Cardiology in the Young

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Life satisfaction, health-related quality of life and physical activity after treatment for valvular aortic stenosis

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Abstract

Objective: To investigate health-related quality of life and life satisfaction in children and adolescents treated for isolated congenital valvular aortic stenosis compared to healthy peers. Our second aim was to investigate the relationship between objectively measured physical activity, health-related quality of life and life satisfaction in the same group. *Methods:* Forty-eight patients, 8–18 years of age, were recruited, as well as 43 healthy peers matched for age, gender and residential area. Health-related quality of life was assessed by the KIDSCREEN-52 self-report and parent proxy report, and life satisfaction was evaluated with the Satisfaction With Life Scale. Physical activity was measured with an accelerometer for 7 days. Sports participation was self-reported. *Results:* No differences in the health-related quality of life domains were found between patients and controls in the self-reports. In the proxy reports, parents of the adolescents rated their child's autonomy lower than did the parents of the healthy controls. A negative relationship was found between moderate to vigorous physical activity, sports participation, life satisfaction and the psychological well-being domain in adolescent patients. In children there was a positive relationship between moderate physical activity and the physical and psychological well-being domains. *Conclusion:* Overall, children and adolescents treated for valvular aortic stenosis reported similar life satisfaction and health-related quality of life as their healthy peers. The negative relationships between intense physical activity and sports participation with health-related quality of life and life satisfaction in adolescent patients might be explained by both physical and psychological factors in these teenagers with complex, lifelong heart disease.

For the general population of children and adolescents, there is support for a positive relation between physical activity and indicators of physical, psychological and cognitive health.[1] Thus, it is tempting to assume that physical activity should have the same positive associations for children and adolescents with congenital heart disease (CHD). Of the children born with a CHD, 3–5% have an isolated valvular aortic stenosis, with 80% of the patients being male. Valvular aortic stenosis is a complex and lifelong disease often requiring repeated interventions, particularly in patients with neonatal treatment[2,3], and residual or acquired abnormalities of the left heart structure might affect cardiovascular capacity.[4] For the growing individual, this uncertainty regarding future operations and the timing of treatment might affect many aspects of life. Physical activity may be a complicated issue with physical and emotional barriers such as restricted cardiovascular capacity[5] and overprotective parents.[6] Conflicting advice from the patient's cardiologist may also hinder engagement in physical activities[7] as restrictions have traditionally been recommended to prevent sudden cardiac death[8] In the modern era, the perceived risk for sudden cardiac death in children and adolescents with valvular aortic stenosis has decreased, probably due to a more active approach to intervention[9] For adolescents, there is increased pressure from peers to engage in physical activity[10,11] Consequently, engaging in physical activity may evoke mixed emotions that in turn may have complex effects on some aspects of the child's or adolescent's health-related quality of life and life satisfaction but also on motor development and future physical health[12,13]

No clear relationship between objectively measured physical activity and health-related quality of life or satisfaction with life has been established in children and adolescents with CHD, but their overall health-related quality of life is not found to be lower than that of healthy controls[14,15] The focus in previous studies has mainly been patients with a univentricular heart

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after Fontan procedure[16–18] and these relationships have not been evaluated in patients with valvular aortic stenosis.

The aim of this study was, therefore, firstly to investigate whether there are any differences in health-related quality of life and life satisfaction between children and adolescents treated for valvular aortic stenosis and their healthy peers. Secondly, we aimed to investigate the associations between physical activity, health-related quality of life and life satisfaction.

Materials and method

Participants

All patients treated for congenital isolated valvular aortic stenosis at the two referral centres for paediatric heart surgery in Sweden and born between 2001 and 2012 (age range 8–18 years, M = 12.72, SD = 3.48) were identified in local surgical registers, constituting a complete national cohort (n = 114, female 22.6%). For each patient, five healthy controls matched for age, gender, and geographical location were generated from Statistics Sweden (www.scb.se).

The patients were asked for health problems restricting their ability to be physically active. None were excluded for this reason. One patient who was willing to participate was excluded due to a recent surgical intervention. The response rate among patients was 43%. Participants were in median 18 days (range 0 days–12.5 years) at primary aortic valve intervention and had in mean 1.33 interventions while non-participants were in median 25 days (1 day–8,1 years) at first intervention and had in mean 1.66 interventions.

Our final sample consisted of 48 patients with completed questionnaires for KIDSCREEN-52 of whom 46 also completed the Satisfaction with Life Scale and 41 had a valid physical activity measurement. The control group consisted of 43 healthy participants with completed KIDSCREEN-52 questionnaires of whom 39 also completed Satisfaction with Life Scale and 37 performed a valid physical activity measurement.

After completing the study, the participants received a cinema ticket worth approximately 15 USD.

Procedure

Patients and controls were sent postal invitations to participate including information about the study adapted to children, adolescents, and parents, and two postal reminders were sent. One parent of a non-responding patient was also contacted by phone to verify that they had received the invitation. Data collection was performed during the same week in patients and controls to adjust for seasonal variation in physical activity. Questionnaires and the accelerometer were delivered by post with age-customised instructions. All participants and/or parents provided a written consent.

Measures

Health-related quality of life

Children's and adolescents' health-related quality of life were assessed with the KIDSCREEN-52 self-report and parent proxy report.[19] KIDSCREEN-52 has been validated and found to have good reliability in several countries, including Sweden, and can be used as a measure of subjective health in both healthy and chronically ill children and adolescents.[20] It consists of 52 items divided into ten domains: Physical Well-being, Psychological Well-being, Moods and Emotions, Self-Perception, Autonomy, Parent Relations & Home Life, Financial Resources, Social Support and Peers, School Environment, Social Acceptance (Bullying). The answer alternatives range from 1 = Never to 5 = Always. A higher score indicates better health-related quality of life for each subdomain. The KIDSCREEN-52 items meet the assumptions of the Rasch model; thus, the subdomain items are summed and transformed into Rasch person parameter estimates. The Rash scores are then transformed into T scores, which are easier to interpret, as the mean T score is always 50 and the SD is 10. Participants with more than one missing item on a subdomain are excluded according to the manual. Reference norms have been obtained for a large European sample of children aged 8–17 years [20], and Swedish norms exist for adolescents aged 12–18 years. Cronbach's alpha values for the self-reports were .72–.84, except the physical well-being scale with an alpha of .69. For the proxy reports, the values ranged from .76–.91, except the self-esteem subscale with a value of .63.

Life satisfaction

Life satisfaction is a person's global assessment of their satisfaction with life.[21,22] We used the child version of the Satisfaction with Life Scale for children 8–12 years [23] and the adult version for adolescents 13–18 years.[21] The scale consists of five items with answer alternatives from 1–5 for the child scale and 1–7 for the adolescents. It has been successfully used in similar age groups in a Swedish context.[24] The measure was calculated by using the mean across items; thus, higher values represent better life satisfaction. Cronbach's alpha values for the scales were .81 and .82 for the children and adolescents, respectively.

Physical activity

Free-living accelerometer data were collected using the triaxial accelerometer Axivity AX3 (Axivity Ltd, Newcastle upon Tyne, UK). The participants were instructed to wear the accelerometer over the right hip for 7 consecutive days and only to remove the sensor for water-based activities (including showers, baths and swimming). Daytime activities, sleep time, and sports participation were recorded in diary.

Accelerometer protocol. We used OmGUI software (Axivity Ltd., Newcastle upon Tyne, UK) for accelerometer initialisation and data extraction, with a sampling frequency of 50 Hz and ± 8 g sensitivity (1 g is equivalent to Earth's gravity). The accelerometer output data were resampled to 30 Hz and processed by the frequency extended method [25,26] with a three-second epoch length, as recommended for children.[27] Time spent at different intensity levels was estimated from previously published cut-off points.[28] Non-wear time was defined as 60 min of uninterrupted zeros, allowing exceptions of < 2 min of activity. Valid criteria for accelerometer data were set to ≥ 4 days of measurement (≥ 3 weekdays and ≥ 1 weekend day) with a valid day set to ≥ 10 hours per day of wear time.

Statistical analyses

t-tests were used to investigate age group differences in health-related quality of life and life satisfaction. Bivariate Spearman's correlation was used to investigate the association between time spent at different physical activity intensities and health-related quality of life and life satisfaction. In addition, some associations were visualised by scatter plots with lines fitted by linear regression. No adjustments were performed for multiple statistical tests, as this procedure also has limitations.[29] Instead, it is recommended to present the outcome of all tests, to allow understanding of whether reasonable conclusions can be drawn from data. Data processing and statistical analyses were performed in MATLAB, version

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Table 1a. Descriptive statistics and t-test comparisons of HRQoL scores between children 8–12 years treated for valvular aortic stenosis and their controls, for both self-report and parent proxy reports

	Self-report: Children 8–12							Parent report: Children 8–12						
	Controls			Patients			t-test	Controls			Patients			t-test
KIDSCREEN-52 domain	*M*	*SD*	*n*	*M*	*SD*	*n*	*p*	*M*	*SD*	*n*	*M*	*SD*	*n*	*p*
Physical well-being	50.20	8.53	25	51.19	8.94	24	0.695	48.83	8.83	23	47.67	9.34	23	0.669
Psychological well-being	52.43	5.84	25	53.01	7.23	24	0.761	52.33	7.91	25	54.04	7.98	24	0.456
Moods and emotions	52.21	7.56	25	53.63	8.74	24	0.545	50.25	10.28	23	53.23	9.49	24	0.306
Self-perception	58.94	7.84	25	55.97	8.45	24	0.209	52.40	10.23	25	54.77	8.57	24	0.386
Autonomy	52.80	8.32	25	53.67	5.94	24	0.674	50.83	9.21	24	53.90	6.15	23	0.188
Parent relation and home life	54.34	7.44	25	55.62	7.51	24	0.552	53.90	8.19	24	56.11	6.42	24	0.304
Financial resources	58.31	6.16	25	56.36	6.37	23	0.285	58.58	7.25	24	60.82	5.86	24	0.247
Social support and peers	50.62	8.18	25	54.19	8.41	24	0.138	50.28	7.93	24	51.94	8.48	22	0.495
School environment	53.97	10.38	25	57.88	10.06	24	0.187	52.07	11.36	24	55.53	9.95	23	0.273
Social acceptance (Bullying)	52.53	8.26	24	50.92	9.80	24	0.544	49.74	11.48	25	50.39	8.01	23	0.823

(HRQoL, health-related quality of life.)

R2020b (The MathWorks Inc., Natick, Massachusetts) and IBM SPSS Statistics, version 25 (IBM Corp., Armonk, NY). The statistical analysis has been chosen based on the distribution of data.

Results

Data were collected between September 2019 and June 2020. Descriptive statistics for health-related quality of life can be found in Table 1a and Table 1b. The cohort reflects the gender distribution for the diagnosis. No differences between the health-related quality of life domains were found between patients' and controls' self-reports, either for the children or for the adolescents. However, the parents of the adolescent patients experienced that their offspring had less autonomy than reported by the parents of the healthy controls. Because the Swedish KIDSCREEN-52 norm values (mean T scores) differ from the European norm mean T scores, the results were compared with the control group and with the Swedish norm values for healthy adolescents. The only difference found between the Swedish norm values and our patients was that the patients experienced less physical well-being than the healthy population norm (Table 1b). T scores for the patients, controls and parents are depicted in Figure 1.

No difference in life satisfaction was found between the child patients ($M = 4.61$, $SD = 0.54$) and controls ($M = 4.63$, $SD = 0.46$), $t(44) = 0.12$, $p = .907$. Neither was any difference found between the adolescent patients ($M = 5.60$, $SD = 1.05$) and controls ($M = 5.24$, $SD = 1.85$), $t(44) = -1.014$, $p = .795$.

Associations between physical activity, health-related quality of life, and life satisfaction

Time spent in physical activity of different intensities is shown in Table 2. A pattern indicating a negative correlation between time spent in moderate to vigorous physical activity and sports participation with life satisfaction and psychological well-being for the adolescents with aortic stenosis can be seen in both self-reports and parent proxy reports (Fig 2). This pattern is only evident for the adolescent patients, not for their healthy controls nor for the child group. Figure 3 illustrates the parent proxy reports of psychological well-being correlated with time spent in physical activity at the three highest intensity levels. For the children with aortic stenosis, a statistically significant positive correlations between time spent in moderate physical activity and psychological and physical well-being were seen. As can be seen in Figure 2, sports participation correlated highly with the amount of vigorous and very vigorous physical activity, indicating that a lot of the high-intensity physical activity could be due to high engagement in sports. A strong negative correlation was seen between sedentary time and psychological well-being (parent proxy) in children with aortic stenosis, with life satisfaction for the control adolescents and with physical well-being for the control children (parent proxy). For exact correlation figures, see Appendix.

Discussion

Life satisfaction and health-related quality of life scores did not differ significantly in children and adolescents with valvular aortic stenosis compared to healthy controls. Parents of the adolescent patients did, however, report that their adolescents had less autonomy compared to the healthy controls. In comparison to the Swedish norm values, adolescent patients rated their physical well-being lower. Our findings are in line with a systematic review and meta-analysis that concluded that health-related quality of life is not lower in adolescents with CHD.[15] Other studies have reached the same conclusion for children and adolescents with CHD of varying severity [30,31], although subgroups of patient with complex CHD are reported to have impaired health-related quality of life scores.[16,32,33] Interestingly, we found a negative relation between adolescent patients' physical activity and sports participation and their life satisfaction and psychological well-being. These results were not evident for the children with aortic stenosis. There may be many reasons for this difference. In younger children, the family is often able to help the child adjust to the consequences of the disease and can adjust the family's activities to fit in with the child's needs.[34] This allows the child with CHD to engage in physical activities at their own pace and according to their own wishes, providing a more positive association between physical activity and different domains of health-related quality of life, such as physical and psychological well-being. Adolescence is a time marked by transition and changes which in themselves

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Table 1b. Descriptive statistics and t-test comparisons of HRQoL scores between adolescents aged 13–18 years with congenital valvular aortic stenosis and their controls, for both child and parent reports

	Self-report: Adolescents 13–18											Parent report: Adolescents 13–18						
	Controls			Patients			t-test	Reference norms		t-test		Controls			Patients			t-test
KIDSCREEN-52 domain	*M*	*SD*	*n*	*M*	*SD*	*n*	*p*	*M*	*SD*	*p*		*M*	*SD*	*n*	*M*	*SD*	*n*	*p*
Physical well-being	48.92	10.34	18	45.56	4.35	24	0.159	48.58	9.76	.002**		50.01	9.45	18	46.78	7.59	19	0.259
Psychological well-being	49.88	8.41	18	47.54	8.57	24	0.382	49.99	10.08	0.175		51.35	7.65	18	46.99	11.01	21	0.167
Moods and emotions	53.90	11.08	18	50.50	9.76	24	0.298	50.70	11.08	0.921		50.81	8.83	18	47.06	11.91	22	0.275
Self-perception	49.51	11.71	18	51.22	9.41	23	0.607	50.27	10.70	0.633		51.30	9.12	18	50.45	10.22	23	0.785
Autonomy	55.49	6.82	18	52.98	10.14	24	0.369	51.29	9.61	0.424		55.43	7.16	18	49.87	8.62	22	0.035*
Parent relation and home life	55.53	7.87	18	54.31	8.63	24	0.641	52.45	10.11	0.301		52.60	6.91	18	52.08	10.61	21	0.860
Financial resources	56.77	8.13	17	55.43	8.00	24	0.602	52.58	9.14	0.094		60.30	6.25	18	56.00	9.67	23	0.094
Social support and peers	53.43	10.18	18	49.53	8.82	24	0.193	51.61	9.70	0.260		50.77	9.51	18	52.02	9.73	23	0.681
School environment	54.17	8.42	18	53.07	6.72	24	0.640	51.30	9.39	0.211		54.75	6.65	17	53.79	7.81	23	0.685
Social acceptance (Bullying)	56.02	6.85	18	53.44	9.22	24	0.325	52.65	9.24	0.678		54.41	6.74	18	51.60	9.01	23	0.278

*$p < .05$.
**$p < .01$. Note: the reference norms refer to healthy Swedish adolescents aged 12–18 years. (HRQoL, health-related quality of life.)

may affect aspects of subjective well-being and life satisfaction.[35] Expectations of physical performance and competition increase, the influence of peers becomes more important, and feelings of fitting in become the focus of this developmental phase.[36] During this phase, adolescents' physical activity is influenced by their peers, and studies show that the patients will try to match their friends' activity patterns, [11] and they can even increase their level of activity to match a friend's level.[10] In order to fit in and to perform as their peers do, adolescents with aortic stenosis are at risk of pushing their physical activity to extremes. Supporting this, a study has shown that adolescents with higher physical activity levels may be more aware of their physical limitations than less active patients.[37]

Another contributing factor could be that some adolescents treated for valvular aortic stenosis have more severely impaired physical performance than they themselves perceive and thus fail to take their limitations into account in their daily lives.[4] This could add to the struggle for the adolescent to meet requirements and expectations set not only by themselves but also by parents, teachers, sports coaches, and peers. This may contribute to our finding that adolescents who spent more time in high-intensity physical activity and had higher sports participation, rated their psychological well-being lower than adolescents who spent less time in high-intensity physical activity.

In adolescence, training intensity might reach an elite level and although cardiologists stress the importance of physical activity, training at such high intensity may not be recommended due to the risk of sudden cardiac death.[8] This may result in mixed messages from the health care providers, as physical activities that were encouraged during early childhood need to be limited in adolescence. Thus, providing children and adolescents with individualised advice on physical activity on a level appropriate to promote a healthy lifestyle remains a challenge.

Future studies need to further address the negative relation between physical activity intensity and psychological well-being and life satisfaction. For example, qualitative interview studies could be conducted with the adolescents engaged in more intense physical activity to better understand how they experience their quality of life.

Another implication of our results is that follow-up programmes should assess both medical issues, physical activity, and physical and psychological well-being, as new challenges need to be addressed when children progress into new developmental phases.

Limitations

Strengths of the study are the use of an objective method of measuring physical activity, which has made it possible to correlate different health-related quality of life domains and life satisfaction with time spent in different levels of physical activity and a study group of patients with one well-defined diagnosis. As the complete national cohort of patients treated for valvular aortic stenosis was invited to participate, no power analysis was performed. A limitation is that loss of patients and controls during recruitment made the sample rather small, which may have influenced the outcome of the analysis. It is possible that participants are more physically active and have higher health-related quality of life than non-participants. Information from non-participating controls was not accessible in accordance with ethical regulations.

It should be noted that the cross-sectional design of the study makes the inferences regarding differences between children and adolescents in the association between physical activity and certain aspects of health-related quality of life slightly limited. It could be that the differences are not a result of differences in developmental

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Table 2. Time spent in physical activity at different intensity levels, comparing children and adolescents with congenital valvular aortic stenosis with their controls

	Children 8–12 years			Adolescents 13–18 years		
	Controls n = 21	Patients n = 21	p	Controls n = 16	Patients n = 20	p
Female	14.3%	14.3%	1	25.0%	35.0%	0.517
Age in years, mean (SD)	10.1 (1.5)	10.0 (1.5)	0.856	14.7 (2.0)	15.3 (2.0)	0.357
Valid days	6.9 (0.3)	6.9 (0.3)	1	6.8 (0.4)	6.9 (0.3)	0.242
Wear time	91.7 (8.2)	95.3 (3.5)	0.073	95.3 (5.2)	94.0 (4.1)	0.398
Wear time day	97.2 (2.9)	99.0 (1.2)	0.012	97.8 (5.5)	97.2 (4.6)	0.758
Intensity category						
Sleep	587.3 (51.2)	585.6 (34.3)	0.90	535.1 (68.6)	518.0 (41.8)	0.363
SED	515.7 (70.5)	528.1 (61.5)	0.545	620.3 (99.3)	655.9 (88.3)	0.264
LPA	155.9 (19.8)	145.2 (25.8)	0.139	153.4 (36.6)	150.3 (41.9)	0.818
MPA	140.6 (30.1)	142.5 (26.3)	0.827	113.3 (32.5)	102.8 (37.5)	0.380
VPA	27.8 (12.0)	28.7 (10.2)	0.777	11.6 (6.8)	8.1 (5.7)	0.102
V-VPA	12.7 (7.8)	9.8 (5.6)	0.176	6.3 (5.3)	4.9 (5.4)	0.468
Sports	3.3 (1.8)	2.3 (1.2)	0.052	4.4 (2.4)	2.9 (2.2)	0.059

Note: Physical activity intensity categories are defined by VO_{2net} (mass-specific net oxygen consumption) cut-off points. Time for each intensity category is shown as minutes per day, mean (SD), and wear time in percent, mean (SD). Sports is presented as number of times per week, mean (SD)
(SED, sedentary physical activity; LPA, light physical activity; MPA, moderate physical activity; VPA, vigorous physical activity; V-VPA, very vigorous physical activity; Sports, participation in sports.)

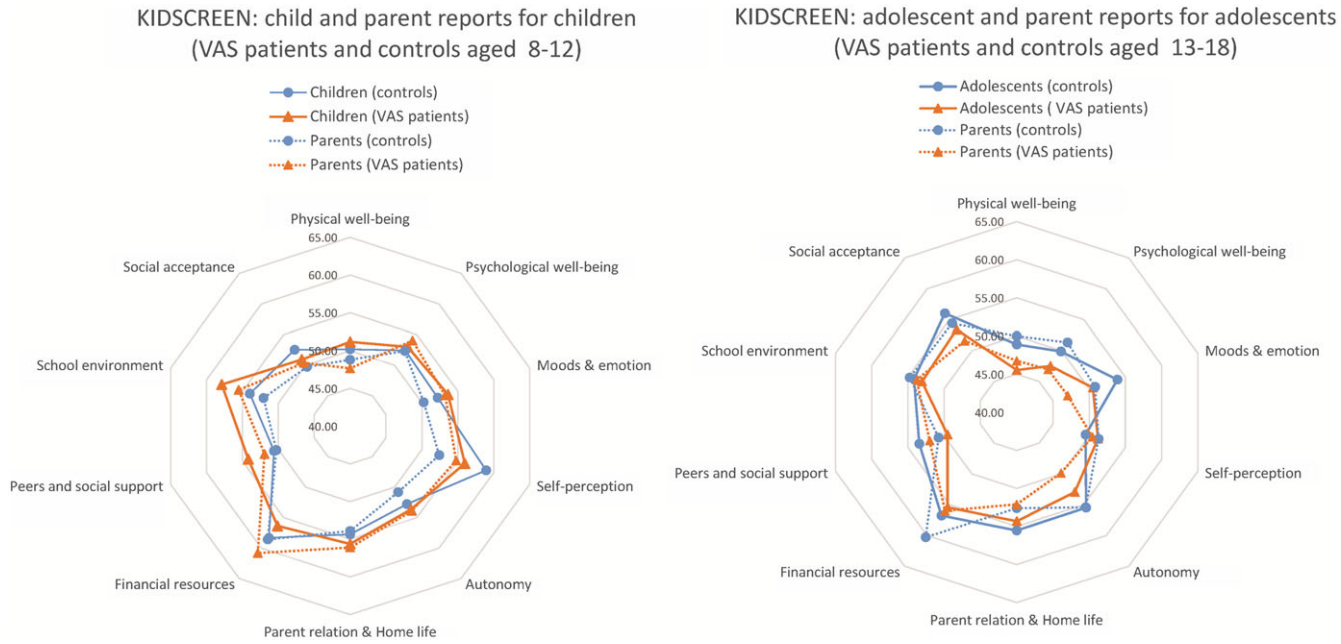

Figure 1. (*Left*) Sum score scale comparison showing the HRQoL self-reports of children aged 8–12 years with valvular aortic stenosis, their parents' proxy reports, the control children's self-reports and their parents' proxy reports. (*Right*) Sum score scale comparison showing the HRQoL self-reports of adolescents aged 13–18 years with valvular aortic stenosis, their parents' proxy reports, the control adolescents' self-reports and their parents' proxy reports.

phases but rather due to cohort effects. However, the suggestion of cohort effects is not so plausible, given that the recommendations for the care of these patients have not changed substantially over the last two decades.

Conclusion

Overall, children and adolescents treated for valvular aortic stenosis showed similar life satisfaction and health-related quality of life to their healthy peers. Adolescents experienced their physical well-being as slightly lower than the Swedish reference norm. In children, a positive correlation between physical activity and well-being was present but in adolescents a pattern of negative correlations between time spent in high-intensity physical activity and more frequent sports participation with life satisfaction as well as psychological well-being was found, both in self-reports and in the parent proxy reports. In conclusion, our study highlights the

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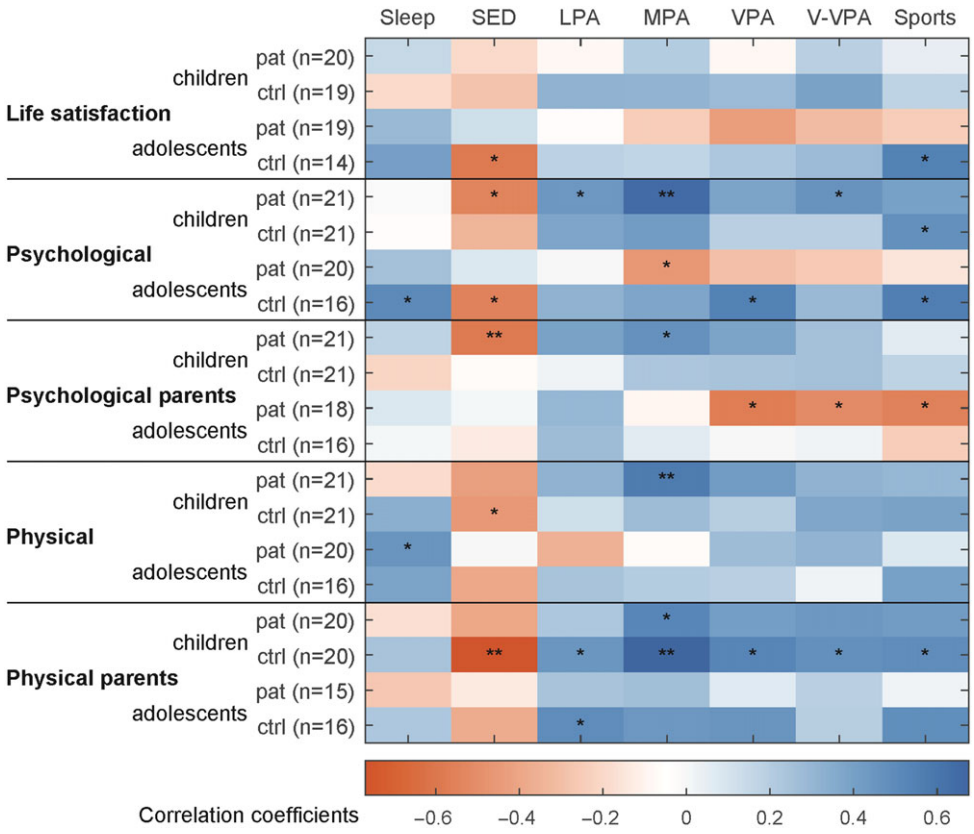

Figure 2. Bivariate Spearman correlations between time spent in physical activity at different intensities, life satisfaction, physical well-being and psychological well-being, for both self-reports and parent (proxy) reports.
Note. Blue and red cells represent positive and negative correlations, respectively. * $p < 0.05$, ** $p < 0.01$. (Pat, patients; ctrl, controls; SED sedentary; LPA light physical activity; MPA moderate physical activity; VPA vigorous physical activity; V-VPA very vigorous physical activity.)

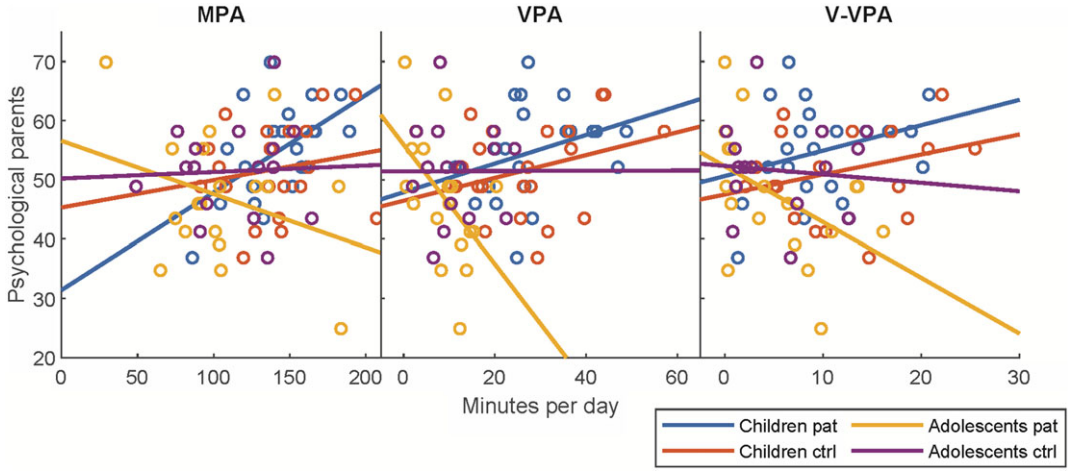

Figure 3. Scatterplots of the association between parent reports of psychological well-being and three levels of physical activity intensity.
Note. Separate linear regression lines are fitted, based on age group and responder. (MPA moderate physical activity; VPA vigorous physical activity; V-VPA very vigorous physical activity.)

positive effect of physical activity in children as well as the challenge and the need to give individualised advice on physical activity to adolescents with CHD. While moderate exercise may be beneficial to several patients' well-being, high-intensity physical activity and sports participation in particular may have the opposite effect.

Supplementary material. For supplementary material accompanying this paper visit https://doi.org/10.1017/S1047951122000920

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Conflicts of interest. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation in Sweden and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the Central Ethical Review Board in Gothenburg, approval no. 582-18.

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