













ORIGINAL RESEARCH

Exploring Health-Related Quality of Life in Children With Hypertrophic Cardiomyopathy and Relationship to Physical Activity

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BACKGROUND: Hypertrophic cardiomyopathy is a burdensome condition that inflicts both physical and psychological impairment on those with the disease, negatively impacting health-related quality of life (HRQoL). Given the abundance of evidence suggesting a role of physical activity (PA) in modulating HRQoL in healthy populations of children, we sought to determine the relationship between HRQoL and PA in children diagnosed with hypertrophic cardiomyopathy.

METHODS AND RESULTS: A multicenter prospective observational cohort study was conducted, with patients with hypertrophic cardiomyopathy aged 10 to 19 years being provided a wrist-worn activity tracker (Fitbit Charge HR) to wear for 14 days. Patients self-reported on Pediatric Quality of Life 4.0 quality of life inventory items, which were associated with PA metrics following covariate adjustment using linear regression. A total of 56 participants were recruited to the study. The median age at enrollment was 15.5 years (interquartile range, 13.8–16.8), and 16 out of 56 (29%) of the cohort were girls. The cohort reported decreased metrics of physical, psychosocial, and total summary scores compared with health reference populations, with scores comparable with that of published populations with chronic disease. Increased physical HRQoL scores were significantly associated with increased daily steps taken, distance traveled, and flights of stairs climbed.

CONCLUSIONS: These results show that impaired PA correlates with reduced HRQoL in children with hypertrophic cardiomyopathy, suggesting PA may partially mediate HRQoL in this population.

Key Words: exercise ■ health-related quality of life ■ hypertrophic cardiomyopathy ■ pediatrics

Hypertrophic cardiomyopathy (HCM) is the most common inheritable cardiac condition, characterized by disorganization of the myocytes and sarcomeres, myocardial fibrosis, and pathological thickening of the myocardium.^{1,2} HCM can impact physical activity (PA) because it may cause exercise-induced arrhythmias, ischemia, and left ventricular outflow tract obstruction.³ Previous studies have suggested that athletes with HCM are at higher risk of sudden cardiac death compared with those without.^{4–7}

These findings have led to historical PA restriction among patients with HCM, particularly from competitive sports.^{8,9} However, ambiguity around the amount and types of exercise patients should safely perform have resulted in some patients adopting a sedentary lifestyle.³ The development of unhealthy habits and behaviors during childhood can tack into adulthood and may contribute to an increased prevalence of obesity.^{10,11} Up to 70% of adults with HCM are overweight or obese, leading to increased risk for cardiovascular

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CLINICAL PERSPECTIVE

What Is New?

- Children and adolescents with hypertrophic cardiomyopathy scored significantly lower than healthy reference populations in measures of health-related quality of life.
- Increases in some everyday physical activities, measured by a wrist-worn activity tracking device, correlated with increases in physical component scores of health-related quality of life.

What Are the Clinical Implications?

- These results suggest that physical activity in children and adolescents with hypertrophic cardiomyopathy could potentially play a role in mediating health-related quality of life.

Nonstandard Abbreviations and Acronyms

| | |
|---------------|-----------------------------|
| HCM | hypertrophic cardiomyopathy |
| MD | mean difference |
| PA | physical activity |
| PedsQL | Pediatric Quality of Life |

complications and a worsening of left ventricular outflow tract obstruction.¹² This may lead to decreased health-related quality of life (HRQoL), especially in children.^{13,14} HRQoL is a global measure of disease burden in the individual, which also quantifies perceptions on functional capability.¹⁵ HRQoL scores reflect subjective perceptions about a patient's overall satisfaction with their health and as such have been an effective method to compare among diverse populations.¹⁶ Although HRQoL has been reported on in adult patients with HCM,¹⁷⁻¹⁹ the association between HRQoL and PA in patients, especially children with HCM, is unexplored.

Thus, the objectives of the current study were to (1) evaluate HRQoL in children with HCM and compare it with the general population and (2) determine if HRQoL in children with HCM is related to objective measures of PA. We hypothesized that HRQoL scores in children with HCM are lower compared with healthy populations and that measures of PA are independently associated with overall, physical, and psychosocial HRQoL.

METHODS

The data that support the findings of this study are available from the corresponding author upon reasonable request. This is a multicenter prospective

observational cohort study (Research Ethics Board registration number Pro00083230, clinical trial registration number NCT05510180) done in collaboration with the Canadian Congenital and Pediatric Cardiology Research Network.²⁰ Children who met diagnostic criteria for primary HCM (secondary causes for myocardial hypertrophy ruled out), aged 10 to 19 years, were recruited from 10 Canadian pediatric care sites: British Columbia Children's Hospital (Vancouver, BC), Stollery Children's Hospital (Edmonton, AB), Jim Pattison Children's Hospital (Saskatoon, SK), Variety Children's Hospital Centre (Winnipeg, MB), The Hospital for Sick Children (Toronto, ON), CIUSS del'Estrie-CHUS (Sherbrooke, QC), L'Hopital de Montreal Pour Enfants (Montreal, QC), CHU de Quebec (Quebec City, QC), IWK Heart Centre (Halifax, NS), and CHU Sainte-Justine (Montreal, QC). Recruitment took place between May 2019 and January 2023. Research ethics board approval for the study was obtained by all participating centers. Patients and their guardians provided written consent.

Demographic data included sex as well as age, height, and weight at enrollment. Body mass index (BMI) was calculated according to World Health Organization standards, with normal weight corresponding to BMI <85th percentile, overweight between 85th and 97th percentile, and obese corresponding to BMI >97th percentile.²¹ Clinical data collected included New York Heart Association class, current heart failure symptoms and medication use, cardiac arrest history, family history, genetic diagnosis, and previous surgical interventions (eg, myectomy, implantable cardioverter-defibrillator placement).

Assessment of HRQoL

To assess HRQoL, participants were administered the Pediatric Quality of Life (PedsQL) Inventory Quality of Life Module 4.0.²² The PedsQL Quality of Life Module is a self-reporting instrument that consists of 23 items in 4 domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). It has been designed for multiple age groups, including a parent proxy report if required. It has been shown to be valid and reliable, with an internal consistency for the total scale score of 0.88 for the child self-report and 0.9 for the parent proxy report^{22,23} in a large US population. It has been used to measure HRQoL in healthy children and adolescents and those with acute and chronic health conditions.^{24,25} Scores within individual areas are reverse scored and linearly transformed into a 0 to 100 scale, such that higher score indicates better HRQoL. One SD below the population mean has been identified as a cutoff for those at risk of impaired HRQoL.^{22,23}

Physical Activity

PA was measured using the wrist-worn Fitbit Charge Activity Tracker (Fitbit, San Francisco, CA). The commercial activity tracker Fitbit has recently been validated in comparison to traditional accelerometers such as Actigraph (GT3x, GT9X; ActiGraph, Pensacola, FL), including in children with congenital heart disease.^{26,27} The device was chosen because it is a popular device, with the hopes of increasing patient compliance in the study, given previous studies describing poor compliance with the Actigraph accelerometer.^{28,29} The Fitbit Charge can measure heart rate, steps taken, distance covered, activity intensity, energy expenditure, stair flights climbed, sleep, hourly activity, and active minutes. The Fitbit can quantify activity intensity via metabolic equivalent of tasks (METs), which is the ratio of energy expenditure during the activity to energy expended at rest. An activity with an intensity of <1.5 METs is classified as sedentary time, an intensity of 1.5 to 3 METs is classified as light activity, an intensity of 3 to 6 METs as moderate activity, and >6 METs is classified as very active. We captured data on average daily heart rate, steps taken, distance covered, activity intensity, stair flights climbed, and active minutes.

Subjects were instructed to wear the Fitbit for 2 weeks, with the goal of capturing at a minimum of 5 complete days of activity to a maximum of 14 days of complete data. Based on previous reports, a cut-off point of approximately 12 500 Fitbit steps per day correlates well with adherence to recommended PA guidelines of 60 minutes of moderate to vigorous PA per day.²⁷ This correlation has been validated with receiver operating characteristic analysis, with an area under the curve of 0.82 (95% CI, 0.74–0.9).²⁷

All study data were collected using Research Electronic Data Capture. Study data were hosted at the University of Alberta (Edmonton, AB) and the Canadian Congenital Pediatric Cardiology Research Network. Research Electronic Data Capture is a secure, web-based software platform designed to support data capture for research studies.^{30,31} Data from Fitbit activity tracking were managed via the Fitabase platform (<https://www.fitabase.com>).

Statistical Analysis

Continuous variables were reported with mean±SD or as median (interquartile range [IQR] [25th percentile–75th percentile]), depending on the distribution. Categorical variables were reported as frequency and percent. Normality was assessed visually using histograms and Q-Q plots. No imputation method was used, and proportions of missing data were presented if needed.

HRQoL scores were calculated and reported as mean±SD and compared with a published cohort of

healthy children and those with children with chronic conditions.²² Comparison with population reference was made using a 1-sample *t* test. A Spearman correlation matrix was calculated for PA parameters. Simple and multiple linear regression modeling was conducted to assess the strength of association between PA metrics as measured by the Fitbit and physical, psychosocial, and total summary scores obtained from the PedsQL Quality of Life Inventory 4.0. Covariate adjustments were made for age at enrollment, sex, BMI class at enrollment, cardiac arrest history, and implantable cardioverter-defibrillator implantation, and activity restrictions were made based on covariances of these variables. Results are presented as mean difference (MD) with 95% CI. Results were obtained using R software version 4.2.3. Results are presented according to best practices on reporting results of statistical tests, with a 2-sided *P* value <0.05 considered a statistically significant result.^{32,33}

RESULTS

Cohort Characteristics

A total of 56 participants were recruited to the study. The median age at enrollment was 15.5 years (IQR, 13.8–16.8), and 16 out of 56 (29%) of the cohort were girls. More than half of participants were overweight or obese (30/56, 54%), and most were activity restricted (42/56, 75%) by their primary cardiologist. A more detailed outline of cohort parameters can be found in [Table 1](#).

Physical Activity

Fitbit Charge activity trackers were worn a median time of 14 days (IQR, 13.3–14.0) throughout the study period. Participants took a median of 7586 average steps per day (IQR, 5333–10324), with 12.5% of individuals reaching an average daily step count of >12 500 steps per day. Participants covered a median daily distance of 5.4 km (IQR, 3.7–7.5 km) and had a median total active time of 246 minutes (IQR, 187–302 minutes) per day. The median daily average flights of stairs climbed was 10.2 (IQR, 5.7–17.0) ([Table 2](#)).

PedsQL Quality of Life Module 4.0

Physical, psychosocial, and total PedsQL summary scores for the cohort are summarized in [Figure 1](#) and [Table S1](#). There was evidence to suggest a difference between child and teen PedsQL mean (±SD) scores of our cohort and a reference population of healthy children aged 5 to 16 years for physical summary scores (76.2 [±20.2] versus 87.7 [±13.1], respectively; *P*<0.0001), psychosocial summary scores (72.5 [±17.5] versus 81.8 [±14.0]; *P*<0.001), and total scores (73.8 [±16.0] versus

Table 1. Baseline Characteristics of the Cohort

| Variable | Sample (n=56) |
|---|--|
| Demographic and comorbidities | |
| Age at enrollment, y, median (IQR) | 15.5 (13.8–16.8) |
| Age at diagnosis, y, median (IQR) | 11 (4.3–13.8) |
| Female sex, n (%) | 16 (29) |
| BMI at enrollment, median (IQR) | 23.3 (19.5–27.7) |
| BMI at diagnosis, median (IQR) | 20.3 (17.4–23.4) |
| BMI class | |
| Normal weight | 26 (46) |
| Overweight | 15 (27) |
| Obese | 15 (27) |
| Clinical presentation | |
| New York Heart Association class, n (%) | Class I: 34 (61.8) Class II: 21 (38.2) Class III and IV: 0 (0) |
| Activity restriction by cardiologist, n (%) | 42 (75) |
| Exercise intolerance, n (%) | 11 (19.6) |
| Cardiac arrest history, n (%) | 6 (11) |
| LVOT gradient, n (%) | 18 (35) |
| LVOT gradient, median [IQR] | 32 [23–57] |
| ICD implant, n (%) | 17 (30.4) |
| Myectomy, n (%) | 7 (12.5) |
| Shortness of breath, n (%) | 11 (19.6) |
| Chest pain, n (%) | 9 (16.1) |
| Dizziness, n (%) | 10 (17.9) |
| Palpitations, n (%) | 12 (21.4) |
| Fainting, n (%) | 1 (1.8) |
| Edema, n (%) | 3 (5.4) |

BMI indicates body mass index; ICD, implantable cardioverter-defibrillator; IQR, interquartile range; and LVOT, left ventricular outflow tract.

83.9 [±12.5]; $P < 0.0001$). No difference was suggested between child and teen PedsQL scores of our cohort and a reference population of children with chronic conditions for physical, psychosocial, and total summary scores (71.3 [±17.1], 79.5 [±10.1], and 74.2 [±15.4], respectively) for children with chronic disease ($P > 0.05$

Table 2. Statistics of Physical Activity as Measured by the Fitbit Device

| Variable | Sample (n=54) |
|--|-------------------|
| Time Fitbit worn, d, median [IQR] | 14 [13.25–14] |
| Average daily step count, median [IQR] | 7586 [5333–10324] |
| Average daily step count ≥ 12500 , n (%) | 7 (12.5) |
| Average daily distance covered in km, median [IQR] | 5.4 [3.7–7.5] |
| Total of very, moderate, and lightly active, min, median [IQR] | 246 [187–302] |
| Daily average flights of stairs climbed, median [IQR] | 10.2 [5.7–17] |

IQR indicates interquartile range.

for each in comparison with our cohort) (Figure 1 and Table S1). For child and teen reports, the cohort reported mean (\pm SD) emotional functioning scores of 71.6 (± 23.5), social functioning scores of 77.2 (± 20.9), and school functioning scores of 68.7 (± 22.7). For parent proxy reports, the cohort reported mean physical functioning scores of 66.6 (± 20.4), emotional functioning scores of 69.9 (± 24.1), social functioning scores of 70.2 (± 23.9), school functioning scores of 70.2 (± 23.9), psychosocial health summary scores of 72.5 (± 20.7), and total scores of 72.9 (± 20.3). The proportions (95% CI) of individuals >1 SD below the sample mean for psychosocial, physical, and total HRQoL summary scores are 17.8% (8.9–30.4), 19.6% (10.2–32.2), and 19.6% (10.2–32.2), respectively (Figure 2, Table S2). There was no evidence to suggest these proportions differed from a general pediatric reference population's proportions >1 SD below the mean for psychosocial, physical, and total HRQoL summary scores of 15.8% (14.9–16.7), 14.8% (13.9–15.7), and 16.9 (16.0–17.9), respectively ($P > 0.05$, Figure 2, Table S2).²²

Relationship of HRQoL by Child and Teen Report and Physical Activity

Unadjusted linear regression models showed a significant association between physical score and both average daily distance covered (MD of 2.22 per km [95% CI, 0.40–4.04]; $P = 0.018$) and daily average flights of stairs climbed (MD of 0.57 [95% CI, 0.04–1.10]; $P = 0.037$). We could not conclude any significant association with any metric of HRQoL with other metrics of PA (P values all > 0.05 , MDs presented in Table 3).

Adjusted linear regression models found that average daily step count (per 1000 steps, MD of 1.83 [95% CI, 0.53–3.13]; $P = 0.007$) and average daily distance covered per km, MD of 2.88 [95% CI, 1.06–4.7]; $P = 0.003$) were significantly associated with physical HRQoL score. The adjusted daily average flights of stairs climbed was significantly associated with physical (MD of 0.76 [95% CI, 0.24–1.28]; $P = 0.005$) and total summary scores (MD of 0.62 [95% CI, 0.09–1.14]; $P = 0.020$) of HRQoL, but despite a moderate effect size, we could not conclude any significant association for psychological measures (MD of 0.54 [95% CI, 0.06–1.15]; $P = 0.078$).

Average daily heart rate and total active time were not associated with any measure of HRQoL for either adjusted or unadjusted MDs (Table 3).

DISCUSSION

The aim of this study was to investigate HRQoL and determine its relationship with PA in children with HCM. We report that children with HCM have significantly

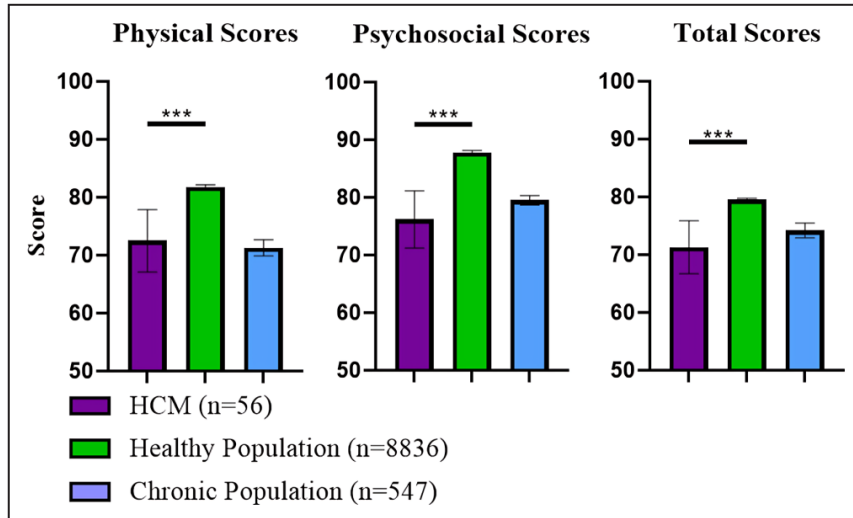


Figure 1. Physical, psychosocial, and total PedsQL 4.0 summary scores in comparison to a published large cohort of healthy children and children with chronic disease.²²

Results are presented as mean with 95% CI error bars. *** $P < 0.001$. HCM indicates hypertrophic cardiomyopathy; and PedsQL, Pediatric Quality of Life.

diminished HRQoL dimensions in comparison to healthy populations of children, with HRQoL similar to that of children with chronic conditions.²² With regard to a reference population of healthy children aged 5 to 18 years, there was a comparable proportion of individuals within our cohort who were at risk for decreased HRQoL (>1 SD lower than the mean). We also found a correlation between PA and dimensions of HRQoL. Generally, these findings support the notion that HCM is a chronic disease with a similar impact on HRQoL to other chronic disorders and suggest there are opportunities for HRQoL to be improved, with PA potentially playing a role.

It is widely acknowledged that children and adolescents with chronic health conditions exhibit lowered HRQoL than their healthy peers.^{16,34,35} Conditions that especially impair physical functioning and the ability to partake in activities with peers are expected to yield larger reductions in HRQoL, given that they indirectly affect all dimensions of HRQoL in addition to the physical dimension.³⁴ A report comparing HRQoL in a multitude of chronic conditions in children and adolescents found that conditions with high physical impairment, such as cerebral palsy or rheumatoid disorders, had the most impaired HRQoL of a variety of chronic conditions.¹⁶ In children with congenital heart disease, HRQoL scores

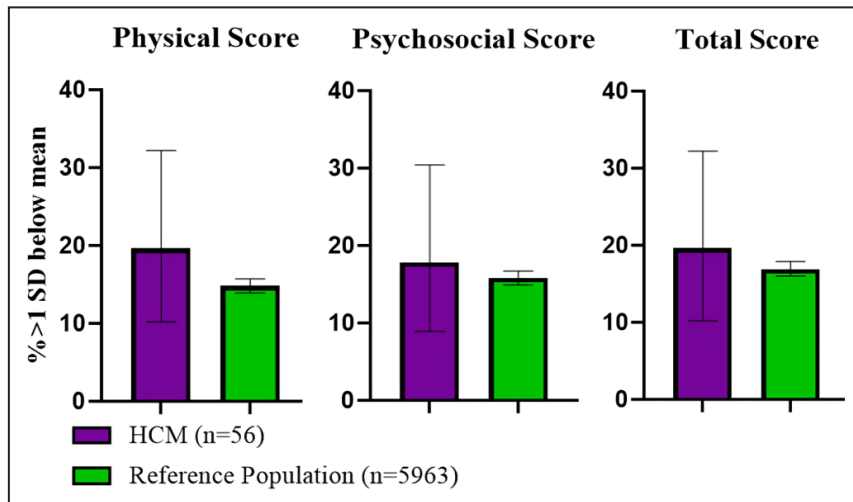


Figure 2. Proportions (%) of the cohort >1 SD lower than the sample mean with comparison to a reference population²² with 95% CI error bars.

HCM indicates hypertrophic cardiomyopathy.

Table 3. Strength of Association of Activity Level as Measured by Fitbit on Health-Related Quality of Life Measures According to Linear Regression Model

| Outcome | Unadjusted mean differences (95% CI) | P value for unadjusted mean differences | Adjusted mean differences (95% CI) | P value for adjusted mean differences |
|---|--------------------------------------|---|------------------------------------|---------------------------------------|
| Average daily heart rate, per bpm | | | | |
| Psychological score | −0.01 (−0.59 to 0.57) | 0.97 | 0.14 (−0.46 to 0.75) | 0.64 |
| Physical score | −0.19 (−0.75 to 0.36) | 0.48 | −0.06 (−0.61 to 0.495) | 0.84 |
| Total score | −0.08 (−0.6 to 0.46) | 0.78 | 0.07 (−0.47 to 0.62) | 0.79 |
| Average daily step count, per 1000 steps | | | | |
| Psychological score | 0.27 (−1.1 to 1.6) | 0.70 | 0.48 (−1.06 to 2.04) | 0.53 |
| Physical score | 1.2 (−0.07 to 2.5) | 0.06 | 1.83 (0.53 to 3.13) | 0.007* |
| Total score | 0.6 (−0.7 to 1.8) | 0.35 | 0.95 (−0.4 to 2.3) | 0.16 |
| Average daily distance covered, per km | | | | |
| Psychological score | 1.04 (−0.94 to 3.02) | 0.30 | 1.27 (−0.93 to 3.47) | 0.25 |
| Physical score | 2.22 (0.40 to 4.04) | 0.018* | 2.88 (1.06 to 4.7) | 0.003* |
| Total score | 1.45 (−0.35 to 3.25) | 0.12 | 1.83 (−0.07 to 3.74) | 0.06 |
| Total of active times, min, per 100 min | | | | |
| Psychological score | −0.06 (−5.4 to 5.3) | 0.98 | −0.4 (−6.03 to 5.16) | 0.88 |
| Physical score | 4.2 (−0.8 to 9.2) | 0.10 | 4.4 (−0.47 to 9.29) | 0.075 |
| Total score | 1.4 (−3.5 to 6.4) | 0.56 | 1.25 (−3.7 to 6.21) | 0.61 |
| Daily average flights of stairs climbed, per flight | | | | |
| Psychological score | 0.39 (−0.17 to 0.96) | 0.17 | 0.54 (−0.06 to 1.15) | 0.08 |
| Physical score | 0.57 (0.04 to 1.1) | 0.037* | 0.76 (0.24 to 1.28) | 0.005* |
| Total score | 0.45 (−0.06 to 0.97) | 0.08 | 0.62 (0.09 to 1.14) | 0.020* |

*Indicates a *P* value <0.05.

showed significant correlations with cardiopulmonary exercise test variables, further suggesting that exercise capacity impacts HRQoL.^{36,37} In the case of HCM, PA restriction or exercise intolerance can similarly prevent individuals from partaking in activities with their peers and place limitations on age-appropriate functions. Therefore, these limitations may have manifested in lowered HRQoL in the current study, explaining the similarity we find to the reference population for children with chronic conditions. Another contribution to decreased HRQoL may also be obesity. Children and adolescents with severe obesity are shown to have decreased HRQoL in comparison to individuals with normal body weight, and the BMI Z score was correlated with reduced HRQoL.^{38–40} Although we adjusted for BMI in our analysis, half of our cohort was overweight or obese, similarly to other cohorts of adults and children with HCM.^{12,41} Therefore, physical activity may be another potential target for future interventions to improve HRQoL in children with HCM.^{36,42}

Therefore, we explored whether the current activity level of children with HCM in Canada was associated with HRQoL. Using the objective measures of PA obtained through the Fitbit, this study was able to correlate PA with HRQoL. Participants in our study showed high compliance with the Fitbit over the study period, with a median wear time of 14 out of 14 days (Table 2), adding to previous reports of increased compliance with

wrist-worn activity trackers compared with hip-mounted accelerometers.^{28,29} The PA parameters of total daily steps, distance covered, and daily flights of stairs were all correlated with physical HRQoL. A meta-analysis by Wu et al found a dose–response relationship between PA and HRQoL.¹³ In agreement, a study by Brudy et al showed that daily steps and minutes of moderate to vigorous physical activity were associated with physical well-being and everyday functioning in children and adolescents with congenital heart disease via the Kinder Lebensqualität questionnaire.⁴³ Given that physical HRQoL scores represent an individual's ability to do activities independently or partake in physical activities, the associations made in the current study suggest that regular participation in PA could have a positive effect on HRQoL in the context of HCM. This is supported by studies that have shown that increased PA is associated with improved HRQoL in other pediatric populations with chronic illnesses, such as children with cancer⁴⁴ or following kidney transplant.⁴⁵ A systematic review and meta-analysis of the effect of PA on HRQoL in children and adolescents from a number of chronic and healthy populations found a positive effect in both descriptive and intervention studies.¹⁵ Thus, there is ample evidence to suggest the impact of PA on HRQoL.

Although there was not a specific parameter that was associated with psychological HRQoL, an increase in the number of flights of stairs was associated with

overall HRQoL. This finding may suggest that more difficult types of exercise (eg, climbing flights of stairs) may have a more well-rounded effect on HRQoL, because accomplishing more difficult activities can be a sign of improved self-efficacy.⁴⁶ Studies on the impact of exercise type on HRQoL in various adult and pediatric populations have varied in their conclusions, with some holding that exercise participation matters more than what type of exercise,^{42,47} and others suggesting only certain types of exercise mediate a benefit to HRQoL.^{48,49} It is yet to be established which may be true for children with chronic cardiac conditions like HCM.⁵⁰ Nonetheless, other studies in healthy children have associated increased physical activity with physical dimensions of HRQoL.^{51,52} Given the small proportion of patients who completed >12 500 steps per day in this study, further work is needed to determine if prescription of PA can lead to improvements in all scoring metrics of HRQoL and potentially reverse some of the impact of having a chronic disease.

PA could be in the form of exercise programs that in turn have the potential to boost HRQoL. Casey et al found that implementation of an exercise intervention program in adolescent girls without chronic disease resulted in increases in all measures of HRQoL.⁵³ An additional study targeting an aerobic training program for individuals with metabolic syndrome found that in almost all metrics of HRQoL (via Short Form-36 scores), motivation and mental health were significantly improved in the intervention group.⁵⁴ Although our study demonstrates that walking is associated with physical HRQoL in patients with HCM, longer-term and intentional aerobic exercise may be more relevant in improving psychosocial HRQoL in this patient population. Studies in adult patients with HCM have trialed mild exercise programs and have concluded that they are safe (neither study reported serious adverse events) and can even boost quality of life.^{55,56} These studies resulted in small increases in exercise capacity, so it remains to be established what the optimal exercise intensity is in this population and what would be deemed safe.^{57,58} This current study supports the notion that participation in physical activities measurable by the Fitbit associates with increases in physical HRQoL in patients with HCM.

LIMITATIONS

Certain limitations should be considered when interpreting the results of our study. We note a modest sample size, with a low proportion of the cohort being girls (29%), which may skew results given that PA profiles between sexes may be different. However, other studies of HCM in children also report a mostly male cohort.^{59,60} In our study, the metrics provided by the

Fitbit were not supported by objective characterizations of physical fitness (eg, cardiopulmonary exercise testing, the 6-minute walk test); however, we contend that passive assessment of everyday activities by the Fitbit were more appropriate to associate with HRQoL than measurements of maximal exercise capacity. A time period of 2 weeks to collect Fitbit data may be a relatively short time to evaluate exercise, given that PA can vary seasonally in pediatric populations with cardiac conditions, being highest in the late spring and autumn.⁶¹ This is especially true in northern climates such as Canada, where cold winter temperatures can limit outdoor PA. Weather over the study period may be a confounding variable that prevented some individuals from exercising on certain days, which may dampen the association between the cohort's PA and HRQoL. It should also be emphasized that some study participants were enrolled in the study throughout intermittent COVID-19 pandemic lockdowns. Although it is uncertain how the PA habits of our cohort were impacted by lockdowns, these circumstances may have influenced the study. We also note that measurement of active minutes by the Fitbit device is only done if the activity at hand reaches a threshold MET; therefore, brief and sporadic bursts of activity may be missed and contributed to sedentary time instead. Finally, in the current study we did not report on the individual correlates with lowered levels of PA. These analyses are the subject of another article on this cohort currently in preparation, with the focus of the current article specifically on the relationship between HRQoL and PA.

CONCLUSIONS

Overall, we report low HRQoL in pediatric patients with primary HCM, noting their similarity to individuals with chronic disease. We show that objective measures of PA via wrist-bound activity tracking were significantly associated with physical measures of HRQoL in children with HCM. Our study further emphasizes the lack of PA in this population, highlighting that exercise interventions in this population of children may have benefits beyond cardiovascular health.

ARTICLE INFORMATION

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Disclosures

None.

Supplemental Material

Data S1

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