Physical activity levels of adolescents with congenital heart disease

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Regular physical activity prevents chronic disease and moderate to vigorous participation provides additional health benefits. Therefore, adolescents with congenital heart disease risk developing latent diseases due to real or perceived physical activity restrictions. Habitual physical activity levels, psychological determinants and advice received were examined by postal survey of 434 West Australian adolescents aged 12-18 years with congenital heart disease. Survey results (n = 153) were compared with published normative adolescent data. Total activity was classified as vigorous, adequate or inadequate according to metabolic equivalents, reported frequency and duration. Comparable numbers of respondents and healthy peers were active (winter 62% vs 74%; and summer 73% vs 82% respectively, p = 0.27). However, significantly fewer male respondents were classified as vigorously active compared with healthy peers, in both winter (48% vs 67%, p < 0.02), and summer (48% vs 69%, p = 0.04). Similar, but non-significant, trends were found when comparing female respondents with healthy peers and for mild versus severe disease groups. Self-efficacy ratings did not explain differences in physical activity intensity. Congenital heart disease may impact on the intensity of physical activity undertaken by affected adolescents thus denying additional health benefits. Physiotherapists could facilitate these adolescents to achieve more moderate to vigorous physical activity, to offset adult sedentary behaviour. **[Lunt D, Briffa T, Briffa NK and Ramsey J (2003): Physical activity levels of adolescents with congenital heart disease. Australian Journal of Physiotherapy 49: 43-50]**

Key words: Adolescence; Exercise; Heart Defects, Congenital; Heart Diseases

Introduction

Australian adolescents may be underactive, according to research showing increasing body fatness, increased participation in sedentary pursuits, less leisure physical activity and low fitness levels (Australian Bureau of Statistics 2000, Australian Institute of Health and Welfare 1998). A continuation of these health markers, particularly physical inactivity, into adulthood is projected to increase the prevalence of chronic diseases (Bauman and Egger 2000). Therefore, health authorities encourage children to undertake daily physical activity, with additional cardiovascular benefits gained from structured moderate to vigorous exercise for 20 minutes or more three times weekly (Bauman et al 2001).

Physiotherapists have a key role in promoting physical activity, with childhood and adolescence being a critical phase in the development of health behaviours. Little is known about physical activity levels among adolescents, especially in those with pathology. Young people with congenital heart disease, the most common congenital abnormality (Paridon 1997), have an exercise capacity similar to (Paridon 1997) or lower than (Fredriksen et al 1999) healthy peers. This was attributed to abnormal cardiac physiology (Paridon 1997), psychological restraints or low habitual physical activity levels (Fredriksen et al 1999).

In a randomised controlled trial, compliant children with

congenital heart disease who increased their physical activity after surgery achieved levels of fitness equalling healthy controls and significantly higher than non-(Longmuir compliant subjects et al 1990). Cardiorespiratory capacity and habitual physical activity levels have been measured in children following atrial septal defect repair (Reybrouck et al 1991). Those with surgery performed later showed significantly lower daily physical activity and cardiorespiratory capacity compared with those having early surgery or without heart conditions, suggesting that non-physiological factors affected subsequent behaviour. Moreover, many young adults with congenital heart disease have misconceptions about safe, desirable levels of physical activity, and have lower activity levels than recommended for their cardiac condition (Swan and Hillis 2000).

These findings suggest that adolescents with congenital heart disease may be less active than their healthy peers. Therefore, this study aimed to describe habitual physical activity levels of Australian adolescents with congenital heart disease, and compare these with published data for adolescents without congenital heart disease.

Methods

Subject selection Eligible participants were identified from records at Princess Margaret Hospital for Children (PMH), and from the three private paediatric cardiologists in Western Australian (WA). Adolescents with acquired

cardiac conditions, intellectual or physical disabilities or extremely severe cardiac illness, determined by their cardiologist, were excluded.

Children born between 1982 and 1988 were included, providing a study population of 434 adolescents aged 12-18 years in 2000. Their cardiac disease was classified as either mild (Category 1: no activity restrictions) or severe (Categories 2-5: some activity restrictions), according to published guidelines (Gutgesell et al 1986). Recommendations for children in restricted categories (2-5) range from avoiding contact or endurance sports to undertaking wheelchair activities only. However, these conditions are rare, so subjects in these categories were grouped together.

Ethical considerations Approval was received from the Human Research Ethics Committees of PMH and Curtin University of Technology and the WA Health Department's Confidentiality of Health Information Committee. Participants were deemed to have consented by responding to the survey. To reduce the likelihood of contacting the family of a child who was deceased, the subjects list was checked against the WA death registry.

Instrument A survey instrument providing recently published data from a population of Australian adolescents, and which differentiated those participating in physical activities at recommended minimal levels or at intensities which promote additional health effects (Bauman et al 2001), was required. The New South Wales (NSW) Schools Fitness and Physical Activity Survey (Booth et al 1997), shown to have good reliability and validity (Booth et al 2003), was chosen to provide the reference sample for this study.

Selected items from the NSW schools survey included in this instrument were demographics and physical characteristics, physical activity participation throughout 12 months, family and social support, and feelings and beliefs about physical activity. Adolescents recalled participation in organised sports and games and nonorganised physical activities in a normal week during summer and winter school terms, reporting frequency and duration of participation in each activity, including training sessions. Further, adolescents were asked to recall receiving advice from health professionals concerning physical activity. Copies of the survey instrument may be obtained from the authors.

Procedures A letter from the child's cardiologist inviting families to participate, the four-page survey instrument, a participant information sheet and de-identified and reply-paid envelopes were posted to parents/guardians of eligible adolescents. Distribution occurred in February, as for the reference survey, with one follow-up letter sent to non-respondents three weeks later.

Data management Physical activity data were managed according to procedures described by Booth et al (1997).

1. Separate calculations were conducted for summer

and winter. Organised and non-organised activities were combined.

- 2. Each activity was assigned an estimated rate of energy expenditure drawn from Ainsworth et al (1993) using MET values, where one MET represents the rate of energy expenditure at rest, which is approximately equal to 1 kcal/hour/kg or 3.5 mL/min/kg of oxygen.
- 3. Adjustments and exclusions:
 - Activities with MET values less than 3.5, plus cricket, softball, baseball, T-ball, sailing, handball, school sports, or fishing were not included, and time reported as surfing was divided by four, since these activities are mostly sedentary with only intermittent aerobic activity.
 - Activity participation of less than 10 minutes was not included.
 - Where duration and/or frequency of an activity was not reported, the most common values reported by others were used.
 - If a returned survey had insufficient activity information, two more general survey questions covering activity outside school hours allowed category allocation or the individual was telephoned for clarification.
- 4. Total activity was categorised as vigorous, adequate or inadequate.
 - *Vigorous* Adolescents who participate at least three times weekly, for 20 minutes or more per session, in activities with a MET value of 6.0 or greater. The three sessions may include different activities.
 - *Adequate* Adolescents who participate in a total of at least 3.5 hours over at least five sessions of activities with a MET value of 3.5 or greater but whose activity cannot be categorised as vigorous.
 - *Inadequate* Adolescents not allocated into either the vigorous or adequate categories.
- 5. Self-efficacy with physical activity was calculated across a five-item Likert scale (range 1-5, 1 being low) over six questions. Fourteen barriers to doing more exercise were examined using a five-item Likert scale, with responses ranging from "does not apply" to "applies strongly".
- 6. Subjects' address postcodes were used for allocation into socio-economic levels, based on the SEIFA index calculated from 1996 census data and published by the Australian Bureau of Statistics.

Data comparison Data collected in this survey were compared with normative data from two sources. Booth et al (1997) surveyed males and females in school years 8 and 10 (NSW) with a mean age of 14.2 years. When comparing data from adolescents with congenital heart disease with

	Respondents n = 153	Non-respondents n = 241	Test statistic and <i>p</i> -value	Sub-group of respondents in school years 9-11 n = 74		
Age (years at 28/2/01)						
Mean (SD)	14.6 (1.8)	14.6 (2.0) p = 0.78	$t_{(402)} = .28$	14.3		
Gender ¶						
Females	58 (38%)	103 (43%)		30 (40%)		
Males	95	138	χ^{2} [1, N = 394] = 0.90 p = 0.34	44		
CHD group ¶						
*Mild disease	110 (72%)	196 (81%)		57 (74%)		
#Severe disease	43	45	$\chi^{2}[1, N = 394] = 5.08$ p = 0.02	17		
Residence ¶						
Perth metropolitan	116 (76%)	181 (75%)		59 (79%)		
WA non-metropolitan	37	60	$\chi^{2}[1, N = 394] = 0.06$ p = 0.34	14		
Socio-economic status ¥						
< 25%	31 (20%)	68 (28%)				
25-50%	41 (27%)	59 (24%)				
50-75%	35 (23%)	64 (27%)	χ²[3, N = 428] = 2.36	3		
> 75%	33 (22%)	67 (28%)	p = 0.5			

Table 1. The population of WA adolescents with congenital heart disease, showing demographic characteristics of respondents, non-respondents and the comparison sub-group of subjects.

Test statistics and *p*-values refer to comparisons of respondents and non-respondents. SD = standard deviation. CHD = congenital heart disease. \P = values are number of subjects (percentages). * = 'Mild' CHD group diagnoses include: atrial or ventricular septal defect, patent ductus arteriosis, coarctation of aorta, < moderate valvular stenosis or incompetence, mild tetralogy of Fallot, stable arrythmias. # = 'Severe' CHD group diagnoses include: transposition of the great arteries, pulmonary or tricuspid atresia, \geq moderate aortic stenosis, Fontan surgery, heart transplant, truncus arteriosis, double outlet right ventricle, cor triatum, total anomolous pulmonary vasculature. ¥ = Quartiles based on ABS SEIFA Index.

this reference group only that from respondents in years 9 to 11 (WA), with a mean age of 14.3 years (n = 74), were used, to ensure groups were of comparable ages. Another data set available for comparison, published by the WA Ministry of Sport and Recreation (1998), reported the frequency of physical activity participation by 12 and 16 year olds.

For some comparisons, where numbers were small, the adequate and vigorous categories were combined and renamed active, while the inadequate group was renamed inactive.

Statistical analysis Data analysis was performed using the SPSS Base 6.1 for WindowsTM statistical package. Students' *t*-tests for parametric data and chi square tests for categorical data were used for comparisons within the congenital heart disease group and between the congenital heart disease and reference groups. Statistical significance was inferred at two-tailed p < 0.05.

Limitations The low (38%) response rate may produce sample bias, however respondent/non-respondent comparisons used to measure bias show no differences except in disease severity. Also, since probability sampling methods were used, lower response rates do not necessarily suggest low representation or accuracy, and may even be more accurate than higher response rates resulting from incentives or persistent follow-ups (Krosnick 1999).

The postal survey method may produce bias to those more interested in physical activity, therefore adolescents with congenital heart disease may be even less physically active than these results suggest. Questions regarding physical activity advice, developed for this study, have not been validity or reliability tested and results should be interpreted with caution.

The NSW schools survey was administered in classrooms, with assistance available. Respondents needing parental help with survey completion may have given overly **Table 2.** Percentage of all respondent WA adolescents with congenital heart disease classified into physical activity categories and season.

		Summer				
	Males	Females	All subjects	Males	Females	All subjects
	n = 95	n = 58	n = 153	n = 95	n = 58	n = 153
Physical activity category						
Vigorous (%)	38	45	41	47	29	40
Adequate (%)	31	33	31	34	24	30
Inadequate (%)	31	22	28	19	47	30

Chi square analysis comparing physical activity categories for males/females in summer - χ^2 [2, N = 153] = 1.2, p = 0.5. Chi square analysis comparing physical activity categories for males/females in winter - χ^2 [2, N = 153] = 4.9, p = 0.08.

Table 3. Physical activity levels of adolescents with congenital heart disease (CHD) and the adolescent reference group (Ref) classified according to gender and season (percentages).

		Sun	nmer		Winter				
	Males		Females		Males		Females		
	CHD	Ref	CHD	Ref	CHD	Ref	CHD	Ref	
	n = 44	n = 1081	n = 30	n = 945	n = 44	n = 1081	n = 30	n = 945	
Physical activit	y category								
Vigorous	48	69	50	60	48	67	30	46	
Adequate	29	15	17	19	25	13	17	22	
Inadequate	23	16	33	21	27	20	53	32	
	* <i>p</i> = 0.006		<i>p</i> = 0.13		*p =	* <i>p</i> = 0.018		<i>p</i> = 0.055	

* Statistically significant difference obtained by chi square analysis comparing CHD/Ref data. Data for Reference Group adolescents obtained from the NSW Schools Fitness and Physical Activity Survey (Booth et al 1997).

optimistic answers, especially regarding parental influence.

There may be inherent differences in physical activity participation between adolescents throughout Australia. However, participation rates in organised sports outside school hours of children aged 5-14 years in WA and NSW are very similar, with less than an 8% difference (Australian Bureau of Statistics 2000).

Results

One hundred and fifty-three completed surveys (38%) were returned. Forty (9%) blank surveys returned marked "not at this address" were removed from the non-respondents list. Table 1 shows comparisons and characteristics of the study population. The male/female, rural/metro ratios, socio-economic status and age distributions were comparable between respondents and non-respondents, indicating respondents were representative of the population of adolescents with congenital heart disease in these respects. However,

respondents included a significantly higher proportion of adolescents with severe congenital heart disease compared with non-respondents. Twenty-seven respondents had left school, 15 to attend tertiary institutions, and six were employed.

Parental help for survey completion was required by 47% of respondents, and 14 gave incomplete information to physical activity questions. Information from alternate questions regarding participation frequency allowed classification for five respondents and nine were telephoned for clarification.

Physical activity Total congenital heart disease group Table 2 shows the physical activity levels of all respondents according to season and gender. During a typical week in either summer or winter, on average, 70% of adolescents with congenital heart disease participated in either adequate or vigorous levels of physical activity.

Age and congenital heart disease Comparisons were made between age groups 12-14 (n = 58), 15-18 (n = 68), and

 Table 4.
 Physical activity levels of adolescents with congenital heart disease, classified according to season and disease severity.

		Sum	nmer	Winter				
	Mild n = 110		Severe n = 43		Mild n = 110		Severe n = 43	
Physical activity category								
Vigorous	47 ((43%)	16	(37%)	50	(48%)	12	(28%)
Adequate	34 ((31%)	14	(33%)	40	(36%)	19	(44%)
Inadequate	29 ((26%)	13	(30%)	20	(18%)	12	(28%)

Chi square analysis: summer χ^2 [2, N = 153] = 0.43, p = 0.80; winter χ^2 [2, N = 153] = 4.2, p = 0.12.

Table 5. The physical activity levels of adolescents with congenital heart disease (n = 153) classified according to season and advice from their cardiologist.

		Sum	nmer	Winter				
	Active n = 105		Inactive n = 48		Active n = 94		Inactive n = 59	
No advice	41	(39%)	16	(33%)	35	(37%)	22	(37%)
Yes advice - no limits	42	(40%)	22	(46%)	44	(47%)	20	(34%)
- limits	22	(21%)	10	(21%)	15	(16%)	17	(29%)

Chi square analysis: summer χ^2 [2, N = 153] = 0.9, p = 0.63; winter χ^2 [2, N = 153] = 4.1, p = 0.12.

school-leavers (15-18 years, n = 24), with categories regrouped into active and inactive due to small numbers. With results combined for both males and females, in summer and winter, a higher percentage of the younger age group were classified active (71%) than the older adolescents (65%) or school-leavers (46%). The male school-leavers (n = 20) were more inactive than those still at school (winter school-leavers 60%: compared with 33% of those aged 15-18 and 18% of those aged 12-14, p = 0.007 respectively).

WA Ministry of Sport and Recreation data The percentage of adolescents participating at least four times weekly in physical activities which make them "get out of breath or sweat", was similar in both the healthy population and in adolescents with congenital heart disease. Reported participation rates were 50% vs 51% for 12 year olds and 28% vs 26% for 16 year olds respectively.

Congenital heart disease compared with reference group Table 3 shows the physical activity levels achieved according to season and gender. When results of males and females are combined, in summer 73% of adolescents with congenital heart disease were active compared with 82% of reference adolescents and in winter 62% were active compared with 74% of reference group (p = 0.27)

At least 10% fewer males and females with congenital heart disease were classified as vigorously active compared with their healthy counterparts in both summer and winter, with data for males being significantly different. Males with congenital heart disease were more likely to be classified as undertaking adequate levels of activity than their reference group peers, (summer χ^2 [2, N = 1125] = 10.17, *p* = 0.006, and winter χ^2 [2, N = 1125] = 7.96, *p* = 0.018).

A greater proportion of females with congenital heart disease were classified as inadequately active in summer and winter compared with reference peers, and this approached statistical significance in winter (summer χ^2 [2, N = 975] = 4.0, *p* = 0.13, and winter χ^2 [2, N = 975] = 5.8, *p* = 0.055).

Severity of congenital heart disease Table 4 shows the activity levels of all respondents with congenital heart disease according to cardiac disease severity. Distribution of adolescents (male and female combined) across three levels of activity did not differ significantly between 'mild' and 'severe' groups. (summer χ^2 [2, N = 153] = 0.43, p = 0.8, and winter χ^2 [2, N = 153] = 4.2, p = 0.12).

Physical activity advice and congenital heart disease Most adolescents (61%) recalled receiving physical activity advice from their cardiologists, 41% from their family doctors, 25% from their heart surgeons, and 7% from hospital physiotherapists. However, 31% could not recall receiving advice from any listed health professional. Physical activity behaviours in relation to receiving advice are shown in Table 5.

Twenty-six (18%) adolescents with congenital heart disease recalled advice about activities that they should not undertake including, in order of frequency mentioned: scuba diving (10), rugby/football/contact sports (10), endurance sports (7) and weight lifting (5). Only one-third of the 43 adolescents with severe congenital heart disease recalled receiving medical advice about specific activity restrictions.

Psychosocial aspects of physical activity Self-efficacy scores, measuring confidence to participate, for adolescents with congenital heart disease (means: active group 3.3 and inactive 2.9) were not significantly different from the reference group scores (means: active group 3.15 and inactive 2.8; p = 0.28).

The barriers to doing more exercise most frequently reported to apply "strongly" or "very strongly" by the reference group were "I already do a lot of exercise" (21-50%, dependent on age and sex), reported by only 7% of the congenital heart disease group. "There are other things I like doing more" was reported by 20-31% of the reference group (dependent on age and sex) and by 27% of adolescents with congenital heart disease. The two barriers least often reported by adolescents with congenital heart disease with congenital heart disease with congenital heart disease. The two barriers least often reported by adolescents with congenital heart disease were "My parents don't encourage me" (3% but 13-18% of reference group) and "My health is not good enough" (1% but 5-18% of reference group).

Adolescents with congenital heart disease and the reference group reported similar levels of family support. Most parents of adolescents with congenital heart disease were positive role models for physical activity (mother 77%, father 73%), or provided help (mother 77%, father 70%) or praise and encouragement to play sport or exercise (mother 89%, father 82%).

Discussion

This study examined the habitual levels of physical activity in 153 WA adolescents with congenital heart disease. They are equally as active as WA adolescents without congenital heart disease when compared using the criterion of frequency of aerobic activity. However, when more detailed information including the intensity of physical activity was examined, significant differences were found between this group of adolescents with congenital heart disease and their healthy peers.

Although approximately two-thirds of these adolescents are habitually active, a smaller proportion report participating in vigorous physical activity when compared with reference group peers. For both males and females, in summer or winter, the adolescents with congenital heart disease were less likely to be classified into the vigorous and more likely into the inadequate category than were the reference adolescents. This finding is similar to that reported for adolescents with cystic fibrosis by Nixon et al (2001) and suggests these adolescents may not obtain the additional benefits conferred by undertaking vigorous activity.

Also of concern is the finding that 33% of adolescents with congenital heart disease, compared with 22% of reference adolescents, failed to reach the minimum level of activity recommended in the Australian National Heart Foundation's Physical Activity Policy (Bauman et al 2001). This has serious implications for their current mental and physical health and may lead to an increased risk of developing the chronic diseases associated with sedentary lifestyles.

Measuring physical activity involves physiological and behavioural aspects (Sallis et al 1992). If reported low physical activity levels were due to cardiovascular physiology alone, it should be reflected in relationships between severity of cardiac disease and physical activity levels. However, although those with severe disease were less likely to be vigorously active in winter, no significant difference was detected between the "mild" or "severe" groups in this study, suggesting that behavioural factors are influencing activity levels in addition to their cardiac condition.

The group of school-leavers (n = 24) with congenital heart disease reported lower activity levels than students of the same age and younger, with activity levels decreasing at an even greater rate than occurs in the general population (Bull et al 2000). Although results are derived from small sample numbers, this group may be at high risk of continuing a sedentary lifestyle as adults.

Although over-protection by parents is often described as a factor in lower physical activity levels in children with disabilities, these results do not support this assertion. Only four adolescents reported "My parents don't encourage or help me" as being a barrier to their activity, a smaller percentage than in the reference group. However, parental help in survey completion may have affected this response. Similarly, Swan and Hillis (2000) found only 3% of their subjects with congenital heart disease felt their parents were inappropriately concerned about sport and exercise. High levels of reported parental modelling, support and encouragement (> 70%), also suggest that respondents' parents are not restricting physical activity.

Stereotyping of sport participation may affect the decline in physical activity levels among males with congenital heart disease. The most popular winter sports are Australian Rules football, rugby, basketball, soccer and hockey, which may be described as competitive, contact or endurance sports. Limited sports participation is a sensitive issue for male adolescents, with implications for their physical strength and prowess, body image, and opportunities for team support (Tong et al 1998) impacting their self-esteem.

Whitehead (1995) suggests that if individuals protect their self-esteem by discounting the importance of physical fitness, their motivation to take part in fitness promoting activities would be reduced. This may present as a subtle lowering of an individual's goals as they accept the diagnosis of congenital heart disease. Expecting to be unable to participate in vigorous activities may shift their focus onto less demanding physical activities or onto other leisure pursuits entirely. This is supported by the finding that proportionately more adolescents with congenital heart disease, especially males, were classified as adequately active compared with healthy peers. The barrier most frequently supported by the congenital heart disease group, "There are other things I like doing more", may also reflect this priority change.

Perceptions of physical appearance are the major determinant of self-worth in teenagers and low self-worth depresses motivation by impacting on energy levels (Whitehead 1995). Therefore, another factor for low activity rates in this group of adolescents may be that those with obvious surgical scars, or with small stature or cyanosis, have developed a more negative self-concept than have their healthy peers. However, in this study there were insufficient data available to draw any conclusions concerning this hypothesis.

It appears that receiving advice from medical staff had little impact on these adolescents' subsequent physical activity behaviours, since one-third of those advised "no limits" on physical activity remained inactive. Also, only 19% of young adult subjects with congenital heart disease received advice about physical activity, and little relationship existed between advice received and current activity levels (Swan and Hillis 2000).

Many adolescents with congenital heart disease are seen infrequently by their cardiologist and the most common mode of imparting advice about physical activity is verbal. This data suggests these methods should be reviewed and new systems evaluated. Written instructions may be more effective, however studies show most adult patients do not read physical activity pamphlets (Sheedy et al 2000).

Currently at PMH, children with congenital heart disease are not routinely seen by a physiotherapist unless requiring acute inpatient care. Inactivity at early ages may restrict the ability to develop basic motor skills, isolate children from healthy peers and affect their quality of life (Tong et al 1998). Most surgery for congenital heart disease is performed when children are very young, and since postoperative rehabilitation programs provide long-term improvement in physical activity levels in children with congenital heart disease (Longmuir et al 1990), this could be the optimum time for physiotherapists to initiate programs.

Early review encouraging physical activity and regular

follow-up contacts with parents and older children may provide vital opportunities for education, motivation, and guidance to choose appropriate activity options. Affecting the physical activity behaviours of children may have lifelong consequences, and physiotherapists have a unique opportunity to use their clinical and motivational skills to become important contributors in this field.

Conclusion

The majority of adolescents with congenital heart disease are as physically active as healthy peers. However fewer, particularly boys, are as vigorously active as their peers during either summer or winter. Congenital heart disease therefore appears to impact on the intensity of physical activity undertaken by affected adolescents. Severity of disease did not account for these differences and physical activity advice from their cardiologist had little influence on their likelihood of being physically active. Thus adolescents with congenital heart disease may fail to achieve the additional benefits which can be derived from structured moderate to vigorous exercise.

With estimates of up to one half of the WA adolescents with congenital heart disease being classified as inactive, the risk of decline into sedentary adulthood and associated latent lifestyle diseases is considerable. It is important therefore, that promotion of increased physical activity in this group is implemented and evaluated, to improve their current health and reduce these risks. Physiotherapists, with their clinical knowledge and inclination toward promoting physical activity, may be perfectly placed to take on this challenge.

Acknowledgments The authors appreciate the assistance of Ms Mary Tallon, PMH cardiac liaison nurse and Drs Bullock, D'Orsogna, and Wallman, paediatric cardiologists, and thank Dr Michael Booth, The University of Sydney, for his advice. Ms Emily Lunt provided support and HeartKids (WA) Inc. contributed funding.

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