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Physical activity in the Fontan population: provider recommendations and patient actions

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Abstract

Background: Emerging evidence suggests that routine physical activity may improve exercise capacity, long-term outcomes, and quality of life in individuals with Fontan circulation. Despite this, it is unclear how active these individuals are and what guidance they receive from medical providers regarding physical activity. The aim of this study was to survey Fontan patients on personal physical activity behaviours and their cardiologist-directed physical activity recommendations to set a baseline for future targeted efforts to improve this. *Methods:* An electronic survey assessing physical activity habits and cardiologist-directed guidance was developed in concert with content experts and patients/parents and shared via a social media campaign with Fontan patients and their families. *Results:* A total of 168 individuals completed the survey. The median age of respondents was 10 years, 51% identifying as male. Overall, 21% of respondents spend > 5 hours per week engaged in low-exertion activity and only 7% spend > 5 hours per week engaged in high-exertion activity. In all domains questioned, pre-adolescents reported higher participation rates than adolescents. Nearly half (43%) of respondents reported that they do not discuss activity recommendations with their cardiologist. *Conclusions:* Despite increasing evidence over the last two decades demonstrating the benefit of exercise for individuals living with Fontan circulation, only a minority of patients report engaging in significant amounts of physical activity or discussing activity goals with their cardiologist. Specific, individualized, and actionable education needs to be provided to patients, families, and providers to promote and support regular physical activity in this patient population.

Introduction

Despite a lack of evidence, it was historically assumed and often recommended that individuals with Fontan-palliated single ventricle heart disease should be restricted from regular physical activity and exercise. Concern over potential life-threatening sudden cardiac events and a previous lack of evidence-based support for the benefits of exercise were likely drivers for these recommendations. However, there is now mounting evidence that regular physical activity is not only acceptable but should be encouraged in patients with Fontan circulation. Several recent studies have outlined the physiologic limitations of exercise for those living with single ventricle heart disease and also highlight that exercise is safe for many patients with single ventricle heart disease and may provide many benefits. In this population, exercise has been demonstrated to augment peripheral venous return via increased muscle mass, improve ventilatory efficiency, and improve quality of life,[1–3] which are all likely beneficial in this population. The positive impact of a formal exercise training programme on exercise performance has been described[4–13] however, it remains unclear how often these recommendations reach patients. Khoury et al demonstrated that paediatric patients without signs of heart failure are more likely to receive formal exercise recommendations, whereas those with these signs are more likely to be restricted. These differences are even more pronounced based on whether the patient was managed by a general cardiologist or a heart failure-trained specialist, with the latter more likely to recommend physical activity.[14] Further potentially supporting the benefit of exercise, the concept of the super-Fontan phenotype, or those with single ventricle heart disease and relatively normal exercise capacity, has been termed in the literature.[15] These individuals have been shown to be more active throughout childhood and have higher exercise self-efficacy.[16,17] To better provide formal physical activity recommendations to this specific population, several groups have attempted to develop formal exercise programmes for individuals with single ventricle heart disease.[6,8,9,11,12,18–20] Despite these efforts, there remains a lack of literature

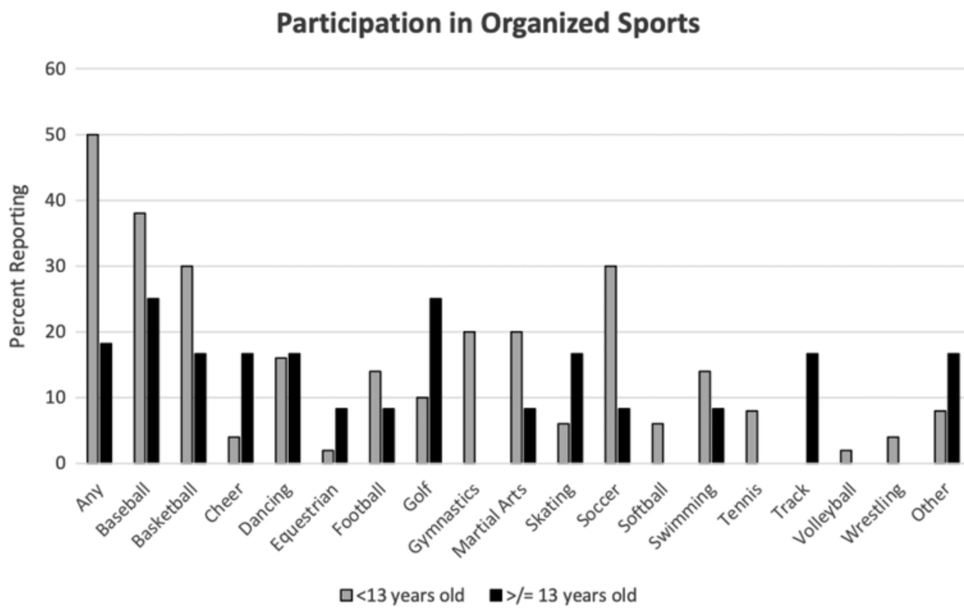

Figure 1 Respondent self-reported participation in organized sports at time of survey.

surrounding best exercise practices for those with single ventricle heart disease, and thus lack of literature to guide cardiologist recommendations.

To understand the scope of exercise participation in the general Fontan patient population as well as what patients/parents report they receive as exercise instructions from their cardiologists, we surveyed individuals living with or caring for those with single ventricle heart disease. We hypothesised that the prevalence of effective recommendations for specific physical activity guidance is low, and that the overall patient population would report low levels of physical activity despite evidence suggesting its importance.

Materials and methods

Study design

An electronic survey to assess the physical activity habits of individuals living with single ventricle heart disease and cardiologist-driven recommendations was administered. This survey was developed by an expert, multidisciplinary panel with experience in survey design, psychology, and clinical expertise in multiple domains of cardiac and surgical care. Two parents of individuals with single ventricle heart disease also helped author the survey. The survey included fixed response and Likert rating scale items across the following domains: demographic/disease information, physical activity habits, patient and parental perceived importance of and reservations/concerns about physical activity, and recommendations from their cardiologists regarding physical activity instructions and/or restrictions. No direct patient identifying information was included. The survey, which took < 10 minutes to complete, was administered using REDCap (Research Electronic Data Capture) survey software (Vanderbilt University; UM grant UM1TR004404) with dynamic routing capabilities. Some questions could be skipped allowing participants to complete the survey without answering questions they did not know or understand. The study was reviewed and approved by the University of Michigan Institutional Review Board with electronic consent obtained from participants. The survey instrument was piloted by 5 patients/families at the University of Michigan Congenital Heart Center, and their feedback was used to make final adjustments.

The survey itself can be seen here (Supplemental Figure 1). It includes a series of queries to gauge the availability of opportunities, frequency, duration, type, and intensity of exercise. The type of activity was categorised as either low-exertion (defined as going for a walk or a leisurely bike ride) or high-exertion (defined as running, playing soccer or basketball at the park, skateboarding, weightlifting, or skiing). It also specifically queried type and frequency of recommendations from their cardiologist, as well as respondent opinions about exercise and limitations to exercising.

Participants and recruitment

Eligible participants included caregivers of children living with single ventricle heart disease and adolescents or young adults with single ventricle heart disease. Participants were recruited through a social media campaign including social media postings on Facebook support groups, dispersal by at least 11 paediatric and adult CHD organisations advertising the survey, and postings by well-known support groups for those with single ventricle heart disease. This methodology for recruiting patients and obtaining information from individuals with single ventricle heart disease has been previously utilised and found to provide reliable information without concerns about reporting validity or erroneous participation by our group.[21,22] The survey was open from 11/13/2020 through 3/4/2021. Partial responses to the entire survey were included if the response included demographic information and report of exercise/physical activity.

Statistical analysis

Survey responses were summarised as frequency with percentage (%) for categorical variables and median with interquartile range for continuous variables. Patients were divided into two groups: pre-adolescents (< 13 years of age) and adolescents and young adults (13 years and older), and the survey results were compared between the age groups using Chi-square test or Fisher's exact test for categorical variables and Wilcoxon rank sum test for

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Table 1. Participant characteristics (N = 168)

Age of Fontan participant (years)	10 (7-18)
Respondent Type	
Fontan patients	39 (23.2%)
Parents or guardians	129 (76.8%)
Biologic Sex	
Male	85 (50.6%)
Female	83 (49.4%)
Country of Living: United States	140 (83.3%)
Co-morbidities	
Respiratory Problem	33 (19.6%)
Musculoskeletal Problem	37 (22.0%)
Neurologic Problem	13 (7.7%)

*Data are presented as n (%) for categorical variables and median (interquartile range) for continuous variable.

continuous variables. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA), with a statistical significance level of 0.05 using two-sided tests.

Results

Participant characteristics

Of the 196 respondents who started the survey, a total of 168 (86%) provided adequate responses to be included in the analysis. Of the included respondents, 39 (23%) were individuals living with single ventricle heart disease (all but one was 18 years or older) and 129 (77%) were caregivers of a child living with single ventricle heart disease. Participant characteristics are shown in Table 1. Participants were followed at a large variety of institutions for cardiac care. One hundred four respondents (62%) reported seeing their cardiologist more than once a year and 56 respondents (33%) are followed or co-followed in a dedicated Fontan clinic.

Reported exercise participation

Of the respondents, 138 (82%) reported enrolment in school (not home schooled). Of these, 103 (75%) reported that gym class was offered at their school. As shown in Table 2, only 36 (35%) of those offered gym class fully participate, while 62 (60%) have some degree of limited participation in gym class. Significantly more pre-adolescents participated fully in gym class (41%) than adolescents (14%) ($p = 0.02$). Reasons for limited participation include insufficient energy (71%), symptoms with physical activity (23%), and cardiologist restrictions (8%). Only 37% of participants reported participation in an organised sport, which is broken down by sport in Figure 1. Significantly more pre-adolescents participated in organised sports (50%) than adolescents (18%) ($p < 0.0001$).

Activities outside of school were queried. Distribution of low-exertion activity is shown in Figure 2. There was no difference between the number of days that pre-adolescents and adolescents participated in low-exertion activity for 30 minutes or more (median 3 days vs. 2.5 days/week; $p = 0.13$); however, pre-adolescents were significantly more engaged in low-exertion activity lasting less than 30 minutes (median 4 days vs.

Table 2. Individual participation in gym class at school

	Full participation	Limited participation	No participation
All	36/103 (35%)	62/103 (60.2%)	5/103 (4.9%)
< 13 years old	33/81 (40.7%)	46/81 (56.8%)	2/81 (2.5%)
≥ 13 years old	3/22 (13.6%)	16/22 (72.7%)	3/22 (13.6%)

2 days/week; $p = 0.01$). Type and distribution of high-exertion activity is shown in Figure 3. While pre-adolescents engaged in short (<30 minutes) high-exertion exercise more than adolescents (median 2 days vs. 0 day/week; $p = 0.0002$), there was no significant difference between the age groups for high-exertion exercise lasting 30 minutes or more (median 1 day vs. 0 days/week; $p = 0.26$), with both groups overall reporting very low participation.

Participants were then queried about limitations to physical activity; adolescents more frequently reported limitation to their activity level due to perceived necessity based on their heart condition (73% vs. 35%, $p < 0.0001$). Conversely, 65% of adolescents reported a desire to participate in physical activity more but were unable to due to limitations from their heart condition, compared to 43% of pre-adolescents ($p = 0.01$). Activity restriction across different activities is broken down based on the source of restriction in Figure 4. The majority of restrictions were either self- or parental-imposed, rather than cardiologist-imposed. Almost half of respondents reported restrictions to heavy weightlifting (46%) and intense aerobic activity (48%) (irrespective of source of restriction), with no significant difference based on age. Many more adolescents (29%) than pre-adolescents (8%) self-restrict intense aerobic activity, and almost none of them had cardiologist-imposed restrictions. Only 35% of all individuals reported restriction from competitive sports; however, many more adolescents were restricted than pre-adolescents (45% vs. 23%, $p < 0.05$). This was both in part due to self and cardiologist restrictions. Only about one-quarter (27%) of individuals reported complete activity restrictions, and this was primarily self-induced rather than cardiologist-recommended, regardless of age. No participants reported complete activity restriction from their cardiologist.

One-third of individuals reported being seen in a dedicated single ventricle clinic in addition to regular visits with their general cardiologist. Some respondents reported receiving guidance from both the single ventricle clinic and general cardiologists. Fifty-seven per cent of individuals seen by general cardiologists-only reported discussing specific activities or exercise recommendations during visits compared to 69% of individuals seen in Fontan-specific clinics (Figure 5). Even with more guidance, those who were seen in a single ventricle clinic were not more active (in gym class, high-exertion activity, or number of active days per week) than those only seen by a general cardiologist. The general cardiologist discussed specific goals for time spent in activity with only 32% of respondents, whereas 50% of respondents had this discussed in the single ventricle clinic. Lastly, the general cardiologist discussed specific goals for the intensity of activity with 21% of respondents compared to the single ventricle clinic who discussed this with 33% of respondents. Twenty per cent of respondents reported that their cardiologist recommendations regarding exercise have changed over the past few years.

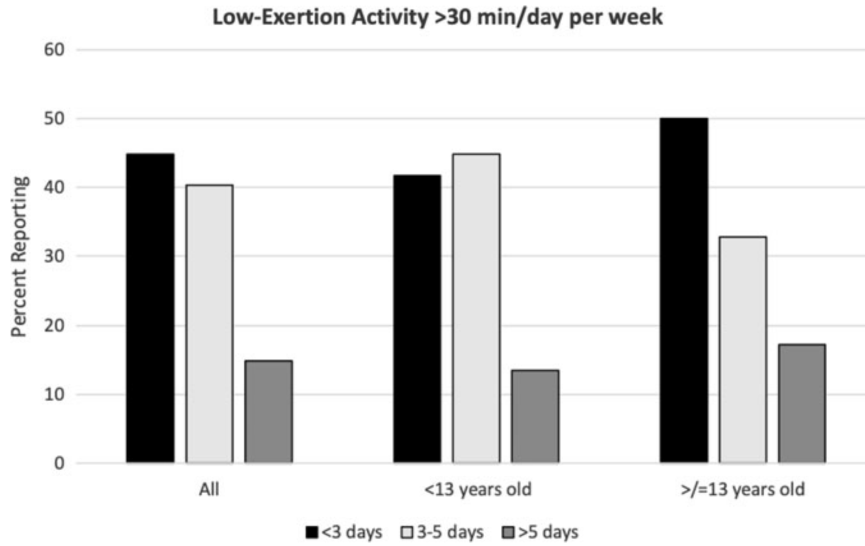

Figure 2 Participant report of low-exertion activity of more than 30 minutes a day per week.

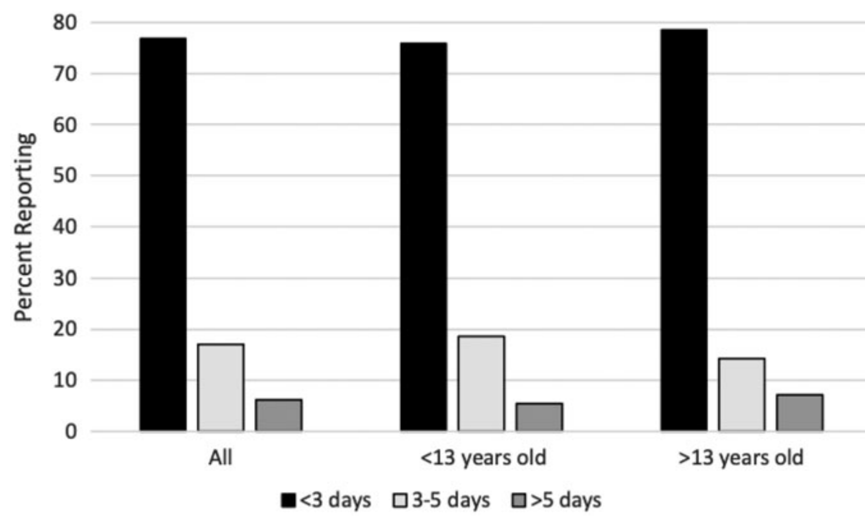

Figure 3 Participant report of high-exertion activity of more than 30 minutes a day per week.

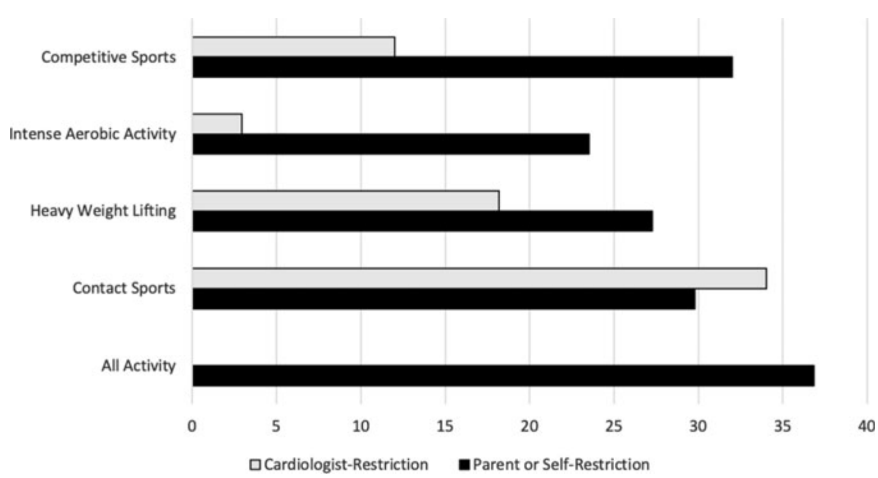

Figure 4 Participant report of type of activity restriction and imposer of each restriction.

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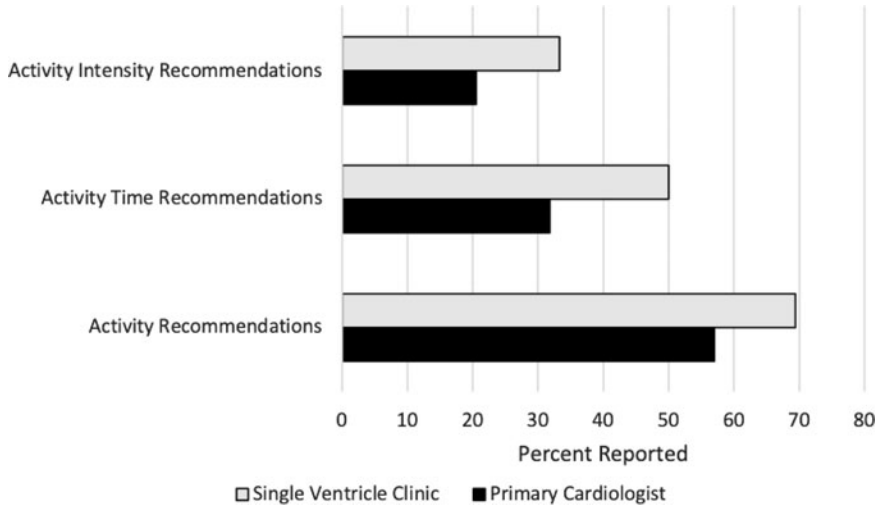

Figure 5 Specific exercise recommendations based on General Cardiologist vs Single Ventricle Clinic.

Discussion

This survey of individuals with Fontan physiology is the largest contemporary assessment of physical activity and cardiologist-driven activity recommendations. We found that physical activity varies widely but overall reported activity levels decrease as individuals get older. Perceived recommendations from cardiologists also vary widely, but few people report that their cardiologists restrict them from vigorous aerobic activity. A minority of patients report ever receiving specific physical activity instructions; however, this occurred more frequently in those who attended Fontan-specific clinics. These findings highlight educational opportunities to (1) positively modify physical activity behaviours in the Fontan community and (2) to better support cardiologists in providing specific, individualised exercise and activity recommendations in each clinic encounter.

Our study surveyed a wide geographic and age range to assess exercise practices and cardiologist recommendations. Most of our respondents were of school age; thus, our data was broken down as younger (pre-adolescent) or older than 13 years of age (adolescents). This corresponds with age around which most children enter high school, when reported physical activity levels decline significantly.[23–26] Although there are many factors that can lead to activity limitation, including physical and mental constraints, most respondents reported restrictions imposed by a parent or by the patient themselves, often due to fear that something bad could happen or that exercise and activity may be harmful for themselves/their child. Although many of these results are not surprising, they have not yet been reported in those with single ventricle heart disease. Similar to our findings, others have reported a decline in gym class participation and overall physical activity levels typically starting around high school age in the general population.[23–26] This is also the time where most sports become more competitive and less recreational. Importantly, those who participate in gym class are more likely to be physically active outside of school and meet daily activity recommendations,[27] which has recently also been shown to hold true in this population.[28] These differences are likely more important in those with single ventricle heart disease because the decline in exercise tolerance is more pronounced over time,[29–32] leading to poor exercise capacity in late adolescence. This decrease in exercise participation as individuals with Fontan circulation enter adolescence should be anticipated and provides an important opportunity to target interventions during clinic visits. Earlier intervention and discussion of exercise with this cohort may have a stronger impact on exercise habits and allow continuation of school-age levels of exercise into adolescence. In addition, exercise recommendations can be reviewed and targeted exercise prescriptions (including practical skills-building, training, and coaching) may be most helpful as the individual enters high school and has less school-based activity available.

Over the last few decades, there has been a data-driven paradigm shift in activity and exercise recommendations for patients with Fontan physiology. There are many studies reporting on the safety and benefits of exercise in this patient cohort, but little evidence to support specific types of exercise to recommend.[1,2,4,5,33–35] There are many programmes now focusing on exercise training and optimal type of training in these individuals, but it remains unclear what is optimal in those with single ventricle heart disease.[4,14,18,19,33,34,36] There is evidence from the Pediatric Heart Network-funded Fontan study that submaximal exercise (exercise at anaerobic threshold) is more preserved in this population, which is typically moderate level of exertion.[37] Our data show that Fontan patients are more likely to participate in low rather than high-exertion activity, but whether low-exertion activity is beneficial or sufficient in this population needs to be studied further. While many of our respondents reported parental or self-imposed activity restrictions, many of their limitations may be addressed with physical activity and better conditioning. Reported limitations included insufficient energy, respiratory or musculoskeletal problems, and symptoms with physical activity. Motivating patients to begin to exercise with steady advances in training may enable them to beat this cycle. In addition, starting these discussions when patients are young may help build a resilient and positive mindset towards physical activity, healthy movement, and specific activity modifications to support continued participation in school and community activities into adolescence and beyond. Our study did find that those individuals seen in a multidisciplinary clinic focused on the specific care of patients with single ventricle heart disease were more likely to discuss specific exercise recommendations. However, even in dedicated Fontan patient clinics, a significant proportion of patients still report not receiving any exercise-specific information. In addition, reported physical activity levels were not any different from those being seen in these specialised clinics. This clearly demonstrates an opportunity to improve direct patient education and instruction across the board for cardiologists and that what is being done right now is not adequate. Physical activity and exercise instructions to patients and family's needs to start early and be reinforced often, with specific goals of types and time of physical activity recommendations.

While clear, detailed exercise instructions are important, it is notable that many individuals who did receive exercise instructions still reported minimal exercise and self-imposed restrictions. Motivating individuals who would benefit from exercise to engage in physical activity is not a problem restricted to individuals with Fontan; however, those with Fontan physiology may be among the most likely to benefit. Cardiac rehabilitation programmes have been shown to be effective in adult cardiac disease but is likely not feasible in this small population. Formal, targeted, proctored exercise programmes that can be completed asynchronously at home may provide the most access for individuals and improve individual compliance with exercise. These types of programmes should be considered and designed for the specific population and the outcomes assessed for viability and efficacy.

Although this survey methodology has been previously effective, inevitably there are limitations related to surveys.[21] Given the method of dissemination of the study, only individuals or families active in social media sites for those with single ventricle heart disease would have been included, likely excluding a proportion of individuals with Fontan circulation who do not use social media regularly. Even with effective dissemination, there is likely voluntary response bias, with individuals who are more active being more likely to participate and want to show their activity, and social desirability bias, meaning people are more likely to overrepresent their "good behaviours" and underreport their "bad behaviours." Given this, we would expect the reports to be biased toward increased exercise, yet our study largely demonstrated low exercise participation. In addition, since the survey was distributed on social media there is the chance that individuals without single ventricle heart disease could spuriously respond to the survey although the survey was lengthy and there was no incentive to participate that would induce a non-Fontan related individual to participate. Second, patient-reported memory of physician recommendations is limited. At best, we can expect patients to recall about two-thirds of information told to them in clinic visits.[38,39] With this, we can assume some of the respondents to our survey were given different recommendations about exercise and activity than they remember, but the most important aspect is the takeaway message that patients understand. Family behaviours, socio-economic status, and neighbourhood safety are important factors that may impact individual activity levels and should be included in future studies of this population. Lastly, despite recruiting efforts our study size is limited. This also limited the ability to analyse data based on demographic variables such as race, ethnicity, or socio-economic status which have all been shown to impact physical activity levels in the general population.

In conclusion, despite mounting evidence of the benefits of consistent exercise in patients with Fontan circulation, only a small minority of patients report engaging in significant regular exercise. Additionally, a significant proportion of cardiologists do not discuss or recommend activity for these patients. Active discussions between patients and providers regarding specific exercise and activity should begin early and recur often to encourage the establishment of good behaviours and limit self-imposed restrictions.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1047951124026076.

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Competing interests. None.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the University of Michigan Institutional Review Board.

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