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Patient reported outcomes are associated with physical activity level in adults with congenital heart disease

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ABSTRACT

Background: In general, adults with congenital heart disease (CHD) have impaired exercise capacity, and approximately 50% do not reach current recommendations on physical activity. Herein we analysed factors associated with physical activity level (PAL) in adults with CHD by using patient-reported outcomes (PRO).
Methods: Patients with CHD ($n = 471$) were randomly selected from the national register on CHD and categorized according to complexity of lesions — simple ($n = 172$, 39.1 ± 14.6 years), moderate ($n = 212$, 39 ± 14.1 years), and severe ($n = 87$, 31.7 ± 10.7 years). Participants completed a standardized questionnaire measuring PRO-domains including PAL. Variables associated with PAL were tested in multivariate logistic regression.
Results: PAL was categorized into high (≥3 METs ≥2.5 h/week, $n = 192$) and low (≥3 METs <2.5 h/week, $n = 279$). Patients with low PAL were older (42.6 *vs.* 35.8 years, $p \leq 0.001$), had more prescribed medications (51% *vs.* 39%, $p = 0.009$), more symptoms (25% *vs.* 16%, $p = 0.02$) and comorbidity (45% *vs.* 34% $p = 0.02$). Patients with low PAL rated a lower quality of life (76.6 *vs.* 83.4, $p < 0.001$), satisfaction with life (25.6 *vs.* 27.3, $p = 0.003$), a lower Physical Component Summary score (PCS) (78.1 *vs.* 90.5, $p < 0.001$) and Mental Component Summary score (MCS) (73.5 *vs.* 79.5, $p < 0.001$). Complexity of heart lesion was not associated with PAL. The included PROs — separately tested in the model, together with age were associated with PAL.
Conclusions: PCS and MCS are stronger associated with PAL than age and medical factors. The use of these PROs could therefore provide valuable information of benefit for individualized advice regarding physical activity to patients with CHD.

1. Introduction

Owing to advances in paediatric cardiac care, adults with congenital heart disease (CHD) are a growing population [1–3]. A consequence of the improved survival is that long-term complications and the need for re-interventions increase as the patients grow older [4]. The presence of CHD, along with required heart surgery in childhood and the potential need of re-intervention, renders the prevention of acquired cardiovascular disease even more important. In the prevention of acquired cardiovascular disease physical activity plays an important role [5–7]. Given the increasing number of adults with CHD, and thereby also the increased risk of acquired cardiovascular disease, a physically active lifestyle has been advocated in this population [8].

It was previously shown that nearly half of the persons with CHD do not reach current recommendations on physical activity [9]. Furthermore, reduced exercise capacity is common in CHD [10], and a more pronounced reduction is associated with a worse prognosis [11]. In addition, it was reported that patients with more complex CHD have impaired muscle function [12,13].

Studies on physical activity level (PAL) and exercise training in patients with CHD have shown that they are equally active as their healthy peers [9], and that exercise training increases their aerobic capacity [15].

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Moreover, studies on adolescents with CHD have shown that self-concept influences PAL [16]. It also appears that other factors than the heart defect *per se* (*e.g.* parents' attitudes, cardiologists' recommendations, exercise self-efficacy, other interests), play a more important role in determining how adolescents and adults experience physical activity and their own ability [17,18]. There are still unanswered questions regarding what factors might contribute to or predict an increase in physical activity in adults with CHD. In order to establish potential targets for interventions within this group of patients, there is a need to increase the knowledge. The aim of the present study was to investigate factors associated with physical activity level among adults with CHD.

2. Methods

2.1. Patients

All patients were part of the Swedish branch of the international multicenter study APPROACH-IS (Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease — International Study) that aims to investigate Patient-Reported Outcomes (PRO) in adults with CHD [19]. APPROACH-IS was performed from April 2013 to March 2015, in partnership with the International Society for Adult Congenital Heart Disease and included patients from 15 countries from 5 continents [19].

The inclusion criteria in APPROACH-IS were as follows: (i) had a diagnosis of CHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that was present at birth and was actually or potentially functionally significant [20], (ii) was 18 years of age or older, (iii) had diagnosis established before adolescence (*i.e.* before 10 years of age), (iv) attended continued follow-up at a CHD centre or included in a national/regional register, and (v) had physical, cognitive, and language capacities to allow completion of the self-report questionnaires. Patients with prior heart transplantation, primary pulmonary hypertension, or impaired cognitive abilities were excluded [19]. The cardiac lesions were classified as simple, moderate or complex [19,20].

In total 4028 adults with CHD participated [21] of which 471 lived in Sweden [22]. The Swedish participants of APPROACH-IS were initially identified and randomly selected from the national register SWEDCON (http://www.ucr.uu.se/swedcon.se). There were 912 eligible patients who met the inclusion criteria and of these, 43 patients could not be reached ($n = 12$) or actively declined ($n = 31$) to participate; of the remaining 869 patients, 471 sent the questionnaire back [22]. All patients had their regular follow-up at one of the three large tertiary care centres for adult patients with CHD, *i.e.* Gothenburg ($n = 173$), Stockholm ($n = 162$) and Umeå ($n = 136$). APPROACH-IS was approved by the institutional review board of the University Hospitals Leuven/KU Leuven Belgium (the international coordinating centre) and the study was then also approved by the regional Ethics Review Board in Gothenburg (the national coordinating centre) (nos.: 713-13, T100-14 and T207-14).

2.2. Procedure

The data in the present study were collected from the SWEDCON registry and in APPROACH-IS. Data from SWEDCON consisted of the following variables: social and demographic variables (*e.g.* age, gender, marital status, housing, highest education, and employment status), medical data (*e.g.* diagnosis, medication, catheterization or catheter interventions, type of surgery, and need of pacemaker), physiological data, (*e.g.* electrocardiogram (ECG) and echocardiogram), general symptoms (not strictly associated with physical activity) and physical function scored by a cardiologist according to the New York Heart Association (NYHA) classification system.

2.3. Outcomes

The self-report questionnaires in APPROACH-IS consisted of validated and reliability-tested instruments that were compiled into one test battery to measure PROs within different PRO domains [19]. The different domains were; perceived health status, psychological functioning, health behaviour, quality of life and sense of coherence. The APPROACH-IS survey package was sent by surface mail to the included patients. General medical data were added to the APPROACH database by the local investigator such as number of previous interventions, history of arrhythmia and comorbidities. Comorbidity was defined as any diagnosis other than the cardiac lesion that was judged relevant by the investigator.

2.3.1. Perceived health status

To measure perceived health the 12-item Short Form Health Survey (SF-12) was used, which consisted of eight domains where the patient scored from 0 to 100 [23]. A higher score reflects better perceived health. The SF-12 produced a Mental Component Summary (MCS) and Physical Component Summary (PCS) [23]. Calculations of SF-12 were performed according to the classification into PCS and MCS. Prior studies have demonstrated good validity and reliability [23].

2.3.2. Health behaviour

To measure physical activity level (PAL) and health behaviour, the Health Behaviour Scale (HBS-CHD) [24] was used. The HBS-CHD contained items regarding physical activity such as sports during school hours, extreme physically demanding sports (*e.g.* basketball and long distance running) and moderate demanding sports (*e.g.* jogging and volleyball). The levels of physical activity assessed in the present study were those considered equal to or exceeding 3 Metabolic equivalent (METs) [25]. The participants were asked to assess how many hours/week they participated in various physical activities. The HBS-CHD has good psychometric properties [24].

2.3.3. Quality of life

Quality of life (QoL) is defined as the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain aspects of life that are important to them [26]. These included matters both related and unrelated to health. QoL was measured using the linear analogue scale (LAS) and the Satisfaction with Life Scale (SWLS). The LAS is a vertically oriented scale graded from 0 (worst imaginable QoL) to 100 (best imaginable QoL). The SWLS includes five statements and assesses the patient's judgment of life satisfaction [19]; it ranges from 1 (strongly disagree) to 7 (strongly agree) with a total sum from 5 (extremely dissatisfied) to 35 (extremely satisfied). The validity and reliability when used in adults with CHD has been found good [27].

2.3.4. Sense of coherence

For the measurement of sense of coherence (SOC), the short version of Antonovsky's SOC scale (SOC-13) was used [28]. The total score ranged from 13 to 91 where the higher score indicated a stronger SOC. SOC-13 has good psychometric properties when used in individuals with CHD [29].

2.3.5. Statistics

PAL was calculated by summarising the time spent at an activity ≥3 METs. Based on the current World Health Organization recommendations on physical activity for promoting health in adults aged 18–64 (2.5 h/week spent ≥3 METs), the population was grouped into two categories — high PAL (≥3 METs ≥2.5 h/week) and low PAL (≥3 METs <2.5 h/week) [30].

All calculations were performed using SPSS 23 (IBM, Armonk, NY, USA). The data were assessed for normality. Differences in means were tested with Student's *t*-test, ranks tested with Mann-Whitney *U* test, and ratios tested with chi^2-test. A multivariable model was constructed including variables statistically significant at the univariate level. Multivariable testing was performed in a manual backward manner. Collinearity was tested for during analysis. Sensitivity and specificity of the PCS scoring to predict high level of PAL were analysed for PCS score in the range of 50–100. The null hypothesis was rejected for *p*-values <0.05.

3. Results

Four hundred seventy-one patients with CHD participated in the study, of which 241 (51%) were men and 230 were women; the mean age was 38.0 ± 14.1 years. The degree of complexity of CHD was distributed into simple ($n = 172$, mean age 39.1 ± 14.6 years, women $n = 88$), moderate ($n = 212$, mean age 39 ± 14.1 years, women $n = 109$) and severe lesions ($n = 87$, mean age 31.7 ± 10.7 years, women $n = 33$). The characteristics of the study population are presented in Table 1.

3.1. Associations with physical activity level (PAL)

High PAL (≥3 METs ≥2.5 h/week) was reported by 192 patients (41%), whereas 279 patients (59%) reported low PAL (≥3 METs <2.5 h/week). Patients with low PAL were older (42.6 *vs.* 35.8 $p \le 0.001$), had more prescribed medications (51% *vs.* 39% $p = 0.009$), had more symptoms (25% *vs.* 16% $p = 0.02$) and comorbidity (45% *vs.* 34% $p = 0.02$) (Table 1). Patients with high PAL rated higher on Linear analog scale (83.4 *vs.* 76.6 $p \le 0.001$) and SWLS (27.3 *vs.* 25.6 $p = 0.003$). In addition, they rated higher on SF-12′s Mental Component summary (73.5 *vs.* 79.5 $p \le 0.001$) and on SF-12′s Physical Component summary (78.1 *vs.* 90.5 $p \le 0.001$).

Variables with a possible influence on high PAL were tested in univariate mode as shown in Table 3. Notably, the degree of complexity of the heart lesion was not associated with PAL (Table 3). Distribution of heart lesions and PAL is shown in Table 2. The result for multivariable analysis is shown in Table 4, separated into first-step model and final model Age and Physical component summary were found independently associated with high PAL. In Table 4, we only present data on Physical component summary but the other Patient reported outcomes, when separately tested in the model, yielded similar results.

In a separate sensitivity analysis the influence of Physical component summary to predict a high level of PAL was investigated. This was performed for Physical component summary scores of 50 to 95 (Fig. 1), to