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Changes in Perceived Health of Children with Congenital Heart Disease After Attending a Special Sports Camp

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Abstract. Sports camps for children with cardiac anomalies have existed for many years. However, no formal evaluation of the benefits of attending such camps has been undertaken heretofore. We assessed potential changes in the self-perceived health of children with congenital heart disease who attended a special sports camp. Thirty-one children with cardiac anomalies attended a 3-day multisports camp. Sixteen children, all of whom were 10 years or older, literate, and Dutch- or French-speaking, completed the Child Health Questionnaire (CHQ-CF87) before and after attending the camp. The scores of the children were compared with those of healthy peers by calculating mean standardized differences. After attendance at the sports camp, the children achieved significant improvements in the self-perception of their physical functioning, role functioning due to emotional problems, role functioning due to behavioral problems, mental health, and general behavior. The children's self-esteem and general behavior after the camp were significantly better than that of their healthy counterparts. We conclude that children with congenital heart disease who participate in activities at special sports camps may reap benefits in terms of their subjective health status. Although further research is needed, we recommend the participation in sport activities by children with heart defects, and more specifically their participation in sports camps.

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In many countries, summer camps and sports camps are available for children with specific chronic medical conditions, such as asthma, diabetes, cystic fibrosis, obesity, or the complications associated with burn injuries. Although the primary aim of such camps is to help the children to have more fun [2], they also have a number of psychological and medical benefits. Depending on the activities and length of stay at the camp, as well as the target group, the following benefits have been reported: an increase in self-esteem [2, 22], a more favorable body image [22], improved physical condition [3, 9], and enhanced knowledge and self-management [10, 19].

Congenital heart disease (CHD) can also be considered to be a chronic condition. Some studies in children with CHD indicate that they have worse general health [5, 23], lower perceived capacity [17, 23], lower self-esteem [17], a less positive image [1], and more behavioral and emotional problems than healthy children [21]. Hence, these children should benefit from specific interventions that promote a positive self-image.

The first description of a summer camp for children with CHD was published as early as 1953 [16], indicating that there is a long tradition of organizing such camps for these afflicted children. However, to our knowledge, there have been no studies evaluating the effects of these camps on the self-perception or

exercise tolerance of participating children. Admittedly, many of these children are advised against participating in competitive sports, and many also have subnormal levels of exercise capacity [6, 14, 18]. In addition, many young patients with CHD have misconceptions about safe and desirable levels of physical activity [20]. However, limited participation in sports is allowed, even recommended, so that these children can achieve physical fitness and subsequently reap health benefits [8].

Therefore, the aim of the present study was to evaluate potential changes in the self-perceived health status of children with CHD after attending a special sports camp. We accomplished this by assessing the perceived health status in these children before and after they attended the sports camp.

Methods

The Sports Camp

In April 2004, a 3-day multisports camp for children with CHD was organized by the Belgian National Foundation for Research in Pediatric Cardiology. The camp program included participation in diverse sports: athletics (1. high jump, 2. long jump, 3. 30 meters spurt), tennis, baseball, and hockey. Children could participate in any sports that interested them. All sport activities were supervised by professional sports teachers. "Meet and greet" visits by famous Belgian sportsmen in soccer, bicycle racing, and Formula 1 racing were scheduled. Pediatric cardiologists were present in the sports stadium and at the sleep facilities throughout the 3-day event. There were no specific physical or psychosocial interventions, and no patient education was provided.

Thirty-one children (22 boys and nine girls) aged 6 to 14 years attended the sports camp. Children were included in our study if they were 10 years or older, literate, and Dutch- or French-speaking. Overall, 17 children were eligible for participation. One child did not want to complete the questionnaire a second time; thus, our final sample consisted of 16 children.

Variables and Measurement

Using a repeated-measures, pre–post design, we assessed self-perceived health status using the 87-item version of the Child Health Questionnaire (CHQ-CF87) [7]. The CHQ-CF87 is a generic measure that covers 12 physical and psychosocial health state domains and contains 87 items that predominantly refer to the subject's self-perceived health status 4 weeks prior to completing the questionnaire. The instrument is specifically designed to be completed by children and adolescents aged 10–17 years. With the exception of the "changes in health" item, which was scored on a rating scale of 1 (much worse now than 1 year ago) to 5 (much better now than 1 year ago), the items within each of the 12 domains were recoded, summed, and transformed into a scale of 0 (worst possible score) to 100 (best possible score). Dutch and French versions of the CHQ-CF87 were available. Good validity and reliability have been reported for both the Dutch [13] and French [15] versions. As of our test date, no CHQ-CF87 data existed for the general Belgian population. Therefore, for comparison, we used CHQ-CF87 data from a healthy cohort of children in the Netherlands [13]. To assess the self-perception of the children after they attended the camp, we modified the CHQ-CF87 by rephrasing its questions to refer to the 3 days they attended the camp. The children completed this instrument at the end of the event. The subscale "change in health compared to 1 year ago" was removed from the instrument because the sports camp could not have an influence on this subscale. In addition, the questions on family activities and family cohesion were removed because the children did not have direct contact, except by phone, with their parents. These changes meant that comparisons between before-camp and after-camp scores could be made on only nine of the 12 subscales.

Procedure

Informed consent was obtained verbally. After we informed the children's parents about the aim and procedures of this study, we asked the children to complete the questionnaire before and after attending the sports camp. A researcher (P.M.) and a pediatric cardiologist (C.B.) instructed the children on how to complete the questionnaire. Both remained available during data collection to provide further information if needed; however, they did not influence the children's responses. Because the study was not conducted in a clinical setting, approval of an institutional review board was not required. However, the investigators adhered meticulously to all ethical standards.

Statistical Analysis

Analyses were performed using SPSS 10.0. Although the data were not normally distributed, subscale scores were expressed as means ± SD to allow comparison with published data. The Wilcoxon signed rank test, a nonparametric test for analyzing paired data, was used to compute differences between the scores measured before and after attending the camp. The level of significance was set at $p \leq 0.05$.

Differences between the CHQ-CF87 scores of children with CHD and healthy children were expressed as standardized differences from the norm data. A standardized difference for each child with CHD was generated by subtracting the norm score of healthy peers from the score of each child, then dividing this number by the SD calculated from the norm data. Averaging this difference over all patients resulted in a mean standardized difference. Values less than zero indicate that the perceived health of children with CHD is lower than the perceived health of the norm group. To appraise the magnitude of the standardized differences in terms of effect size, a difference of 0.2–0.5 was considered to be a small effect; 0.5–0.8 was a medium effect; and a standardized difference of ≥0.8 was considered to be a large effect [4]. A one-sample *t*-test was calculated to evaluate whether the mean standardized difference differed significantly from zero.

Results

Patient Characteristics

Sixteen children were included in the study; 11 (68%) were boys and five (31%) were girls. Their median age

Table 1. Demographic and clinical characteristics of 16 children (aged 10–14 years) participating in a special sports camp

Patient no.	Sex	Age (yr)	Heart defect	Treatment (age)
1	Girl	10	Marfan syndrome	Medication: beta-blockers (nadolol)
2	Girl	10	Univentricular heart (DILV) d-TGA Pulmonary atresia	Blalock-Taussig shunt (at birth) Bidirectional Glenn (1 yr) Fontan TCPC (3 yr)
3	Boy	13	Univentricular heart (tricuspid valve atresia)	Blalock-Taussig shunt (1 yr) Fontan CPAP + closure ASD (2 yr) Reclosure ASD (3 yr) Reconversion TCPC (12 yr)
4	Girl	11	Univentricular heart (DILV) d-TGA	Banding pulmonary artery (1 mo) Bidirectional Glenn (1 yr) Fontan TCPC (7 yr)
5	Boy	10	Univentricular heart (pulmonary atresia) DORV Situs inversus	Blalock-Taussig shunt (4 mo) Bidirectional Glenn (age 1 yr) Fontan TCPC (5 yr)
6	Girl	14	Univentricular heart (pulmonary atresia)	Blalock-Taussig (1 mo) Blalock-Taussig (2 yr) Fontan TCPC (4 yr)
7	Boy	10	Univentricular heart (DILV) l-TGA	Banding pulmonary artery (1 mo) Hemi-Fontan (2 yr) Fontan TCPC (4 yr)
8	Girl	13	l-TGA VSD Subvalvular pulmonary stenosis Ebstein ASD secundum	Resection left ventricle outflow tract; closure ASD; pacemaker (6 yr)
9	Boy	10	Supra aortic valve stenosis	Surgical patch enlargement (7 yr)
10	Boy	10	Tetralogy of Fallot	Correction with transannular patch (1 yr) Homograft pulmonary valve replacement (10 yr)
11	Boy	12	d-TGA	Arterial switch (at birth)
12	Boy	10	Bicuspid aortic valve with aortic valve stenosis and regurgitation	none
13	Boy	12	Coarctation of the aorta bicuspid aortic valve Subvalvular aortic membrane	Coarctectomy (at birth)
14	Boy	10	VSD	Closure (3 yr)
15	Boy	14	Rheumatic valve disease (7 yr)	Mitral repair (10 yr)
16	Boy	11	Univentricular heart (DILV) d-TGA Coarctation of the aorta	Coarctectomy + PA banding (1 mo) Fenestrated Fontan + DKS anastomosis (1 yr)

d-TGA, complete transposition of the great arteries; ASD, atrial septal defect; CPAP, cavopulmonary atriopulmonary connection; TCPC, total cavopulmonary connection; DILV, double-inlet left ventricle; DORV, double-outlet right ventricle; l-TGA, congenitally corrected transposition of the great arteries; VSD, ventricular septal defect; DKS, Damus-Kay-Stansel procedure; PA, pulmonary artery

was 10.5 years (Q1 = 10; Q3 = 12.75). The most prevalent heart defect was univentricular heart. The Demographical and clinical characteristics of the participating children are shown in Table 1.

Perceived Health Status

The domain scores of the CHQ-CF87 measures at the start of the sports camp ranged from 72.61 for general health to 93.75 for role functioning due to emotional problems (Table 2). Except for bodily pain, scores for all dimensions as assessed at the end of the event were higher than those obtained at the start. We observed significant improvements in physical functioning, role functioning due to emotional problems, role functioning due to behavioral problems, mental health, and general behavior.

Comparison of the mean standardized differences between the children with CHD and their healthy peers revealed that the precamp scores of the afflicted children were lower than the postcamp scores on all dimensions except for self-esteem (Fig. 1). Only the physical functioning dimension had large standard-

Table 2. Mean scores on the Child Health Questionnaire (CHQ-CF87) of 16 children with congenital heart disease before and after participating in a special sports camp

	Before camp mean (SD)	After camp mean (SD)	*p* value[a]
Physical functioning	90.28 (8.75)	94.91 (6.33)	0.045
Role functioning — physical	93.06 (13.38)	97.22 (8.61)	NS
General health	72.61 (13.45)	75.06 (7.25)	NS
Bodily pain	76.88 (24.96)	75 (21.29)	NS
Role functioning — emotional	93.75 (10.71)	100 (0.0)	0.041
Role functioning — behavioral	89.58 (14.89)	100 (0.0)	0.017
Self-esteem	79.16 (13.31)	84.10 (12.53)	NS
Mental health	74.51 (13.18)	82.49 (10.99)	0.007
General behavior	81.13 (8.79)	90.04 (7.27)	0.01
Family activities	80.05 (19.70)		
Family cohesion	74.69 (28.49)		
Changes in health	4.2 (1.01)		

[a]Wilcoxon signed rank test

ized difference pre-camp scores (≥0.8), reaching statistical significance. Postcamp scores were higher than the norm values for role functioning due to emotional problems, role functioning due to behavioral problems, self-esteem, mental health, and general behavior. These differences were statistically significant for self-esteem and general behavior.

Discussion

Although summer camps for children with CHD have existed for many years, the benefits of such camps have yet to be formally evaluated. The present study is the first to assess the potential effects of a special sports camp on the perceived health of children with CHD.

Improvements in Perceived Health

We found that participation in the sports camp activities significantly improved specific dimensions of self-perceived health. Before attending the sports camp, children with CHD scored their physical functioning significantly lower than their healthy peers. After attending the camp, however, their perception of physical functioning improved substantially. Although the scores of the children as measured after the event did not differ significantly from the scores of their healthy counterparts, the mean standardized difference (–0.77) between the two groups was notable. This indicates that the sports camp dramatically enhanced the children's perceptions of their physical functioning, even though their perceptions remained lower than that of healthy children.

Significant improvements were seen in the postcamp scores of role functioning due to emotional problems and of role functioning due to behavioral problems. For role functioning due to behavioral problems, we found a moderate difference between the children's postcamp scores and the norm values. Hence, the children's perception of these two dimensions rose substantially above that of their healthy peers. We could not perform a *t*-test on these data, however, because the postcamp score was 100 for all children with CHD; this resulted in an SD of zero. Although the children's self-esteem scores pre- and postcamp did not differ significantly their post camp self-esteem scores were significantly higher than those of their healthy peers, suggesting that the camp had a beneficial effect on self-esteem. The children's postcamp scores for mental health and general behavior improved significantly, surpassing the scores of their healthy counterparts. Camp attendance failed to improve role functioning due to physical problems, general health perception, and bodily pain.

In general, children with CHD have a subnormal exercise capacity [6, 14]. In addition, many young patients have misconceptions about safe and desirable levels of physical activity [20]. This may account for the observation that such children exert themselves less vigorously when participating in sport activities [8, 20]. However, a recent survey on habitual physical activities among adolescents with cardiac anomalies indicated, that these adolescents are as physically active as healthy youngsters [8]. Yet differences were found in the level of participation intensity, which was lower in the afflicted adolescents. These findings are in line with those of another study on the functional abilities of patients who have undergone Mustard or Senning operations [11]. This study showed that the percentage of patients who regularly participated in sporting activities was somewhat higher than their age-matched counterparts in the general population. However,

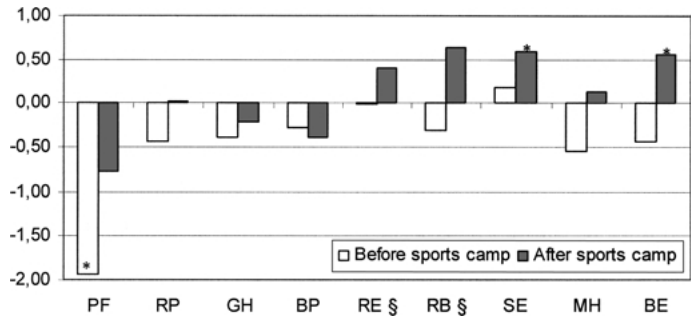

Fig. 1. Mean standardized differences between the scores on the Child Health Questionnaire (CHQ-CF87) of children with congenital heart disease before and after participating in a sports camp and healthy counterparts. * $p < 0.05$; ** $p < 0.01$. §One sample *t*-test could not be computed because the SD was zero. Small difference (0.2–0.5); moderate difference (0.5–0.8); large difference (≥0.8). *PF*, physical functioning; *RP*, role functioning due to physical problems; *GH*, general health; *BP*, bodily pain; *RE*, role functioning due to emotional problems; *RB*, role functioning due to behavioral problems; *SE*, self-esteem; *MH*, mental health; *BE*, general behavior.

these activities were less vigorous. These data confirm what many studies have previously indicated that is, although exercise capacity is below normal levels, most cardiac patients are able to participate in normal physical activities without developing adverse symptoms [12].

The sports camp described here offered a variety of recreational activities, but it excluded intense sports. Because attendance at the camp lasted for only 3 days, its effects on exercise tolerance, as shown for instance in cystic fibrosis [3], are unlikely. However, in addition to the known physical benefits of playing in sports, the present study corroborates the psychological and social benefits of exercise and participation in sports activities [20]. Therefore, sports activities, and more specifically participation in sports camps, should be strongly advised for children with CHD.

Methodological Limitations

Although the present study showed significant improvements in the self-perceived health of children with CHD who participated in a special sports camp, there were some methodological limitations to our study. Thus, our results should be interpreted with a measure of caution.

One potential limitation is that we had a small sample. Although 31 children participated in the sports activities at the camp, only half of them were 10 years or older and were thus capable of reasonably completing the self-perceived health questionnaire. This resulted in a select sample of 16 children. However, this limited sample size did not affect the power of the study because we computed within-subject changes. When data are unpaired, *post hoc* sample size calculations indicate that a sample of 2385 patients, for instance, would be required to obtain enough power to analyze bodily pain. However, when data are paired, as in our study, a sample of 16 patients is more than sufficient to achieve a power of 80% with an α of 0.05. Given the small sample, we did not correct for multiple testing using a Bonferroni correction,

A second possible limitation is that the design of our study did not permit us to assess causal relationships that may have affected the self-perceived health of the children. Although we are not aware of any confounding factors that might have been present during the camp, we nonetheles cannot conclude firmly that our findings resulted merely from the effects of the sports camp.

A third limitation is that our study addressed only short-term effects. We do not know whether the Children's positive self-image will persist in the weeks and months after leaving the camp. An assessment of the long-term effects of sports camps is planned.

There are also other potential limitations of the present study. For one, the questionnaire used to assess the children was adapted to fit the duration of the sports camp. For another, the norm data used for comparison were from a different nationality of children. To measure perceived health with an interval of 3 days, we had to rephrase the questionnaire used at the end of the camp to refer to "these 3 days" instead of "the preceding 4 weeks". Because the changes may have altered the validity of the questionnaire used at the second time point, the results obtained at that time ought to be interpreted cautiously. In addition, because norm values for the Belgian population did not exist at the time of the study, we used norm data obtained from healthy children in the Netherlands. This factor may also have affected our results.

A final limitation to consider is that the group of children described here may not represent the general population of children with CHD. The children included in this study *voluntarily* registered to partici-

pate in the camp, probably because they were inherently interested in sports. Hence, it is possible that, for children who are less interested in sports, participation in such a camp would not result in the beneficial effects that we observed. For such children, camps including alternative activities could be developed and tested. On the other hand, children with complex heart diseases are overrepresented in this sample: seven children with univentricular heart (44%), one child with d-TGA, one child with L-TGA, and one child with tetralogy of Fallot. The camp may have had an even greater impact if the included group had children with a more balanced distribution of mild, moderate, and complex heart defects. Congenital heart disease is an umbrella term for mild, moderate, and complex defects. It is beyond the scope of this article to name all defects in the respective categories.

Conclusion

In this study, we investigated the potential effects of attendance at a special sports camp on the self-perceived health of children with CHD. We found that physical functioning, role functioning due to emotional problems, role functioning due to behavioral problems, mental health, and general behavior were significantly improved after attendance at the sports camp. The level of self-esteem and general behavior after the event was significantly higher than that of healthy peers. Although further research is needed, these findings indicate that special sports camps have beneficial effects on the self-perception of children with CHD. Hence, participation in sports activities show be advocated for these children.

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