

Exercise capacity and the quality of life late after surgical correction of congenital heart defects

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Abstract

Background: The long-term impact of surgical correction of congenital heart defects (CHD) on exercise capacity and quality of life (QoL) has not been well established.

Aim: To evaluate exercise capacity, QoL, physical activity and depression in young adult patients with a history of congenital heart defect surgery (GUCH) for simple left-to-right shunts, and to compare these parameters with those obtained in healthy volunteers.

Methods: The study group consisted of 30 young adults with congenital heart defects (14 males, 16 females), aged 18–36 (mean 24.6) years who underwent corrective cardiac surgery at least 10 years earlier. The control group comprised 30 healthy students (15 males, 15 females), aged 21–28 (mean 24.4) years. We performed cardiopulmonary exercise testing on bicycle ergometer, QoL and physical activity tests, and depression inventory.

Results: In young adult GUCH patients the exercise parameters were lower when compared to healthy peers. The Stanford questionnaire showed that physical activity was diminished as well as QoL in EuroQoL5 test. The Beck inventory showed more expressed depression in GUCH group.

Conclusions: The exercise capacity, physical activity and QoL of young adults with a history of surgical treatment of CHD are worse than observed in healthy peers, and the health status does not fulfil the definition of complete recovery.

Key words: congenital heart disease, grown ups with congenital heart defects (GUCH) patients, exercise capacity, quality of life, rehabilitation

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INTRODUCTION

Assessment of exercise capacity and the quality of life (QoL) late after surgical correction of a congenital heart defect (CHD) may add to long-term evaluation of treatment efficacy. The group of patients receiving surgery for CHD is becoming more and more numerous, because in addition to the relatively constant population of children born with cardiovascular (CV)

defects, there is an increasing number of adolescents and adults after congenital heart defects treatment (GUCH, grown ups with the congenital hearts defects), i.e. patients who have completed a successful medical or surgical treatment for their defect [1]. The group of patients commencing an active life of people who have undergone a successful treatment for simple CHD should naturally be treated as a group of complete-

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ly healthy individuals. However, the decrease in exercise capacity in GUCH patients, which results from restrictions of psychological rather than strictly medical nature enhances the feeling of being ill, limits the possibilities of full self-actualisation and worsens the QoL in the wide sense [2].

The widespread opinion on incomplete health, the necessity to undergo ongoing monitoring by cardiologists and the restricted accessibility to programmes of multi-profile rehabilitation increases the personal feeling of incomplete value, which results in depression, low self-esteem and not pursuing many life plans [2]. Unfortunately, these processes increase as the person grows older and patients with CHD do not feel completely healthy and their QoL may considerably differ from the QoL perceived by their healthy peers.

This problem is particularly important in young patients who have undergone surgical correction of simple shunt CHD in their childhood, who expect to live in full health, free from physical and psychological restrictions, and should therefore be treated as completely cured, healthy people [2, 3].

The aim of our study was to assess exercise capacity, QoL and depression in young adult patients late after surgical correction of simple shunt CHD.

METHODS

Study group

The study included 60 subjects who underwent functional assessment of exercise capacity and exercise tolerance and a survey of the quality of life and physical activity from 1 June 2008 to 30 June 2010. The study group consisted of 30 adolescents and young adults with CHD (16 males and 14 females), from 18 to 36 years old (mean age: 24.6 years), under ongoing care of the cardiology clinic. The patients were recruited consecutively during routine for follow-up visits, met the inclusion criteria and expressed willingness to participate in the study. The control group consisted of 30 randomly selected medical students (15 females and 15 males). After the aims and the methodology of the study had been explained, all the subjects gave written consent to participate in the study (informed consent declaration).

The main inclusion criterion was a history of surgical correction of a shunt CHD (ventricular septal defect [VSD]: 12 patients; or atrial septal defect [ASD]: 18 patients) which was performed at least 10 years earlier. The exclusion criteria included: contraindications for exercise testing (ET) (arrhythmias, uncontrolled hypertension, residual intracardiac shunts), co-morbidities that might affect exercise capacity parameters (e.g. asthma) and drug treatment.

History was taken and physical examination was performed in both groups. Directly before ET each subject underwent a CV assessment to rule out potential contraindications for exercise testing (the assessments included measurement of resting blood pressure, resting ECG and an echocardiogram).

Exercise testing

Maximal spiroergometric ET on a bicycle cycloergometer was performed using the CORTEX Meta-Soft. The ramp protocol was used with the initial load of 20 W and load increments of 10 W per minute. The following parameters were assessed: duration of exercise, resting heart rate (HR), maximum heart rate (HRmax), age-corrected heart rate (HRmax – age), peak volume of oxygen absorbed (VO₂peak), respiratory exchange ratio (RER) and metabolic equivalent of task (MET) [4]. The following ET discontinuation criteria were adopted: maximum fatigue, blood pressure drop of more than 10 mm Hg from baseline despite increasing load with the accompanying other manifestations of ischaemia such as moderate to severe angina, neurological manifestations, manifestations of limb hypoperfusion, patient's request to stop the test, ventricular tachycardia and ST segment elevation or depression by 2 mm on ECG.

Quality of life assessment

The QoL in both groups was assessed with a written test drawn up for the purposes of our study on the basis of the EuroQoL 5D template [3], consisting of 5 questions. In order to carry out an effective comparative analysis each of the EuroQoL questions were treated as equivalent, assigning a percentage value to each of the possible answers (A, B, C or D) as follows: A = 100%, B = 66%, C = 33%, D = 0%. Objective QoL (oQoL) was assessed on the basis of the arithmetic mean of the percentage values obtained for each of the questions. In addition, each subject rated his or her QoL subjectively (sQoL) on a percentage scale from 0% (the minimum) to 100% (the maximum). We also assessed the difference between subjective and oQoL in both groups (oQoL – sQoL).

Subjects from both groups were asked to complete a detailed physical activity questionnaire containing questions about their current lifestyle (physical activity or avoidance of physical activity, intensity of exercise) drawn up on the basis of the Stanford questionnaire, which included questions about low-activity exercise (Stanford I) and high-activity exercise (Stanford II) [5]. The subjects were additionally asked about their current or previous jobs, course of education and participation in physical education (PE) classes during school days, and about the use of stimulants (smoking). The questions about the readiness to participate in targeted cardiac rehabilitation programmes were only asked in patients with CHD. We assumed that low physical activity increased CV risk to a proportionately higher degree than in the group of less physically active members of the population [6].

The severity of depression in both groups was assessed in a survey in which questions from a written depression questionnaire by A.T. Beck, developed in 1961, were used [7]. The full version of the text was used, which contained 21 most commonly observed symptoms of depression, rated on a 4-point scale of severity self-assessment (0 to 3 points),

which were then summed up. We adopted the following criteria for the assessment of the severity of depressive feelings: 0–9 points: no symptoms of depression, 10–15 points: mild symptoms of depression, 16–23 points: moderate depression, 24 points or more: acute depression.

Statistical analysis

The results are presented as mean \pm SD or numbers and percentages. Data showing a normal distribution were compared with the t-Student test (t-test for equality of means) after previous verification of the normality of distribution using the W Shapiro-Wilk test. Data which did not show a normal distribution were analysed using non-parametric tests (the U Mann Whitney test). Categorical variables were described using absolute and relative frequencies in subgroups, rounding the results up to the tenth. Comparisons of categorical variables were performed using the chi-squared test according to Pearson. For low absolute frequencies in the subgroups exact Fisher's test with Yates' correction was used. The significance level was 0.05. The statistical calculations were performed with the use of SPSS v. 17.0 (SPSS Inc., USA) and Statistica v. 8.0 (StatSoft Inc., USA).

RESULTS

In the study group, the mean time from surgery for CHD was 12 years (range: 10–26 years). Table 1 summarises the clinical

and demographic characteristics of both groups. There were no significant differences between the groups except for HR, which was higher in the GUCH patients.

All the patients completed the spiroergometric test on the bicycle cycloergometer without complications. Patients with a history of surgery for CHD had significantly lower exercise capacity parameters compared to young healthy controls (Table 2). None of the patients in the study group achieved 100% of their HRmax value: only 7 patients from this group (35%) achieved 80% HRmax and 80% HRmax was achieved by 100% of the students. A normal blood pressure response was observed in all the subjects. The reasons for discontinuation of spiroergometric testing in all patients from the study group was maximum fatigue with a request to discontinue the test.

The analysis of the results of Beck's questionnaire revealed that 27 (90%) patients from the study group achieved a summary score of less than 9 points (3.25 points on average), which indicates absence of symptoms of depression and absence of mild depression in the majority of test participants. Three patients from the study group (10%) had symptoms of mild depression (10–11 points in Beck's questionnaire). The most commonly declared symptoms were: the feeling of insufficiency, difficulty in carrying out work, pessimism and low level of life "energy". In the control group 96% of subjects achieved less than 9 points (0.75 points on average), which

Table 1. Comparison of clinical and demographic characteristics of the studied groups

| Parameter | Study group GUCH (n = 30) | Control group (n = 30) | P |
|--------------------|---------------------------|--------------------------|-------|
| Sex: females/males | 14/16 | 15/15 | 0.796 |
| Age [years] | 24.6 \pm 4.63 (18–36) | 24.4 \pm 1.98 (21–30) | 0.777 |
| Height [cm] | 168 \pm 7.3 (155–184) | 173 \pm 11 (147–190) | 0.056 |
| Weight [kg] | 64 \pm 11.7 (44–98) | 69 \pm 14.4 (40–90) | 0.141 |
| Resting HR [bpm] | 91.3 \pm 10.9 (72–119) | 78.5 \pm 15.8 (47–103) | 0.001 |

GUCH — grown-up congenital heart defect patients; HR — heart rate

Table 2. Comparison of the results of spiroergometric testing in the studied groups

| Parameter | Study group GUCH (n = 30) | Control group (n = 30) | P |
|----------------------------------|----------------------------|-----------------------------|---------|
| HRmax [bpm] | 148 \pm 24.8 (87–200) | 182 \pm 8.1 (165–200) | < 0.001 |
| HRmax – age [bpm] | 76 \pm 12.3 (45–99.5) | 93 \pm 4.2 (85–101) | < 0.001 |
| Exercise load [W] | 120 \pm 33.4 (52–184) | 182 \pm 41.2 (124–267) | < 0.001 |
| MET | 6.5 \pm 1.6 (2.6–9.4) | 10 \pm 1.6 (7.1–12.9) | < 0.001 |
| VO ₂ peak [mL/kg/min] | 22.8 \pm 5.6 (9–33) | 35 \pm 5.5 (25–45) | < 0.001 |
| Duration of exercise [min] | 10.7 \pm 3.5 (4.3–19.2) | 18.3 \pm 4.2 (11–26) | < 0.001 |
| RER | 0.99 \pm 0.17 (0.82–1.6) | 1.15 \pm 0.09 (1.01–1.36) | < 0.001 |

HRmax — maximum heart rate; HRmax – age — age-corrected heart rate; MET — metabolic equivalent of task; VO₂peak — peak oxygen absorption; RER — respiratory exchange ratio

Table 3. Comparison of psychological assessment results in the studied groups

| Parameter | Study group GUCH (n = 30) | Control group (n = 30) | P |
|-------------|---------------------------|------------------------|---------|
| Beck | 4.03 ± 3.12 (0–12) | 1.17 ± 2.04 (0–10) | < 0.001 |
| Stanford I | 1.8 ± 0.96 (1–4) | 3.0 ± 1.07 (2–6) | < 0.001 |
| Stanford II | 0.3 ± 0.54 (0–2) | 1.2 ± 0.96 (0–3) | < 0.001 |
| oQoL [%] | 88 ± 7.3 (73–100) | 99.6 ± 1.7 (93–100) | < 0.001 |
| sQoL [%] | 79 ± 9.1 (58–98) | 88.5 ± 9.6 (70–100) | < 0.001 |

GUCH — grown-up congenital heart defect patients; Beck — results of A.T. Beck's depression questionnaire; Stanford I — results of Stanford questionnaire for low-activity exercise; Stanford II — results of Stanford questionnaire for high-activity exercise; oQoL — objective quality of life; sQoL — subjective quality of life

indicates absence of depression. The mean score was significantly lower in the control group (Table 3).

Using the Stanford questionnaire patients with CHD had a significantly lower physical activity than their healthy peers. In addition, the answers to questions in the activity and lifestyle survey showed that 28 (93.3%) CHD patients participated in PE classes during school days *versus* all the students ($p < 0.01$). Four (13.3%) patients from the study group are not working or studying, 16 (53.3%) are in current employment and 10 (33.3%) are studying; it was assumed that 100% of the students showed activity equivalent to employment ($p < 0.001$). The fear of undertaking physical exercise, both in everyday life and at work, was declared by 16 (53.3%) subjects. Smoking was declared by only 3 (10%) subjects with CHD, similarly to the control group. The mean Stanford I and Stanford II scores were significantly better in the control than patient group (Table 3).

The EuroQoL5 test showed that the values of oQoL and sQoL in patients with CHD were lower than that in the group of healthy students. We also found a smaller difference between oQoL assessed in the EuroQoL5 test and sQoL in the study group (9%) *vs* the control group (11.1%) ($p < 0.05$). Table 3 presents summary results for QoL.

In response to the additional questions in the survey, all the patients with CHD expressed the willingness to participate in a targeted programme of comprehensive CV rehabilitation, even if it involved long travel and other organisational difficulties (temporary leave off work, limited social activity, limited time spent with friends etc.). It was our intention not to include a question about the need to undergo rehabilitation in the survey directed to the control group.

DISCUSSION

Our interest in the actual health and QoL of patients with CHD was generated by the analysis of problems reported by adolescent GUCH patients presenting to our department [8]. In a natural way, based on the history of a diagnosed and correctly managed CHD, this group should be completely healthy and the only difference should be the presence of scars secondary to cardiac surgery during childhood [2].

The main problem of GUCH patients seems to be their widespread conviction of having some sort of undefined disability, which affects an increasing group of adolescent patients receiving surgery for CHD during childhood. The issue of reduced exercise capacity in patients with CHD compared to healthy peers has been already addressed in the literature [9, 10]. The study protocol we adopted, which was a combination of a QoL assessment using tests and surveys with an assessment of exercise capacity using ET, is an original method that enables an additional multi-profile evaluation of CHD patients. The results of spiroergometric testing confirmed inferior exercise capacity in adolescent patients with CHD, compared with healthy controls the data literature [10]. In addition to the typical medical assessment of health which is done by using a uniform regimen of capacity tests, the analysis of past medical history and current CV assessments, we drew attention in our study protocol to the poorly accessible, immeasurable area of emotional life (according to Beck), including the need for non-medical assistance often expressed by patients (the lifestyle survey) [11, 12]. Of note is the fact that patients with CHD are commonly treated as incompletely healthy already from their youngest years (they are exempt from PE classes at school), which reflects treating heart defects as incurable conditions. Data from Stanford I and Stanford II questionnaires [5] and the original life activity and QoL questionnaire drawn up on the basis of the EuroQoL5 test [3] were very helpful in determining the current physical activity profile of each of the patients. We additionally confirmed the discrepancy between the objective and subjective QoL, with the former based on test results. The discrepancy was smaller in the group of patients than in healthy students. The employment activity data showed that performing a job as a source of income was possible to achieve only in a part of the study patients who have undergone surgery for CHD.

It is also worth mentioning that the survey confirmed the necessity to use CV rehabilitation programmes aimed at improving function in the form of controlled training of patients who underwent surgery for CHD a long time ago [13]. This

reflects the results of other studies, surveys and social analyses conducted in other European countries [14], where this problem gained focus slightly earlier. All our patients expressed their willingness to participate in a programme of comprehensive CV rehabilitation with the declaration to undergo the regime of psychological classes and physical exercises. It might be concluded that it seems justifiable to create centres of late rehabilitation, which will become an element of a holistic care of adolescent patients with CHD, undertaking education and then commencing social, professional and family life [13, 14].

Taking into account the results of our study and comparing similar reports in literature, it may be concluded that exercise capacity and psychological profile of adolescent patients from the GUCH group differ from the expectations presented by a young person who is fully cured and free from long-term consequences and complications [7]. Whatever the age at heart defect correction, patients who have undergone cardiac surgery are a group of patients who require regular check-ups and CV treatment, but also various forms of assistance to facilitate adaptation to contemporary requirements of independent life in the society [15]. The lower activity and exercise capacity confirmed by our study in the GUCH group may affect the increased risk of civilisation-related CV diseases, natural for all the individuals of the ageing population [6].

Based on the presented studies it may be concluded that the criteria for cure remain unmet among patients who, despite a long time that has elapsed since surgical correction of a heart defect during childhood. Limitations of exercise capacity, mental discomfort and uncertainty about the future, in addition to the persistent cardiac problems, worsen the feeling of being impossible to achieve full self-actualisation and social adaptation. The adolescents patient with CHD are also burdened with a number of additional issues: psychological, social, responsible family life (including procreation) and limited ability to pursue life plans. This is accompanied by the necessity to solve economic problems under the pressure of health-related limitations (upkeep, treatment costs, social benefits) and under the pressure of having to select one's education and job, which may interfere with rehabilitation and late improvement of function [5]. Dependence on drug treatment and its monitoring as well as the perspective of subsequent interventions and cardiac surgeries does not help to solve these problems, including the definition of the timeframes to take strategic life decisions (setting up a family, planning children) [8, 14].

CONCLUSIONS

Exercise capacity, physical activity and QoL of young adults with a history of CHD surgical treatment are worse than observed in healthy peers, and the health status does not fulfil the definition of complete recovery.

Conflict of interest: none declared

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Wydolność fizyczna i jakość życia pacjentów w odległym okresie po kardiologicznej korekcji wrodzonych wad serca

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Streszczenie

Wstęp: Obiektywna ocena wydolności fizycznej i jakości życia młodych dorosłych w odległym okresie po kardiologicznej korekcji wrodzonej wady serca (WWS) stanowi podstawę pełnego określenia ich aktualnego stanu zdrowia i może stanowić uzupełniające kryteria odległej oceny skuteczności leczenia.

Cel: Celem pracy była ocena wydolności fizycznej młodych dorosłych pacjentów w odległym okresie po chirurgicznej korekcji prostej przeciekowej WWS, w porównaniu z parametrami wydolności fizycznej losowo wybranej grupy młodych dorosłych, ocena jakości życia, aktywności fizycznej i nasilenia depresji w obu grupach.

Metody: Badaniem objęto 60 osób poddanych ocenie w okresie od 1.06.2008 do 30.06.2010 r. Grupę badaną stanowiło 30 młodych dorosłych pacjentów z WWS (14 mężczyzn, 16 kobiet) w wieku 18–36 lat (średnio: 24,6 roku) po przebytej operacji kardiologicznej korekcji wady, a grupę kontrolną — 30 zdrowych studentów (15 kobiet, 15 mężczyzn) w wieku 21–28 lat (średnio: 24,43 roku). Przeprowadzono maksymalną próbę wysiłkową spiroergometryczną na cykloergometrze rowerowym, test jakości życia i aktywności fizycznej oraz oceniono nasilenie depresji. Uzyskane wyniki poddano szczegółowej analizie statystycznej.

Wyniki: Na podstawie wyników testów spiroergometrycznych stwierdzono, że pacjenci po korekcji WWS charakteryzują się obniżonymi parametrami wydolności fizycznej w porównaniu z grupą zdrowych rówieśników. Na podstawie kwestionariusza Stanford wykazano, że pacjenci z WWS cechują się znamienne niższą aktywnością fizyczną. Test EuroQoL5 wykazał, że jakość życia pacjentów z WWS jest niższa niż w grupie zdrowych studentów. Analiza kwestionariusza Becka wykazała większe nasilenie odczuć depresyjnych wśród pacjentów z WWS.

Wnioski: Wydolność, aktywność fizyczna i szeroko rozumiana jakość życia młodych dorastających pacjentów w odległym okresie po operacji WWS jest niższa od analogicznych parametrów w populacji zdrowych młodych ludzi i nie spełnia kryteriów pełnego powrotu do zdrowia.

Słowa kluczowe: wrodzone wady serca, dorośli pacjenci z wrodzonymi wadami serca (GUCH), wydolność fizyczna, jakość życia, rehabilitacja

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