eastern Ontario Research Institute.

**Table 2. Question guide for focus groups and interviews**

Categories	Questions for parents	Questions for children	Questions for healthcare professionals	Questions for recreational professionals
Meanings of healthy active lifestyle	What does a healthy lifestyle mean for your child?	What do you like to do when you're being physically active? What foods do you think are healthy and good to eat? What foods do you think are not healthy and should be eaten just as a special treat?	What does a healthy lifestyle for your patient mean to you?	How would you describe a successful physical activity opportunity for children?
Supports, resources, barriers to engage in a healthy active lifestyle	What people, resources, or activities have improved/decreased your child's physical activity and ability to engage in a healthy lifestyle? What supports/resources /services have been beneficial for you/your child in relation to your child's ability to: a) be physically active, b) eat a healthier diet, or c) reduce the risk of injury during physical activity?	Can you tell me about the people or things or reasons that make it easier for you to be physically active?	What people, resources, or activities have improved/decreased your patient's ability to be physically active and engage in a healthy lifestyle? As a healthcare professional, what do you think are the reasons children with heart problems are denied the opportunity to participate in physical activity?	What helps children to be physically active and engage in a healthy lifestyle? As a recreation professional, what do you think are the reasons children with heart problems do not participate in community physical activity opportunities?
Concerns about engaging in physical activity	What concerns do you hear from others about your child engaging in physical activity?	Some kids say that it's hard for them to participate in physical activity. Can you think of what might make it hard for you or other kids your age? When you are active, what do you do so that you don't get hurt? Some kids say that they get hurt when they are active, or that they are worried that they might get hurt. What things do you think kids worry about when they think about physical activity?	What concerns about physical activity do you hear from your patients and their parents?	What concerns about including children with heart defects in physical activity do you hear from parents, your colleagues, or other participants?
Changes that could help or resources required to promote healthy active lifestyles	If you could change or add to the supports/resources/ services that you/ your child received, how would they have been different in relation to: a) being physically active, b) eating a healthier diet, or c) reducing the risk of injury during physical activity? What supports/ resources/services do you think you/your child will need in the future so that your child can: a) be physically active, b) eat a healthier diet, or c) reduce the risk of injury during physical activity?	What could your family do to help you be more active or eat healthier? What could the doctors and nurses do to help you be more active or eat healthier? What could the people in your community, like your teacher or coach, do that would help to make physical activity more fun?	What supports or services would benefit you or would you like to have to better enable your patients to: a) be physically active, b) adopt a healthier diet, c) reduce their physical activity injury risk?	What supports or resources do you know about that you think would help a child with a complex heart problem to successfully: a) engage in physical activity, b) eat healthier, c) reduce the risk of physical activity –related injuries?

*Continued*

Table 2. Continued.

Categories	Questions for parents	Questions for children	Questions for healthcare professionals	Questions for recreational professionals
Advice to other groups	<p>What advice would you give to health professionals who care for your child regarding how they can help to encourage a healthy lifestyle and physical activity for your child?</p> <p>What advice would you give to recreational professionals in your community regarding how they can help to encourage a healthy lifestyle and physical activity for your child?</p>	<p>If you could talk to your friends and family about physical activity and healthy eating, what would you want them to know?</p>	<p>What advice would you give to parents, other health professionals, and recreational professionals who care for your patient in regards to enabling a healthy lifestyle?</p>	<p>What advice would you give to parents or health professionals about how to get their child involved in community recreation opportunities?</p>

The transcripts were read line by line, and quotations were coded to form the basic units of analysis.<sup>23</sup> The content coding identified key concepts related to optimizing healthy active lifestyles. Thematic analysis was completed inductively, employing a process of close scrutiny of the text to understand the perceptions of participants.<sup>24</sup> Interview transcripts were read and analyzed both horizontally (for the content of one focus group/interview) and vertically (for common and diverging content among all focus groups and interviews). Content was initially analyzed separately by 2 coders (S.S., J.M.), with discussions used to resolve coding discrepancies. Codes, subcategories, and categories were compared to the transcribed text to ensure coherence and grounding in the data. Triangulation of responses from patients/families, healthcare professionals, and recreation professionals contributed to the integrity of the data. A concept map was created to summarize the themes from each stakeholder group and the current and desired relationships among them.

## Results

A total of 56 adults (15 men) and 11 children and teens (6 boys) with CHPs participated in this study. Table 3 shows the age, sex, and diagnoses for the child participants. Data were obtained from 6 focus groups with different participant categories: young children with CHPs (n = 2); older children with CHPs (n = 4); parents of young children (n = 4); parents of older children (n = 4); pediatric cardiologists (n = 5); and pediatric cardiac nurses (n = 5). In addition, individual interviews were conducted with 7 parents, 5 parent and child dyads, 2 adults with CHPs (who contributed their perceptions of healthy lifestyles as a child with CHPs), 6 pediatric cardiologists, 3 pediatric cardiac nurses, 4 pediatric cardiology mental health professionals, and 14 recreation professionals.

Four interrelated themes were identified: (i) "It takes a village"—coordinated and collaborative interdisciplinary support; (ii) clear healthy lifestyle communication among children, families, and professionals is critically important; (iii) creating supportive environments by building professional expertise; (iv) inspiring healthy lifestyles in the children's own environments. Each theme had a number of sub-themes, as described below.

### "It takes a village"—coordinated and collaborative interdisciplinary support

Participants identified ways through which they or other caregivers could directly affect children's healthy active lifestyles. All stakeholder groups indicated that they need to act in a coordinated and cohesive manner to support one another's actions and that no one can achieve the desired health behaviours without the support of others. For example, parents and children perceived that the eating and physical activity behaviours of parents have a strong influence on children's lifestyle choices:

*"I think that's something that you try to incorporate within the whole family and not just him as well. . . he eats exactly what we eat . . . we don't have a lot of snacking going on you know. . ."*—Parent 24

*". . . my parents take us outside a lot and they also make eating veggies mandatory at every meal. I don't have a choice. If I do not, I lose a privilege so I eat them!"*—Child 6

Parents and recreation professionals indicated that schools play an important role in promoting healthy active lifestyles. They also suggested that schools should provide programs that cater to the needs of children with CHPs in an inclusive environment:

*“Um, well school does a good job on that, health education—they’ll come home with the food groups and all that. And she can say what she wants, but it’s getting onto her about it. That’s about it, I think school’s about the only place other than home.”*—Parent 3

*“... school should be providing physical activity in a safe and healthy environment for kids to be able to be active in... And again people who, um, you know, having somebody who is knowledgeable about physical activity, and how to get children engaged, how to get them playing together.”*—Recreation Professional 3

Similarly, healthcare professionals emphasized that recreation professionals should deliver programs that can engage children who have different levels of physical fitness. In addition, recreation professionals themselves identified their important role as a link between family, doctors, community, and school.

*“Well I just think there is... in all these different sports there is the elite you know the elite level for all of these sports, but there is also the community level and the school level and the fun level, and we have to make sure there is a place for every kid, whether they are athletes or not, umm to get involved in team sports, individual sports.”*—Healthcare Professional 22

*“I feel as a recreationist, that my role would be to kind of guide them towards the doctor side, professional side and let that doctor be the stepping stone, and then coming back to us with the information, here is what we have, and this is what we’d like to do and moving forward that way.”*—Recreation Professional 6

### Clear healthy lifestyle communication among children, families, and professionals is critically important

The need for clear, healthy active lifestyle conversations between families and professionals was identified by all adult participants. Children with CHPs and their families need to be more aware of the children’s need for a healthy lifestyle and their physical abilities. Clear, accurate, and reliable information can help families make the right choices regarding healthy active lifestyle habits. Recreation professionals and parents also felt that good verbal communication among family members would help them understand the children’s interests, health, and abilities:

*“I would highly suggest that they talk to the kids, and ask the kids how they’re feeling and what they would like to see, because a lot of times kids actually—and especially if they can verbalize it—they’re the ones who can have really great ideas and creative ideas... ”*—Recreation Professional 4

*“Preach to your patient to be to be healthy and have regular exercise... the second thing is to try to portray it in a positive light—not as something that’s hard or difficult—oh, you know you gotta really work at it—but try and portray it in a fun light and also to make it part almost of a prescription, the same way you as you’d write a medication.”*—Healthcare Professional 3

An important factor that was frequently mentioned by participants was the effect of fear among parents, teachers, and recreation professionals regarding physical activity participation

for children with CHPs, which is often a result of a lack of effective communication, and uncertainty about what might be safe for them.

*“Not really—I mean his teachers always worry because as soon as you go in at the beginning of the school year and say, ‘oh yes, my child has a heart condition’ [laugh]. . . oh ya there’s always that . . . what’s he allowed to do, what’s he not allowed to do, what should I watch for, and then usually they’re a little worried and concerned what if something happens to him. . . ”*—Parent 19

On the other hand, healthcare and recreation professionals expressed their concern regarding parents being too protective, and cultural influences on fear:

*“One what I hear from the parents is fear—one, fear for their child—maybe they are going to be too active—they don’t know the child hasn’t been active in a long time. Because there is that fear of being over active if possible. Either the instructor may not have enough knowledge or they may not feel comfortable with, you know...”*—Recreation Professional 1

### Creating supportive environments by building professional expertise

Creating an environment that promotes healthy active lifestyles in children with CHPs requires coordination among all of the professionals who engage with children with CHPs on a day-to-day basis. This includes teachers, recreation professionals, and healthcare professionals. For example, children and parents felt that a stronger connection between healthcare professionals and teachers would help teachers to be better informed about the child’s physical capacities.

*“I think you know one thing that would help in my opinion is... I guess if we had something to take to the teacher... okay... to say you know these are signs or symptoms or umm you know, what we should do, we should do what he shouldn’t do...if we had abhh a form or a brochure or something about [child’s name]’s condition that we could pass along to the teacher...”*—Parent 19

*“They [teachers] usually have a set opinion on something... [we need a] website or something like that to inform them that this [heart condition] is a valid excuse... like doctor’s note...that’s really all you need...so when I stop, just let me stop.”*—Child 28

Other strategies suggested were to educate professionals through websites and programs.

*“If you have a website you need to advertise it so you need a poster... you kinda need both... you should have something to make teachers more aware that we have a heart condition so that we can sit off when we need to.”*—Child 32

*“We don’t have teachers who are trained in first aid, or who know a lot of anatomy, physiology... so the minute they see a child with a heart problem they either ignore it, and the child is doing more than they should, or they over compensate, and the child isn’t doing anything. The second barrier is families—getting them to understand that we want to normalize their children as much as possible.”*—Healthcare Professional 26

In addition to training professionals, it was suggested that there be a physical activity counselor as a part of the healthcare system, who is specifically trained to evaluate and recommend appropriate activities and exercise levels:

*“I think very often parents have questions regarding to what their kids are allowed to [do], and I think having someone who can support you*

**Table 3. Child participant demographics**

Child ID #	Age (y)	Sex	Diagnoses
3	17	Female	Fontan single ventricle
6	8	Male	Not disclosed
17	10	Female	Hypoplastic left heart syndrome, post-Fontan
20	10	Female	Transposition of great arteries, arterial switch, aortic regurgitation
21	9	Male	Catecholaminergic polymorphic ventricular tachycardia
22	17	Female	Partial anomalous pulmonary venous connection, ectopic atrial rhythm
25	6	Male	Catecholaminergic polymorphic ventricular tachycardia
26	14	Male	Bilateral pulmonary artery stenosis, aortic stenosis, ventricular septal defect, pacemaker
27	9	Female	Prolonged cardiac repolarization
28	7	Male	Catecholaminergic polymorphic ventricular tachycardia
32	11	Male	Hypertrophic cardiomyopathy, mitral and aortic regurgitation

ID, identification.

*to explain what type of exercises you actually can do. I think having someone who can actually give advice, and give a better explanation of what exercises they can do, would be a great help.* —Healthcare Professional 1

### Inspiring healthy lifestyles in the children's own environments

Participants suggested different strategies to build supportive healthy active living environments at school, at home, and in the community. For example, seeing and interacting with “experts” or people who are achieving a healthy active lifestyle were suggested to influence both teachers and children.

*“[Name] loves when a guest speaker comes to school—like recently, a pediatric dentist came to his school to talk about healthy dental practice. Seeing us being physically active and eating well... good food and exercise work hand in hand.”* —Parent 6

*“Well there have been inspirations...okay...or like I was recently watching an ad for a video camera that was an absolutely amazing video camera but it showed some very very athletic people doing amazing stuff and it was inspiring...it really was amazing watching people do what they do.”* —Child 26

Healthy active lifestyle information and resources, such as information on available programs and opportunities, need to be taught in school and available from the healthcare professionals who care for children with CHPs.

*“It is a struggle. I have several patients in my practice who want to lose weight ... and [they] know that it's a diet thing. . . know they don't want to be more active and for me to try to help them, as a cardiologist—I feel like I have no resources for that.”* —Healthcare Professional 8

*“School probably is one of the key parts, because they spend most of their day there, in a structured environment. The structured environment of the school provides an opportunity, a place where kids can learn, so that, that I think is essential. And promoting those opportunities.”* —Recreation Professional 11

### The role of caregivers in encouraging children's healthy lifestyles

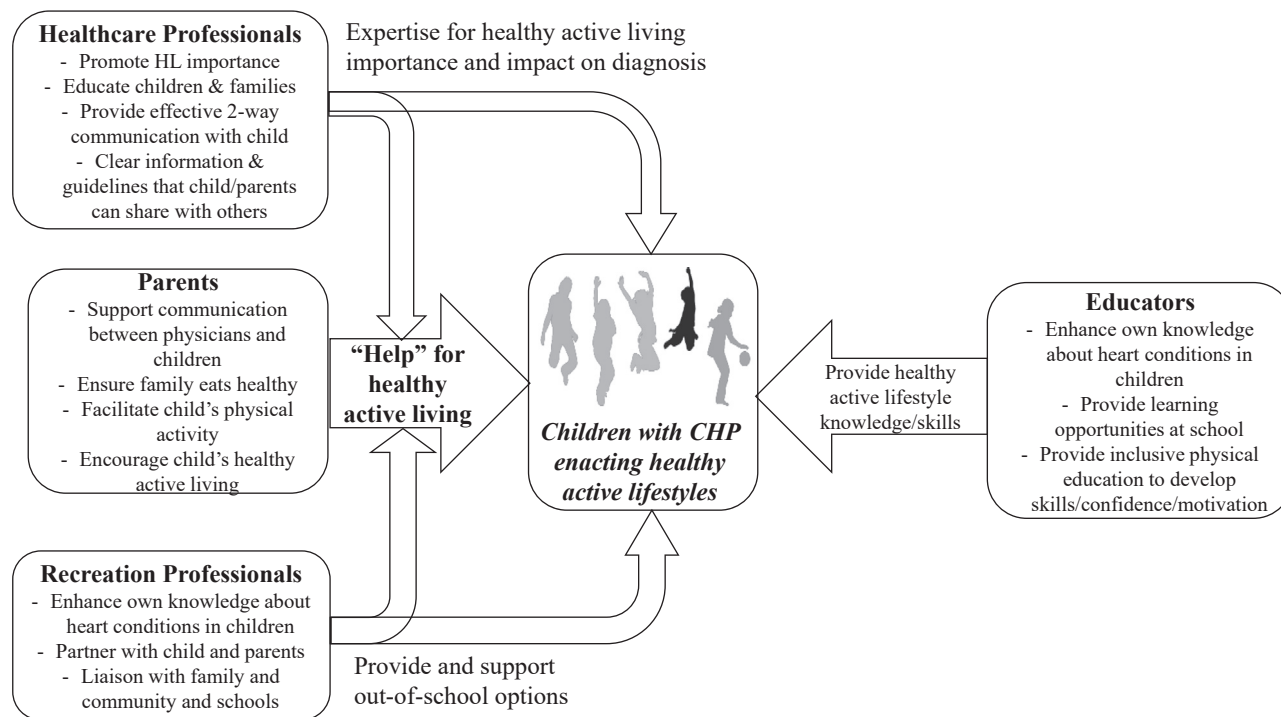
Figure 1 depicts what study participants suggested should be the roles and responsibilities of parents, teachers, and healthcare and recreation professionals in facilitating the promotion of healthy lifestyle behaviours among children with CHPs. Educators were not interviewed in this study, but they were identified by study participants as an integral component of the dynamic interactions among children, families, and health and community professionals in promoting a healthy active lifestyle among children with CHPs.

### Discussion

The present study enhances our understanding of the healthy active lifestyle perceptions of children with CHPs, their parents, and the healthcare and recreation professionals who support them. Previous research focused on exploring the perceptions of just one of these groups to identify the psychosocial barriers and enablers for promoting physical activity to children with heart problems.<sup>22,23</sup> Our study adds novel findings to the current evidence by comparing and analyzing the similarities and contrasting views among these stakeholder groups. Four main themes were identified that describe the barriers and enablers influencing healthy active behaviours among these children. Children indicated that parent health and activity behaviours were important as models for their own behaviours. Parents and professionals emphasized the importance of support and encouragement provided through schools. The important barriers were: (i) lack of communication among different caregivers (families, clinicians, and teachers) and children with CHPs; (ii) lack of clear understanding of physical abilities among children with CHPs, family members, and teachers; and (iii) lack of knowledge among healthcare professionals of the physical activity programs/options in the community.

As shown in Table 3, the child participants reflected our purposive sampling strategy that sought participants who were diverse in their diagnoses and in the severity and types of their symptoms. Although it is assumed that the lifestyle implications would differ by diagnosis, there is also significant lifestyle heterogeneity among children with similar diagnoses, owing to variability in personal, social, and environmental factors.<sup>21,22,30</sup> However, virtually all children who are followed in pediatric cardiac clinics are more similar to one another than they are different in their increased risk for sedentary lifestyle morbidities, even though the contributing factors may be different for each child. Therefore, we chose to understand their perspectives using the common “lens” of living with a CHP, in order to enable the research team to identify perceptions of healthy active lifestyles that contribute to the decreased activity levels observed among all of these patient groups. Purposively selecting such a diverse group of participants enabled us to understand common concerns and identify potential intervention targets that could be broadly applicable.

These factors (barriers and enablers) emphasize the important roles of caregivers in promoting a healthy active lifestyle among children with CHPs. They also indicate the need for better coordination of care within families (children



**Figure 1.** Thematic schema outlining the roles and coordination among different caregivers to promote a healthy active lifestyle among children with complex heart problems. CHP, complex heart problems; HL, healthy living.

and parents), and between families and professionals (clinicians, teachers, and recreation professionals) to ensure children's engagement in healthy active behaviours throughout childhood and adolescence. Figure 1 clearly describes how better knowledge of heart conditions among parents, teachers, and recreation professionals, and improved exchange of information among professionals, and between professionals and parents, can significantly contribute to a better health-related quality of life for children with CHPs. Our findings demonstrate both similarities and differences in the perspectives of children, parents, and professionals, as discussed below.

Children with CHPs perceived parents as playing pivotal roles in supporting and encouraging them to be active and eat a healthy diet. Child–parent relationships have been shown to be critical to the physical activity experiences of children and adolescents living with congenital heart disease.<sup>31</sup> Positive attitudes of parents, particularly mothers, toward physical activity among children with CHPs have been shown to have a strong correlation with the physical activity recommendations provided by cardiologists.<sup>27</sup> Similarly, previous research also supports the potential role of parents in influencing dietary behaviours in their children.<sup>26</sup> In our study, most parents were confident in expressing their knowledge and awareness of healthy eating through the available food guides and school food books. However, previous research suggests that sometimes parents might underestimate the requirement for further education, or rely on outdated information on feeding practices.<sup>26</sup>

Parents expect physicians to provide guidelines and share information with them so that they clearly understand their children's capacities. This study identified the importance of clear communication pathways—all adult groups (parents,

healthcare professionals, and recreation professionals) acknowledged the need for not only information sharing about physical activity but also advocating for all aspects of the child's healthy active lifestyle. Similar communication pathways have been emphasized previously by McCrindle et al., Moola et al., and Bar-Mor et al. for facilitating physical activity among children with CHPs.<sup>12,19,21</sup> However, healthcare professionals indicated that, unlike the option to refer patients to a dietician for healthy eating support, they cannot easily refer patients to a kinesiologist and that when trying to counsel patients about physical activity, they are often at a loss for information on available physical activity resources and programs. This issue emphasizes the need to develop appropriate supports that would better enable healthcare professionals to carry out their healthy lifestyle education and advocacy roles, particularly in relation to the physical activity component, because it is important that each child/family has accurate information for their individual circumstance. In a previous study in which interviews were conducted with 7 clinical caregivers representing different disciplines (medicine, nursing, social work, exercise physiology, child-life specialist, physical therapy, and occupational therapy), these specialists suggested that the public mass media often represents children and youth with cardiac issues as being excessively at risk during physical activity.<sup>21</sup> However, the media in this study were portrayed as providing positive role models and being key resources in influencing healthy active lifestyles.

Other important links in these communication pathways are recreation professionals, teachers, coaches, and sport professionals, who are portrayed as significant sources of verbal persuasion for increasing children's self-efficacy toward sport and physical activity.<sup>19,21</sup> This study contributes to the



evidence by understanding the perceived roles of recreation professionals in promoting healthy active lifestyles among children with CHPs, something that has not been explored in previous research (Fig. 1). Parents and healthcare professionals discussed recreation professionals as being key players for promoting active play outside of the school setting. Recreation professionals could be a great avenue by which parents can communicate their interests and needs, more generally, in the planning and delivery of family and individual recreation options, particularly those that include children with medical conditions.<sup>32–34</sup>

Overall, our findings reveal the challenges in promoting healthy active lifestyles at an individual level for children with CHPs. This study used a strong methodological approach by triangulating the issue in detail from different perspectives. Data collection and analysis were performed by different members of the research team to minimize researcher bias. We used both in-depth interviews and focus groups to extract detailed information on healthy active lifestyle perceptions among these children. Future studies could use a mixed-methods approach to estimate the associations between the various factors and the adoption of healthy active lifestyle behaviours.

### Limitations

Study participants were a heterogeneous sample of patients and families identified by clinicians as well as professionals who volunteered through the collaborating organizations. The findings, therefore, should not be interpreted as a reflection specific to any diagnostic group. Similar themes emerged from patients and families regardless of the specific heart defect, suggesting that healthy active living issues and supports are similar for all children with CHPs. In considering these results, it must be considered that those who volunteered for this study may or may not be representative of the broader population of patients, parents, and recreation and healthcare professionals. We reached saturation with the interviews and discussions conducted with 33 patients/families and 37 professionals. The fact that no new themes emerged during the last interviews would, according to qualitative research theory, suggest that all of the major points of view were represented among the responses. This study did not explore the perspectives of teachers, who participants indicated make a substantial contribution to the promotion of healthy active lifestyles among all children, including those with CHPs.

### Conclusions

The proposed thematic schema (Fig. 1) depicts roles of different caregivers in promoting healthy active lifestyles among children with CHPs. Research is needed to further develop this schema, especially from the perspective of teachers, and test the impact of interventions based on these relationships. Respondents clearly saw strong, sustained relationships among different caregivers as being key for promoting physical activity and healthy behaviours. Such relationships require sustained family–school–healthcare–community partnerships and enhanced capacity among professionals (healthcare and recreation) to create better opportunities for children with CHPs. Faculty and professional development programs can help teachers and recreation

professionals better accommodate individual needs of children with CHPs. Better communication between families, health-care professionals, teachers, and recreation professionals; better training opportunities for teachers and recreation professionals; and linking programs in schools and recreation centres in the same community could bring greater benefits through interdisciplinary collaboration, strengthened partnerships, and the translation of research into practice.

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The authors have no conflicts of interest to disclose.

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