Received: 28 June 2017 | Revised: 5 October 2017 | Accepted: 28 October 2017

DOI: 10.1111/chd.12553

ORIGINAL ARTICLE

WILEY Congenital Heart Disease

Physical activity perceptions and behaviors among young adults with congenital heart disease: A mixed-methods study

Adam McKillop PhD[1] | Brian W. McCrindle MD, MPH[1,2] | Gina Dimitropoulos PhD[3] | Adrienne H. Kovacs PhD[3]

[1]Labatt Family Heart Centre, The Hospital for Sick Children, Toronto, Ontario, Canada

[2]Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada

[3]University Health Network, Toronto, Ontario, Canada

Correspondence
Brian W. McCrindle, Labatt Family Heart Centre, The Hospital for Sick Children, 555 University Ave, Toronto, ON, Canada M5G1X8.
Email: brian.mccrindle@sickkids.ca

Abstract

Objective: A physically active lifestyle can help maintain positive physical and psychosocial health outcomes among adults with congenital heart disease (CHD). This study explored the physical activity perceptions and behaviors among young adults with CHD.

Design: This was a cross-sectional, mixed-methods study that included objectively measured physical activity assessment (accelerometer), individual semistructured interviews, and psychosocial questionnaires.

Results: Fifteen participants (67% male; 21 ± 3 years old) with moderate (n = 10) or complex (n = 5) CHD were recruited from an outpatient adult CHD clinic. Participants accumulated 26 ± 16 minutes of moderate-to-vigorous physical activity per day, and reported a high quality of life, moderate self-efficacy for exercise, and low cardiac-focused anxiety. Qualitative data indicated that participants reported more positive perceptions toward activity if their family members encouraged physical activity participation, including siblings that engaged in physical activity alongside participants. Participants described parents as supportive rather than overprotective. Activity precautions were perceived by participants as being instructions from cardiologists rather than restrictions by parents. Participants described some physical limitations compared to peers, but managed challenges by either working within their limitations or choosing activities that met their expectations and/or in which they could fully participate. Participants often described childhood physical activity in the context of school, physical education, and organized sports. Whereas physical activity in childhood was viewed as recreational, the cardiac health-promoting aspects became more prominent in adulthood. Activities performed during one's employment were considered sufficient to meet physical activity recommendation levels, and participants reported limited time and/or energy to participate in activity outside of work.

Conclusions: The influence of family appeared to help participants adopt a positive perception toward activity participation in childhood that was carried forward to young adulthood. Future clinical work should target adolescents with CHD with less social supports and/or negative perceptions toward physical activity.

KEYWORDS
congenital heart disease, exercise, physical activity, qualitative

1 | INTRODUCTION

The number of adults living with congenital heart disease (CHD) continues to rise and there are now more adults than children living with CHD in North America.[1,2] Physical activity should be encouraged and promoted among the adult CHD population, as a physically active lifestyle contributes to positive physical and psychosocial health outcomes.[3–5]

Despite evidence-based guidelines to promote physical activity among the CHD population,[5] little is known about how young adults with CHD perceive physical activity and exercise. Emerging adults (18–25 years old) represent a distinct population that may experience a burden of adult-onset complications or illnesses and reduced physical functioning while navigating independent decision making.[6,7] As a result, emerging adults with CHD are often faced with challenges in maintaining healthy behaviors.[7] Therefore, it is important to understand the perceptions of physical activity as they relate to the experience of entering adulthood with CHD. This information may help identify key experiences to improve physical activity promotion among the CHD population. Furthermore, qualitative research may provide greater insight into the patient's perception of physical activity participation.

The study aims were to: (1) determine the objective physical activity level of participants using accelerometers; (2) understand perceptions of physical activity and exercise from childhood through emerging adulthood using individual semistructured qualitative interviews; and (3) explore psychosocial outcomes and identify potential factors for consideration in future work.

2 | METHODS

This study received institutional ethics board approval. Study participation included accelerometer-based assessment of physical activity, an individual in-person interview to explore physical activity behaviors and perceptions, and completion of psychosocial questionnaires (for which participants had the option of completing at home), and medical record review.

2.1 | Participants

Participants aged 18–25 years old were recruited from a single adult CHD (ACHD) clinic during an 8-month study period. All participants had undergone prior repair of CHD of moderate to great complexity[8] at least 1 year prior to participation and had the language and cognitive abilities to independently provide informed consent and complete study procedures. Enrollment continued until data saturation for the qualitative component of the study was achieved, whereby no new themes were identified following analysis of the most recent transcript.

2.2 | Medical record review

Data abstraction included CHD diagnosis, years since surgical repair, documented history of psychological difficulties and/or treatment, documented exercise restrictions recommended by the cardiologist, and the number of hospitalizations for cardiac-related problems.

2.3 | Accelerometer-measured physical activity

Participants were provided with an accelerometer (ActiGraph, wGT3X+, Pensicola, California) to measure their daily physical activity. Participants were instructed to wear the monitor around their waist over their right hip at the mid-axillary line for 7 days beginning the day after study enrollment (ie, the collection period included 5 weekdays and 2 weekend days). Participants were asked to record the days they chose to wear the monitor and any unusual circumstances that influenced activity participation (ie, long bus trips, illnesses, etc.) in a logbook. Participants returned the accelerometer and logbook in a prestamped and addressed envelope. The device was programed for a 15-second sampling interval and stored the activity count per 60 seconds to memory at the end of each successive interval. Upon return of the accelerometer, data were downloaded and analyzed using product software (ActiLife). Data were analyzed to determine daily step-count, sedentary time, and activity intensity levels using previously reported physical activity intensity cut points and important data filtering considerations.[9–11] Accelerometer data were analyzed if a minimum of 3 days of data was received (minimum wear time of 10 hours for a valid day). A piezoelectric transducer in the accelerometer measured and integrated changes in acceleration across the x, y, and z directions as counts per minutes (cpm). Physical activity intensity was categorized using previously reported cut-points: sedentary = 0–100 cpm; light = 101–2690 cpm; moderate = 2691–6166 cpm; vigorous= 6167–9642 cpm; very vigorous= $\geq$9643). Moderate-to-vigorous physical activity was categorized as $\geq$2691 cpm.

2.4 | Questionnaires

Participants completed a background questionnaire (eg, marital and parenting status, education, employment, and mental health treatment history) plus 5 validated questionnaires that were selected to characterize the study population. The *Readiness to Change* questionnaire[12] includes 4-items to assess participant's readiness to change their physical activity behavior. Responses classify each participant into 1 of 5 stages of change: precontemplation, contemplation, preparation, action, or maintenance. The *Self-Efficacy for Exercise Scale* measures participants' self-efficacy to be active.[13,14] This 9-item assessment inquires about participants' confidence in being able to be physically active 3 times per week for 20 minutes in various situations. Global quality of life was assessed using a 10cm *Visual Analog Scale*, which has been previously used with adults with CHD.[15–19] The VAS instructs respondents to indicate their overall quality of life from 0 ("worst imaginable quality of life") to 100 ("best imaginable quality of life"). The *Cardiac Anxiety Questionnaire* is an 18-item questionnaire that assesses participants' heart-focused anxiety and feelings toward physical activity (ie, how much do participants worry about their heart condition throughout the day and during specific activities, and how does thinking about their heart change their physical activity behavior).[7,20] A *Patient-based New York Heart Association (NYHA) Classification Assessment* was used to identify self-reported NYHA functional classification.[21]

2.5 | Qualitative interview

The interview explored participants' experience with physical activity throughout their lives. A qualitative descriptive approach was

chosen as basic or fundamental qualitative description is a valuable method that interprets the data with low-inference.[22] Thematic analysis was the chosen data analysis method, as it is considered theoretically flexible and lends itself to apply a low-level of interpretation (ie, presentation of facts as described by the participant using everyday language rather than facts presented beyond experiences described by participants or in terms of conceptual or abstract frameworks).[23,24]

The interviewer (A.M.) collected a detailed narrative from emerging adults with CHD to understand their perceptions of physical activity as a child, adolescent, and emerging adult with CHD. An interview guide was developed with open-ended questions and probes that progressed from questions about childhood physical activity (ie, "How active were you growing up? What physical activities did you do as child?"), toward the participants' outlook regarding activity participation and life as an emerging adult with CHD (ie, "Please describe what type of physical activity you engage in now. What are your reasons for engaging (or not engaging) in physical activity?")

2.6 | Qualitative data analysis

All qualitative interviews were conducted, transcribed, and analyzed by a single investigator (A.M.). Thematic analysis was used to identify, analyze, and report specific patterns (ie, themes) in the data.[25] The following 6-phase approach to thematic analysis was used: familiarization with data; generation of initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report.[25] Provisional results were reviewed with members of the study team (G.D. and A.K.) to discuss the interview progress, preliminary themes, and reliability of the analysis. An iterative approach was relied upon to share and discuss interpretations of the results throughout the data collection and analysis period. New data were presented to the study team to discuss generating new themes or using data to support existing themes already identified.

2.7 | Quantitative data analysis

Accelerometer, questionnaire, and medical record data were calculated as mean ± standard deviation or frequencies. Given the small sample size and heterogeneity of participant characteristics, quantitative results were analyzed for descriptive purposes only. Investigation of factors associated with physical activity was completed for exploratory purposes only to help inform future work; however, this was not the focus of this study.

2.8 | Mixed-methods data synthesis

Quantitative data analysis was completed at the end of the data collection period, whereas qualitative data analysis occurred concurrently as new interviews were conducted. Qualitative interview data were used to help understand the quantitative data and helped identify potential discrepancies in the participant's experience with physical activity and outcome measures. The data sources (quantitative and qualitative data) were used to compare results and develop a greater appreciation for the patient's overall physical activity behavior.[26,27]

3 | RESULTS

3.1 | Participants

Of the first 28 patients who met study eligibility criteria and were approached for study participation, 15 (5 females and 10 males; 21 ± 3 years) provided informed consent and participated in interviews. Other patients typically declined participation due to lack of time or interest to complete study assessments. No participants were married or had children. Medical chart review indicated that participants had CHD of moderate (n = 10, 67%) or great (n = 5, 33%) complexity. Mean number of years since the most recent cardiac surgery was 14 ± 8 years. No participants reported past or current use of psychotropic medication and 1 participant reported a history of psychotherapy. Exercise restrictions were documented for 3 participants (all were encouraged to avoid isometric/strenuous weightlifting) whereas 12 participants had no documented exercise restrictions in their medical charts. A change in exercise restrictions over time (ie, between pediatric and adult care) was not documented for any participants. Hospitalization for cardiac-related problems occurred in 2 participants. Additional details regarding participant characteristics are included in Table 1.

TABLE 1 Participant characteristics (n = 15)

Variable	
Age (y)	21 ± 3
Male	10 (67%)
Never married	15 (100%)
Education	
College/university degree	5 (33%)
Some college/university	8 (53%)
High school	2 (13%)
Employment	
Full-time	3 (20%)
Part-time	7 (47%)
Unemployed	5 (33%)
Primary CHD diagnosis	
Tetralogy of Fallot	3 (20%)
Coarctation of the aorta	2 (13%)
Hypoplastic left heart syndrome	2 (13%)
Atrioventricular septal defect	2 (13%)
Bicuspid aortic valve	2 (13%)
Other (transposition of the great arteries, congenitally-corrected transposition of the great arteries, pulmonary atresia, pulmonary stenosis)	4 (28%)
Years since most recent surgery	14 ± 8
Noninterventional hospitalization for cardiac-related concern	2 (13%)
Documented exercise restriction[a]	3 (20%)

[a]All exercise restrictions specified avoidance of isometric/strenuous weightlifting activity.

TABLE 2 Descriptive statistics for objective physical activity assessment (n = 10)

	Mean ± SD	Range
Total valid wear days	6 ± 0.9	4–7
Wear time (h/d)	11 ± 0.8	10–13
Step-count (steps/d)	8668 ± 2776	5542-13 855
Sedentary (min/d)	567 ± 116	458–598
Light activity (min/d)	67 ± 21	38–101
Moderate activity (min/d)	23 ± 14	7–46
Vigorous activity (min/d)	3 ± 2	1–8
Moderate-to-vigorous physical activity (min/d)	26 ± 16	8–54

Abbreviation: SD, standard deviation.
[a]Intensity levels based on Freedson et al.[28]

3.2 | Accelerometer-measured physical activity

Complete accelerometer assessments were available for 10 participants; 3 patients did not return the accelerometer and 2 participants returned monitors with insufficient wear-times (<10 hours/day). Accelerometer data from the 10 participants with usable accelerometer data are summarized in Table 2. This objective assessment of physical activity indicated that participants spent the majority of their time as sedentary (567 ± 116 minutes/day) and accumulated 26 ± 16 minutes of moderate-to-vigorous physical activity per day.

3.3 | Psychosocial outcomes

Completed questionnaires were returned by 12 of the 15 participants (Table 3). The Readiness to Change questionnaire results indicated that the majority of participants (n = 9) were physically active (Action and Maintenance Phase) and 3 participants planned to be more active in the next 6 months (Contemplation). Additional psychosocial assessment scores are reported in Table 3. The mean Quality of Life visual analogue score (mean of 84/100) is comparable to other reports among adults with CHD and indicates a relatively positive satisfaction with life.[17,19] The association between physical activity data and psychosocial data was investigated for exploratory purposes only. There were no significant associations between physical activity and psychosocial measures, possibly attributed to the small sample size and heterogeneity of participant data.

TABLE 3 Descriptive statistics for psychosocial assessments (n = 12)

Questionnaire	Mean	SD	Range
Quality of life visual analogue scale	84	11	60–100
Self-efficacy for exercise	55	22	19–81
Cardiac anxiety questionnaire total score	25	13	8–53
NYHA functional classification			
I	6	–	–
II	6	–	–

3.4 | Qualitative interviews

Thematic analysis of interviews identified the following 6 themes: (1) importance of family, (2) parental support-not overprotection, (3) adaptation for continued activity participation, (4) influence of school, (5) occupational activity, and (6) activity for health.

3.4.1 | Importance of family

The majority of participants (n = 12) described their family as being supportive of their physical activity participation throughout childhood. When asked, "What helped you be active as a child?" participants described how family members (parents and/or siblings) played a role in their activity participation.

> Besides my parents, my sister—she is also really active. So even if it was a crummy day out, she would always get me off the couch or get me out of bed at 7am to go ride our bikes. . .it helps me get through it, when she keeps playing because I love watching her play too if I can't play the sport.

Some participants (n = 3) commented on the role of older siblings that would also encourage them (the participant) to be more active. Participants shared that family members often participated in activity along with the participant (role-modeling) and facilitated activity participation.

> . . .I have an older brother, and he too is very active, so I think seeing him be that way growing up was normal to me—that people are active because my parents are. . .so just my family being active was normal to me.

Overall, participants reported that family provided a positive support system to be confident in their participation in activities growing up. Parental support in adulthood took more of a passive role but participants indicated that their parents still checked-in and inquired about their activities and health. No participants described unsupportive families.

3.4.2 | Parental support—Not overprotection

Participants (n = 12) did not identify their parents as overly protective of them. Participants experienced a positive upbringing with respect to opportunities to participate in physical activity and sports and attributed these opportunities to parental support.

> . . .I think it made me feel more supported—I just felt like I had somebody that was saying, "you're allowed to do this" and they were supporting me, whereas if I didn't have that, I probably would have not been as excited to go and do all these things I did.

Some participants also recalled supportive parenting at the practical level that facilitated activity participation, including purchasing equipment, program registration, traveling with sports teams, etc. Participants perceived this as the parent's way to help them stay healthy or to fulfill the parent's desire to have them play sports and fit in with other children.

> Like if I wanted to sign up for whatever it was, they would sign me up and even if they thought I wasn't going to be the best, they said at least give it a try. And if she doesn't like it or she can't do it, we will just pull her out. They always encouraged me to try whatever I wanted to do.

3.4.3 | Adaptation for continued activity participation

The majority of participants (n = 11) recalled a relatively "normal" childhood and rarely considered themselves as being different from their peers. Although the perception of a normal childhood was commonly discussed, participants also commented on differences between themselves and their peers in terms of physical endurance and coordination. The existence of some physical limitations did not deter participants from participating in physical activity. Participants managed these challenges by either working within their limitations or choosing an activity that met their expectations and in which they were able to participate fully.

> Growing up I learned to get used to it. Like sometimes I would have to take a break and my friends would understand. . .but I noticed I would take longer breaks than my friends.

Participants commented that they never experienced life without CHD and acknowledged that growing up with CHD was a normal part of their life. Many participants felt the CHD had no bearing on decisions they made with respect to physical activity choices. One participant compared themselves to peers and described an appreciation for the ability to be physically active despite having complex CHD.

> If a kid with half a heart can do it, a kid with a full heart can do it. . .by me showing them [other children without CHD] I can be active with half a heart, and you with a full healthy body and whole heart, you will be able to do it too.

3.4.4 | Influence of school

Participants discussed their activity as a child in the context of school, physical education, and organized sports participation. Daily physical activities in the context of activities of daily living (ie, active transport, house work, leisure activities) were not recalled as frequently or with as much detail compared to the experiences from school. Furthermore, description of activity generally involved a comparison of peers who were regarded as healthier and a group with whom the participants aspired to be included. Some participants (n = 4) recalled instances of being left out from opportunities, but seemed to manage this experience in childhood. Participants' perseverance and positive attitude toward activity helped them adapt to societal expectations, especially in school settings, in order to remain active.

> I had a bit of trouble keeping up with my peers. . .but it wasn't anything serious, it was just I couldn't really keep up that much. . .it was just being picked last for teams.

Participants described some challenges with school and fitting in with their peers. Although participants described an overall positive experience, school-based situations introduced more negative perceptions toward physical activity, specifically those involving sport team participation and interacting with healthy peers. For example, participants described themselves as having suboptimal performance to try-out for, or participate in, team sports.

3.4.5 | Occupational activity

Questions about current situations as an adult resulted in comments regarding their activity level in the context of their work environment. This was apparent across participants regardless of reported activity levels throughout the day. Occupational activity (eg, stocking shelves at a grocery store, construction work) was regarded as high volume and participants described this as sufficient activity to meet daily recommendations. However, participants also acknowledged that it would likely be better if they did more activity outside of work, but they were often too tired after a long workday.

> As I've gotten older I do a lot less physical activity. I mean I do a lot of physical related tasks with my job, but I wouldn't say that I'm going out to go for a run or anything like that. I'm not a super active person.

One participant described the need to change occupations due to the high physical demands of the job. The participant described a conversation about physical activity during a recent clinical appointment and the reality of having CHD and working in a physically demanding job.

> . . . I should look at getting another job because, like right now, it's not bad. . .so he [cardiologist] is like "you may be able to do it for the next 15 years but based on other people with your condition. . .you won't be able to do it."

3.4.6 | Activity for health

Most participants (n = 11) commented that a main reason to participate in activity as an adult was to maintain their physical and mental health. Participants attributed this to their desire to improve the self-management of their disease. Participants also drew comparisons from

other aspects in their lives where they experienced an increased self-management and independence (ie, living independently, paying bills, establishing relationships). While participants described their reasons for participation in activity during childhood as "fun," they commented that the reasons for participating in activity as an adult were primarily related to an increased responsibility for managing their own health.

> . . .because you should be happy and enjoy things in life as a child and that's why I did it as a kid. And now it's important because of health. I'm older and I understand health more, so I also do it [activity] for that factor.

Activity in adulthood was also described in the context of maintaining good health and prevention of future disease to delay future clinical intervention. Participants described an uncertainty regarding long-term future outcomes but knew that regular physical activity might be beneficial to help combat comorbidities. Participants described the many benefits of regular physical activity, including both physical (ie, cardiovascular fitness and weight management) as well as psychosocial aspects (ie, improved mood and decreased feelings of anxiety and depression).

> No matter what school work gets involved, like health wise, I know I am going to get sick again with my heart, so I just try to push it off as much as possible by staying active and eating healthy.

4 | DISCUSSION

Most research investigating physical activity and exercise behavior among the CHD population has focused on children, with limited reports of adult CHD patients. Qualitative research with young adults with CHD is scarce. This study offers a novel exploration of the physical activity perceptions and behaviors of emerging adults with CHD including an objective measure of physical activity and psychosocial outcomes. Participants included in this study demonstrated favorable physical and psychosocial outcomes, were well supported by their family, and were high-functioning in terms of social, school, and occupational endeavors. Therefore, study results should be interpreted as those that represent a unique cohort of high-functioning patients despite having moderate-to-severe CHD. However, adulthood introduced new experiences for participants, including a desire to improve self-management skills and increase independence as well as challenges in navigating new responsibilities.

4.1 | The role of family: Early engagement for positive outcomes

Participants described positive and supportive experiences from childhood and recalled frequent activity participation with family members. The physical activity behavior and health (ie, overweight status) of parents are well known correlates of child physical activity levels.[29,30] Therefore, it is not surprising that participants described an overall active childhood and limited activity restrictions growing up with active and engaged parents. Kendall et al. reported the views of parents of children with CHD, whereby parents described the importance of providing a "normal" upbringing for their child.[31] Parents may have taken it upon themselves to help facilitate a normal life for their children and modeled an active lifestyle alongside their child with CHD.

Interviews revealed that participants felt supported by parents and did not experience over-protective parenting as previously described in the CHD population.[7,32,33] Turgeon et al. described the negative impact that overprotective parenting has on the patient's feelings of dependency and self-efficacy.[34] Taken together, participants in our study reported growing up in an encouraging environment that fostered greater self-efficacy to be active. This likely contributed to the reported low cardiac anxiety, good quality of life, and greater participation in a range of activities throughout childhood. Pediatric providers should emphasize the importance of parental support and encouragement of their child's physical activity goals and accomplishments.

4.2 | Shifting toward independence, success, and improved health in adulthood

Participants in our study described changes in physical activity perceptions as they entered adulthood. Physical activity in childhood was recalled as recreational and was described as primarily health promoting in adulthood. Young adults may become more aware of the severity of their underlying CHD and the importance to manage their condition independently. Furthermore, opportunities for physical activity in childhood were often described in the context of school and organized (recreational) sports. In contrast, participants described more structured exercise regimens in adulthood or work-related activity. Therefore, educating patients with CHD about various ways to be physically active outside school-based opportunities may help establish active lifestyles that can be carried forward into adulthood. Furthermore, pediatric providers should help emerging adults with CHD understand how their physical functioning may change in the future and discuss suitable job options that are consistent with their physical abilities.

Participants viewed success in terms of doing well in school, obtaining work, and establishing a career. At the time of the interview in our study, almost 90% of participants were completing or have completed a university/college degree and two thirds of participants reported working (part-time or full-time). In combination with low cardiac anxiety and good quality of life, these results may indicate a positive trajectory for participants in our study in terms of occupational success. Although participants did not directly discuss occupational outcomes or challenges in the context of barriers/facilitators, this topic did arise throughout the interviews. For example, 1 participant commented on the need to change jobs in the future due to the physical demands. Sluman et al. conducted qualitative interviews with a cohort of young adults (ages 22–35 years) with CHD and identified barriers (increased physical load, lack of time to recover from work, and poor employee-employer relationship) and facilitators (low physical demands

at work, autonomy to choose tasks and increased recovery time from work, and supportive employers and colleagues) regarding occupational tasks.[35] Participants in our study may not have experienced the existing occupational challenges as described by Sluman et al. due to younger age (18–25 years old) and occupational status (73% of participants were students) in our study. An educational approach early in the child's CHD care may frame physical activity as being both recreational and health promoting, while emphasizing the importance of adopting a healthy lifestyle as the patient transitions to adult care.

4.3 | Confident and active: A changing ACHD patient persona?

Overall, study participants reported positive psychosocial outcomes. The good quality of life reported in our study might have been expected as the study population did not include patients with identified risk factors for diminished quality of life, including social impediments, trait anxiety, lower educational level, orthopedic problems, psychosocial problems, and age >23 years.[36–38] The overall quality of life measured using VAS in an international study of adults with CHD was 80/100.[19] This is comparable to the quality of life of participants in our current study (mean score of 84/100). The reported ability to be physically active discussed during the interviews is concordant with this high quality of life score and supports the body of literature indicating that exercise is a marker of one's quality of life.[39–41]

Participants reported a wide range of self-efficacy scores. Assessment of self-efficacy for exercise indicated that participants with CHD were generally confident they could participate in physical activity. Dua et al. reported that adults with CHD had some belief they could participate in physical activity.[42] Self-efficacy is a key tenant in many exercise-training programs that aim to build self-efficacy using interventions based on Social Cognitive Theory. Social Cognitive Theory emphasizes the interaction between people and their environment, and that behavior is a product of personal, environmental, and behavioral factors. Structured programs for the ACHD population that include elements derived from theoretical frameworks like the Social Cognitive Theory may lead to psychosocial improvements, especially among patients with low self-efficacy or quality of life.

4.4 | Physical activity assessment and the role for positive psychosocial health

Our study is one of few that objectively assessed the physical activity of young adults with CHD using accelerometers, which is the recommended approach to avoid pitfalls associated with self-reported instruments.[43,44] Dua et al. used accelerometers and reported that adults (mean age = 31.7 ± 10.9 years) with CHD accumulated 26 minutes/day of MVPA, consistent with the results from our study.[42] Physical activity has also been assessed among adults with CHD using self-report measures. Work by Sandberg et al. and Buys et al. included self-reported activity measures of activity among adults with CHD that indicated suboptimal levels of physical activity.[45,46] In contrast, Muller et al. reported that 76% of their ACHD study population achieved the daily activity recommendation for adults with a mean moderate activity level (>3 METS) of 59.2 ± 39.7 minutes/day.[47] Jackson et al. also reported that emerging adults accumulated adequate MVPA using a self-report instrument.[48] These findings highlight the inconsistent results available in the literature, and may indicate that adults with CHD do not experience reduced activity levels. The Canadian Health Measures survey measured physical activity among healthy adults between 2007 and 2009 and reported that adults 20–39 years old accumulated 25.5 minutes of moderate-to-vigorous physical activity.[9] Therefore, participants in our study accumulated the same amount of physical activity as healthy peers. The comparable daily physical activity participation may be attributed to positive psychosocial outcomes as reported by our participants who chose to participate in our study. For instance, results from the CAQ to assess heart-focused anxiety showed that participants in the current study reported a low heart-focused anxiety, indicating that concerns about their heart during activity are unlikely to contribute to avoidance to be physically active. This finding is comparable to work completed by Ong et al. that reported low CAQ among a cohort of ACHD patients.[7] The lack of reported heart failure symptoms during exercise according to the NYHA Classification Assessment may also allow for a more active lifestyle as demonstrated by our participants. Young adults in this study also linked their positive mental health with regular physical activity throughout the qualitative interviews. Given that approximately 1/3 of adults with CHD meet the diagnostic criteria for mood and anxiety disorders,[49] clinicians should encourage regular physical activity as a nonpharmacological approach to alleviate mental health symptoms.

4.5 | Limitations

The primary study limitation pertains to generalizability of the results. Patients were approached to participate in a study about physical activity perceptions and behaviors. This may have introduced recruitment bias toward patients that were already active and inclined to participate in a study regarding physical activity; we did not have ethics approval to compare patients who did vs did not accept the invitation to participate in the study. Furthermore, we did not assess additional medical factors (eg, oxygen saturation, kidney function, medications) that may have allowed us to better determine the underlying medical complexities to which our findings could most likely be extrapolated. The emerging adults in our study did not have cardiac devices, were psychologically stable, and described having supportive families. This may limit our ability to generalize the study findings to their peers with CHD with different medical and psychosocial characteristics. A second limitation reflects the fact that our quantitative data analyses were limited to descriptive outcomes, given our a priori decision to obtain a sample size based on the qualitative methodology (ie, to end recruitment upon data saturation). Moreover, due to incomplete quantitative assessments pertaining to accelerometer and questionnaire responses, the sample size for quantitative results was further reduced and may not be completely reflective of the emerging adult CHD population. Finally, the cross-sectional study design characterized patients at a

single time point, whereas longitudinal data collection would be necessary to explore long-term physical activity behaviors and trends in this population.

4.6 | Conclusions

Participants in this study reported an overall positive experience regarding the medical care they received as a child and recalled a supportive upbringing and childhood similar to healthy peers in terms of physical activity. Patients with CHD included in this study were comprised of emerging adults for whom physical activity has been fostered and supported. Family played a substantial role in feeling supported to participate in physical activity, primarily through parental encouragement and sibling involvement in active pursuits. Participation in activity as an adult with CHD shifted toward improvement in health rather than recreational enjoyment as experienced in childhood. Participants also described increasing independence and associated challenges experienced as an adult including managing priorities like school, work, relationships, and self-care. Emerging adults with CHD participated in daily MVPA comparable to healthy peers. This likely occurred due to the participants' low cardiac anxiety, high quality of life and moderate self-efficacy for exercise.

Whereas physical activity and exercise guidelines exist for children and adult CHD patients,[5,50] there is a lack of structured programs to integrate published recommendations into clinical care. Therefore, a targeted approach is warranted to address physical activity among the CHD population. The importance of physical activity and exercise should be presented throughout childhood using a family-based approach that engages both parents and siblings. Parents should be provided necessary resources and access to programs that may help improve their own activity level in order to demonstrate positive role modeling for their child with CHD.

CONFLICT OF INTEREST

None

AUTHOR CONTRIBUTIONS

Adam McKillop: Concept/Design, data collection, data analysis/interpretation, statistics, drafting article.
Brian W. McCrindle: Data interpretation, critical revision of article.
Gina Dimitropoulos: Qualitative methodology, qualitative data review and interpretation, critical revision of article.
Adrienne H. Kovacs: Concept/Design, data analysis/interpretation, statistics, drafting article, critical revision of article.

ORCID

Adam McKillop PhD http://orcid.org/0000-0002-4596-0078

REFERENCES

[1] Webb G. Improving the care of Canadian adults with congenital heart disease. *Can J Cardiol*. 2005;21(10):833–838.

[2] Marelli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Dendukuri N, Kaouache M. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. *Circulation*. 2014;130(9):749.

[3] Müller J, Amberger T, Berg A, et al. Physical activity in adults with congenital heart disease and associations with functional outcomes. *Heart*. 2017;103(14):1117–1121.

[4] Tikkanen UA, Opotowsky AR, Bhatt AB, Landzberg MJ, Rhodes J. Physical activity is associated with improved aerobic capacity over time in adults with congenital heart disease. *Int J Cardiol*. 2013;168(5):4685–4691.

[5] Longmuir PE, Brothers JA, de Ferranti SD, et al. Promotion of physical activity for children and adults with congenital heart disease: a scientific statement from the American Heart Association. *Circulation*. 2013;127(21):2147–2159.

[6] Arnett JJ. Emerging adulthood: a theory of development from the late teens through the twenties. *Am Psychol*. 2000;55(5):469–480.

[7] Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123(13):1454–1485.

[8] Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults with Congenital Heart Disease) Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons. *J Am Coll Cardiol*. 2008;52(23):e143–e263.

[9] Colley RC, Garriguet D, Janssen I, Craig CL, Clarke J, Tremblay MS. Physical activity of Canadian adults: accelerometer results from the 2007 to 2009 Canadian Health Measures Survey. *Health Rep*. 2011;22(1):7–14.

[10] Colley RC, Garriguet D, Janssen I, Craig CL, Clarke J, Tremblay MS. Physical activity of Canadian children and youth: accelerometer results from the 2007 to 2009 Canadian Health Measures Survery. *Health Rep*. 2011;22(1):15–23.

[11] Wanner M, Martin BW, Meier F, Probst-Hensch N, Kriemler S. Effects of filter choice in GT3X accelerometer assessments of free-living activity. *Med Sci Sports Exerc*. 2013;45(1):170–177.

[12] Walpole B, Dettmer E, Morrongiello B, McCrindle B, Hamilton J. Motivational interviewing as an intervention to increase adolescent self-efficacy and promote weight loss: methodology and design. *BMC Public Health*. 2011;11(1):459.

[13] King KM, Humen DP, Smith HL, Phan CL, Teo KK. Psychosocial components of cardiac recovery and rehabilitation attendance. *Heart*. 2001;85(3):290–294.

[14] Resnick B, Jenkins LS. Testing the reliability and validity of the self-efficacy for exercise scale. *Nurs Res*. 2000;49(3):154–159.

[15] Moons P, Van Deyk K, De Bleser L, et al. Quality of life and health status in adults with congenital heart disease: a direct comparison with healthy counterparts. *Eur J Cardiovasc Prev Rehabil*. 2006;13(3):407–413.

[16] de Boer AG, van Lanschot JJ, Stalmeier PF, et al. Is a single-item visual analogue scale as valid, reliable and responsive as multi-item scales in measuring quality of life? *Qual Life Res*. 2004;13(2):311–320.

[17] Moons P, Van Deyk K, De Geest S, Gewillig M, Budts W. Is the severity of congenital heart disease associated with the quality of life and perceived health of adult patients? *Heart*. 2005;91(9):1193–1198.

[18] Tong A, Tjaden L, Howard K, Wong G, Morton R, Craig JC. Quality of life of adolescent kidney transplant recipients. *J Pediatr*. 2011;159(4):670–675.

[19] Apers S, Kovacs AH, Luyckx K, et al. Quality of life of adults with congenital heart disease in 15 countries: evaluating country-specific characteristics. *J Am Coll Cardiol*. 2016;67(19):2237–2245.

[20] Hamang A, Eide G, Rokne B, Nordin K, Bjorvatn C, Øyen N. Predictors of heart-focused anxiety in patients undergoing genetic investigation and counseling of long QT syndrome or hypertrophic cardiomyopathy: a one year follow-up. *J Genet Couns*. 2012;21(1):72–84.

[21] Schoormans D, Mager YL, Oort FJ, Sprangers MAG, Mulder BJM. New York Heart Association class assessment by cardiologists and outpatients with congenital cardiac disease: a head-to-head comparison of three patient-based versions. *Cardiol Young*. 2012;22(1):26–33.

[22] Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334–340.

[23] Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15(3):398–405.

[24] Clarke V, Braun V. Teaching thematic analysis: overcoming challenges and developing strategies for effective learning. *Psychologist*. 2013;26(2):120–123.

[25] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.

[26] Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research. Thousand Oaks, CA: Sage; 2011.

[27] Wisdom JP, Cavaleri MA, Onwuegbuzie AJ, Green CA. Methodological reporting in qualitative, quantitative, and mixed methods health services research articles. *Health Serv Res*. 2012;47(2):721–745.

[28] Freedson PS, Melanson E, Sirard J. Calibration of the Computer Science and Applications, Inc. Accelerometer. *Med Sci Sports Exerc*. 1998;30(5):777–781.

[29] Bauman AE, Reis RS, Sallis JF, Wells JC, Loos RJF, Martin BW. Correlates of physical activity: why are some people physically active and others not? *Lancet*. 2012;380(9838):258–271.

[30] Gustafson SL, Rhodes RE. Parental correlates of physical activity in children and early adolescents. *Sports Med*. 2006;36(1):79–97.

[31] Kendall L, Sloper P, Lewin RJ, Parsons JM. The views of parents concerning the planning of services for rehabilitation of families of children with congenital cardiac disease. *Cardiol Young*. 2003;13(1):20–27.

[32] Linde LM, Rasof B, Dunn OJ, Rabb E. Attitudinal factors in congenital heart disease. *Pediatrics*. 1966;38(1):92–101.

[33] Garson AJ, Benson RS, Ivler L, Patton C. Parental reactions to children with congenital heart disease. *Child Psychiatry Hum Dev*. 1978;9(2):86–94.

[34] Turgeon L, O'Connor K, Marchand A, Freeston MH. Recollections of parent-child relationships in patients with obsessive-compulsive disorder and panic disorder with agoraphobia. *Acta Psychiatr Scand*. 2002;105(4):310–316.

[35] Sluman MA, de Man S, Mulder BJ, Sluiter JK. Occupational challenges of young adult patients with congenital heart disease. *Neth Heart J*. 2014;22(5):216–224.

[36] Kovacs AH, Sears SF, Saidi AS. Biopsychosocial experiences of adults with congenital heart disease: review of the literature. *Am Heart J*. 2005;150(2):193–201.

[37] Saliba Z, Butera G, Bonnet D, et al. Quality of life and perceived health status in surviving adults with univentricular heart. *Heart*. 2001;86(1):69–73.

[38] Rietveld S, Mulder BJ, van Beest I, et al. Negative thoughts in adults with congenital heart disease. *Int J Cardiol*. 2002;86(1):19–26.

[39] Fredriksen PM, Kahrs N, Blaasvaer S, et al. Effect of physical training in children and adolescents with congenital heart disease. *Cardiol Young*. 2000;10(2):107–114.

[40] Imms C. Occupational performance challenges for children with congenital heart disease: a literature review. *Can J Occup Ther*. 2004;71(3):161–172.

[41] Smith P. Primary care in children with congenital heart disease. *J Pediatr Nurs*. 2001;16(5):308–319.

[42] Dua JS, Cooper AR, Fox KR, Stuart AG. Physical activity levels in adults with congenital heart disease. *J Cardiovasc Risk*. 2007;14(2):287–293.

[43] Prince SA, Adamo KB, Hamel ME, Hardt J, Connor Gorber S, Tremblay M. A comparison of direct versus self-report measures for assessing physical activity in adults: a systematic review. *Int J Behav Nutr Phys Act*. 2008;5:56.

[44] Sallis JF, Saelens BE. Assessment of physical activity by self-report: status, limitations, and future directions. *Res Q Exerc Sport*. 2000;71(2 Suppl):1–14.

[45] Sandberg C, Rinnstrom D, Dellborg M, et al. Height, weight and body mass index in adults with congenital heart disease. *Int J Cardiol*. 2015;187:219–226.

[46] Buys R, Budts W, Reybrouck T, Gewillig M, Vanhees L. Serial exercise testing in children, adolescents and young adults with Senning repair for transposition of the great arteries. *BMC Cardiovasc Disord*. 2012;12(1):88.

[47] Muller J, Hess J, Hager A. Daily physical activity in adults with congenital heart disease is positively correlated with exercise capacity but not with quality of life. *Clin Res Cardiol*. 2012;101(1):55–61.

[48] Jackson JL, Tierney K, Daniels CJ, Vannatta K. Disease knowledge, perceived risk, and health behavior engagement among adolescents and adults with congenital heart disease. *Heart Lung*. 2015;44(1):39–44.

[49] Kovacs AH, Saidi AS, Kuhl EA, et al. Depression and anxiety in adult congenital heart disease: predictors and prevalence. *Int J Cardiol*. 2009;137(2):158–164.

[50] Baumgartner H, Bonhoeffer P, De Groot NMS, et al. ESC guidelines for the management of grown-up congenital heart disease (new version 2010). *Eur Heart J*. 2010;31(23):2915–2957.

How to cite this article: McKillop A, McCrindle BW, Dimitropoulos G, Kovacs AH. Physical activity perceptions and behaviors among young adults with congenital heart disease: A mixed-methods study. *Congenital Heart Disease*. 2018;13:232–240. https://doi.org/10.1111/chd.12553