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Sense of coherence, rather than exercise capacity, is the stronger predictor to obtain health-related quality of life in adults with congenital heart disease

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Abstract

Objective: Irrespective of their cardiovascular findings, quality of life in patients with congenital heart disease (CHD) is good or even superior to that in healthy controls. The sense of coherence (SOC), a psychological resource that focuses on factors that support human health and well-being, was suggested to act as a potential pathway for maintaining and improving quality of life independently from the disease status.

Patients and methods: From April 2010 to May 2011, we consecutively included 546 young adults (236 female, median age 26.9 years, aged from 16 to 71 years) with various CHD into the study. Patients completed the SOC-13 questionnaire and the health-related quality of life questionnaire SF-36. Afterwards they performed a cardiopulmonary exercise test.

Results: In adults with CHD, SOC was slightly enhanced compared with reference values (CHD: median 74.0 [IQR: 63.8;81.0] vs. reference value: 69.7 [68.5;69.7]; $p < 0.001$) corresponding to 106.1% [91.8;116.7%] of predicted reference value. SOC was not associated with the underlying heart defect (Kruskal–Wallis test, $p = 0.565$) or heart defect severity (Spearman $r = 0.044$; $p = 0.301$). It was moderately related to all dimensions of quality of life ($r = 0.260$ to $r = 0.686$; $p < 0.001$) except to health transition. It was only poorly associated with exercise capacity ($r = 0.098$; $p = 0.023$) and age ($r = -0.097$; $p = 0.023$).

Conclusions: Adults with CHD have an enhanced SOC. SOC is moderately correlated with quality of life, and seems to be a stronger predictor of health-related life quality than exercise capacity. SOC might explain the rather good quality of life in patients with CHD despite their reduction in exercise capacity.

Keywords

Congenital heart disease, sense of coherence, quality of life, exercise capacity

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Introduction

Patients with congenital heart disease (CHD) report a good or even better quality of life than healthy subjects. This holds true even in patients with complex lesions.[1–7] For caretakers this is astonishing as these patients are limited in many fields of daily life. This includes not only exercise abilities, like endurance, strength and coordination, but in many patients also cognitive functions, emotional balance and psychosocial integration. To explain this discrepancy between quality of life and objectively measurable components of (life) functioning, it was assumed that coping strategies, denial mechanisms and family involvement act in concert to obtain this good quality of life.[8,9]

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In the salutogenic model of Antonovsky,[10,11] sense of coherence (SOC) is defined as a psychological resource of health and well-being. In contrast to the usual disease orientation, this model focuses on positive factors that support a subjective state of both physical and mental health. It has three main components: comprehensibility, manageability and meaningfulness. Individuals with a strong SOC perceive the world as predictable, manageable and meaningful, which helps them to identify coping mechanisms as an available resource to minimize feelings of tension and stress, as well as to improve the prospects of staying healthy.[10,11] SOC seems to be a resource that enhances quality of life independent from disease or bad experiences.[12,13]

In patients with CHD, a stronger SOC is suggested to act as a potential pathway for maintaining and improving quality of life.[12] Recent reports[14–16] support that SOC is normal or even stronger in patients with CHD in comparison with healthy subjects, and that it is an independent predictor of quality of life in adolescents with CHD. Moreover, this means that the patients are coping well with their disease and find their lives meaningful.[16] But the impact of SOC seems to wane over the course of a year in almost all of the measured life quality dimensions.[14]

The current study was performed to evaluate whether the strong relationship between SOC and quality of life persists into adulthood and whether SOC has a stronger impact on quality of life than exercise capacity measured as peak VO_2 as the most comprehensive variable for cardiovascular function and fitness.

Patients and methods

Study subjects

From April 2010 to May 2011, 879 patients with various congenital heart defects were referred for exercise testing with various clinical conditions as part of their routine follow-up in our institution. Those 16 years or older filled in the short form of the 'Sense of Coherence' (SOC-13) and the 'Medical Outcomes Study 36 item short form' (SF-36) questionnaire. Afterwards, they performed a cardiopulmonary exercise test (CPET). Those lacking reading ability, those not speaking German and those who were cognitively unable to fill in the questionnaire without any help were excluded from participation.

In total, 546 patients were included. According to the ACC Guidelines,[17] the heart defect was of a simple severity (all native conditions, isolated shunts after repair without sequels) in 85 patients, 154 were of moderate (tetralogy of Fallot, coarctation of the aorta, Ebstein's anomaly, patients after valve repair) and 307 of complex severity (patients with allografts, Fontan circulations, transposition of the great arteries, cyanotic patients). Study subjects are outlined in detail in Table 1.

The study was in accordance with the declaration of Helsinki (revision 2008). Patients and their guardians

Table 1. Study subjects, sense of coherence scores, health-related quality of life physical and mental component scores and peak oxygen uptake according to diagnostic groups

Diagnosis	*n*	Sex ♀/♂	Age median (Q1;Q3)	Sense of coherence (% of predicted)	Physical component summary	Mental component summary	Peak oxygen uptake (% of predicted)
Cyanotic	19	9/10	29.6 (26.3;40.8)	100.4 (77.5;119.1)	93 (78;106)	109 (94;117)	55.1 (49.5;60.9)
Fontan circulation	44	21/23	26.6 (20.9;33.6)	98.4 (87.9;114.1)	105 (99;112)	108 (94;118)	67.9 (57.7;79.9)
TGA (Rastelli and CCTGA)	35	12/23	23.3 (19.2;30.5)	111.8 (97.5;119.1)	104 (96;111)	107 (99;115)	76.0 (63.4;87.9)
TGA (Senning and Mustard)	56	28/28	29.6 (25.8;35.3)	108.3 (96.7;114.8)	107 (96;113)	104 (93;113)	79.5 (66.9;88.9)
TGA (Arterial Switch)	21	7/14	19.1 (17.3;21.0)	110.8 (96.2;121.5)	109 (100;117)	110 (102;114)	94.3 (83.5;105.5)
Tetralogy of Fallot	100	47/53	30.7 (23.3;39.3)	107.0 (93.3;118.1)	105 (91;113)	107 (94;111)	84.5 (71.7;98.9)
Ebstein anomaly	27	14/13	39.3 (25.4;46.0)	104.7 (93.3;115.2)	107 (96;112)	106 (85;113)	84.0 (72.1;96.0)
PS/PR	28	11/17	26.8 (21.8;31.5)	106.1 (96.1;121.9)	109 (99;114)	108 (92;115)	93.7 (83.3;105.6)
Coarctation of the aorta	48	22/26	24.4 (20.6;39.3)	106.5 (92.5;117.3)	112 (107;116)	106 (96;110)	96.1 (83.3;107.0)
Aortic stenosis	80	16/64	25.0 (19.2;32.0)	104.7 (89.6;112.9)	111 (104;116)	106 (91;113)	98.4 (85.6;110.1)
Isolated shunt	54	33/21	27.9 (21.8;37.1)	106.2 (90.4;116.7)	109 (97;113)	99 (90;110)	95.4 (81.7;99.7)
Other	34	16/18	24.0 (21.3;28.8)	94.0 (80.2;118.3)	109 (97;113)	100 (90;110)	90.1 (74,1;97.9)
Total	546	236 / 310	26.9 (21.3;35.2)	106.1 (91.8;116.7)	108 (97;114)	106 (92;113)	86.7 (72.1;99.6)
p-values[a]		**0.002**	<**0.001**	0.565	<**0.001**	0.226	<**0.001**

Values are presented as median (Q1;Q3); [a]Comparing patients with CHD between their diagnostic groups with a Kruskal–Wallis H test. *p*-values <0.05 were displayed in bold.

gave written informed consent and agreed to the anonymous publication of their data.

Sense of coherence

To assess SOC, we used the German short form SOC-13 of the original 29-item SOC questionnaire published by Antonovsky.[11] It was designed to measure the comprehensibility, manageability and meaningfulness of the participants' lives. It comprises 13 questions that can be answered on a seven-point Likert scale. Afterwards a sum score between 13 and 91 points is generated, whereby higher values indicate a stronger SOC. The SOC-13 has been proven to be reliable in research settings with high internal consistency and re-test stability.[18]

Individual age- and sex-adjusted reference values were calculated according to the German evaluation study (community-based sample of the German population; $n = 1994$; 1089 female, mean age 49.9 ± 16.9 years, aged from 18 to 92 years) from Schumacher and colleagues.[19]

Health-related quality of life (QoL)

The medical outcomes study SF-36 was used. It has an acceptable internal consistency and has proven to be useful in various specialties of medicine without any bias for symptoms of a specific disease. The SF-36 measures nine health constructs with scores ranging from 0 (worst) to 100 (best) using eight subscales about physical functioning, physical role, physical pain, general health, vitality, social functioning, emotional role and mental health, with two to 10 items per subscale and one single item about health transition. In addition, two component summaries were calculated that represent perceived physical and mental health-related quality of life.

As described previously[1,3,20,21] we used the German version of the self-report form with a window of 4 weeks. Individual age- and sex-related reference values were drawn from Bullinger and Kirchberger[22] and presented in percentage of the predicted reference value.

Cardiopulmonary exercise test

All patients underwent a symptom-limited CPET on a bicycle ergometer in upright position as previously described.[3,20,21]

In short, after a 3-minute rest to define baseline, patients had a 3-minute warm-up without load, followed by a ramp-wise increase of load with 10, 15, 20 or 30 Watt/min depending on the expected individual physical capacity estimated by the investigator. The aim was to reach a cycling duration of about 8–12 minutes after warm-up. The end of the CPET was marked by symptom limitation and was followed by a 5-minute recovery period, with the first 2–3 minutes cycling with minimal load.

The exercise test featured a breath-by-breath gas exchange analysis using a metabolic chart (Vmax 229, SensorMedics, Viasys Healthcare, Yorba Linda, CA, USA). Peak oxygen uptake (VO_2) was defined as the highest mean uptake of any 30-second time interval during exercise.

Reference values (ml/kg/min) were calculated for those 25 years and older according to the German cohort study from Gläser et al.[23] for age in years, weight in kilograms and height in centimetres.

$$VO_2peak\ (female) = \frac{(-588 - 11.33\ x\ age + 9.13\ x\ height + 26.88\ x\ weight - 0.12\ x\ weight\ x\ weight)}{weight}$$

$$VO_2peak\ (male) = \frac{(-69 + 1.48\ x\ age + 14.02\ x\ height + 7.44\ x\ weight - 0.2256\ x\ age\ x\ age)}{weight}$$

For patients 14–25 years old, reference values (ml/kg/min) were calculated according to Cooper and Weiler-Ravell.[24]

$$VO_2peak\ (female) = \frac{(22.5\ x\ height - 1837.8)}{weight}$$

$$VO_2peak\ (male) = \frac{(43.6\ x\ height - 4547.1)}{weight}$$

Data analyses

All analyses were performed using PASW 19.0 software (SPSS Inc, Chicago, IL, USA). As data were skewed, all descriptive data were expressed in median values and interquartile range [Q1;Q3]. As age and sex differed between the diagnostic groups SOC, SF-36 dimensions and peak oxygen uptake were corrected for age and gender and expressed as '% predicted'. Patients' individual SOC raw value was compared with the corresponding reference value by a Wilcoxon signed rank test to find differences between patients with CHD and a reference population. Gender differences in SOC were estimated by a Mann–Whitney U-test.

Primarily, SOC, health-related QoL and peak oxygen uptake were compared between the diagnostic subgroups using a Kruskal–Wallis test and between the severity classes using Spearman rank correlation. Secondarily, associations of health-related QoL with SOC and peak oxygen uptake were assessed using non-parametric Spearman rank correlation.

For all analyses, a two-tailed probability value <0.05 was considered statistically significant.

Results

Patients' characteristics as well as age- and gender-adjusted SOC, physical component summary and mental component summary scores and peak oxygen uptake according to diagnostic subgroups are presented in Table 1.

Sense of coherence

SOC was slightly stronger in patients with CHD when compared with the reference values (CHD: median 74.0 [IQR: 63.8;81.0] vs. reference value: 69.7 [68.5;69.7]; $p < 0.001$) corresponding to 106.1 [91.8;116.7%] of predicted reference value. After correcting the data with age- and sex-related reference values, there was a trend for an enhanced SOC in women (women 109.1% [92.0%; 118.6%] vs. men 104.7% [90.4%; 114.7%], $p = 0.060$). There was a weak association with age ($r = -0.097$; $p = 0.023$).

No association could be found to the severity of the heart defect or the diagnostic subgroups (Tables 1 and 2).

As seen in Table 3, SOC was moderately correlated to all of the quality of life domains ($r = 0.260$ to $r = 0.686$, $p < 0.001$) except health transition. Its association to peak VO_2 ($r = 0.098$; $p = 0.023$) was poor.

Health-related quality of life

Health-related QoL was good (Table 1). Physical component score decreased with heart defect severity but, paradoxically, mental component score increased (Table 2).

Cardiopulmonary exercise test

Median respiratory exchange ratio was 1.11 (1.06;1.16) showing an adequate test performance. Figure 1 illustrates peak oxygen uptake according to diagnostic subgroups. Correlations to QoL were confined to the more physical subscales (physical functioning, role physical, general health), correlation to SOC was very weak (Table 3).

Discussion

This study showed that adults with CHD have a strong sense of coherence. SOC was moderately correlated with QoL and independent to the severity of the cardiac malformation. It seems to be a stronger predictor of health-related QoL than exercise capacity.

In the past decade, many studies have investigated health-related QoL in patients with CHD. Many of them, including the present study, found values similar to or above those of healthy subjects.[4–6] It was suggested that a possible pathway for mediating QoL in patients with CHD could be a strong SOC,[12] as shown cross-sectionally in various other diseases.[13] Also in adolescents with CHD, an increased SOC was recently found.[15] Our current study extends this finding to adults with CHD. Unfortunately, the SOC-13 did not allow splitting up to find which component of SOC is

Table 2. SOC, physical and mental component summary scores, and peak oxygen uptake according to the severity of the cardiac defect

Severity	*n*	Sense of coherence (% of predicted)	Physical component summary (% of predicted)	Mental component summary (% of predicted)	Peak oxygen uptake (% of predicted)
Simple	85	106.1 (89.6;114.2)	111.6 (98.7;116.3)	98.4 (83.0;110.1)	98.7 (88.7;113.1)
Moderate	154	104.0 (91.8;116.2)	109.8 (101.5;115.0)	106.8 (91.5;111.5)	93.2 (80.3;103.5)
Complex	307	106.1 (90.4;118.1)	105.4 (93.8;112.7)	107.3 (95,4;114.3)	79.6 (64.1;92.5)
p-values[a]		$r = 0.044$ ($p = 0.301$)	$\mathbf{r = -0.168}$ **($p < 0.001$)**	$\mathbf{r = 0.139}$ **($p = 0.001$)**	$\mathbf{r = -0.385}$ **($p < 0.001$)**

Values are presented as median (Q1;Q3), significant associations are marked in bold; [a]Comparing patients with CHD according to the severity of the cardiac defect with a Spearman rank correlation.

Table 3. Association of health-related quality of life with SOC (% of predicted) and peak oxygen uptake (% of predicted) expressed as Spearman's R

Health-related quality of life	Sense of coherence	Peak oxygen uptake
Physical function	**0.341 ($p < 0.001$)**	**0.417 ($p < 0.001$)**
Role physical	**0.260 ($p < 0.001$)**	**0.124 ($p = 0.004$)**
Bodily pain	**0.275 ($p < 0.001$)**	0.056 ($p = 0.199$)
General health	**0.479 ($p < 0.001$)**	**0.260 ($p < 0.001$)**
Vitality	**0.559 ($p < 0.001$)**	**0.107 ($p = 0.013$)**
Social function	**0.468 ($p < 0.001$)**	0.059 ($p = 0.173$)
Role emotional	**0.352 ($p < 0.001$)**	0.001 ($p = 0.994$)
Mental health	**0.686 ($p < 0.001$)**	0.054 ($p = 0.216$)
Health transition	0.057 ($p = 0.184$)	−0.063 ($p = 0.146$)
Physical component summary	**0.263 ($p < 0.001$)**	**0.352 ($p < 0.001$)**
Mental component summary	**0.641 ($p < 0.001$)**	−0.001 ($p = 0.982$)
Peak oxygen uptake	**0.089 ($p = 0.038$)**	

Significant associations are marked in bold.

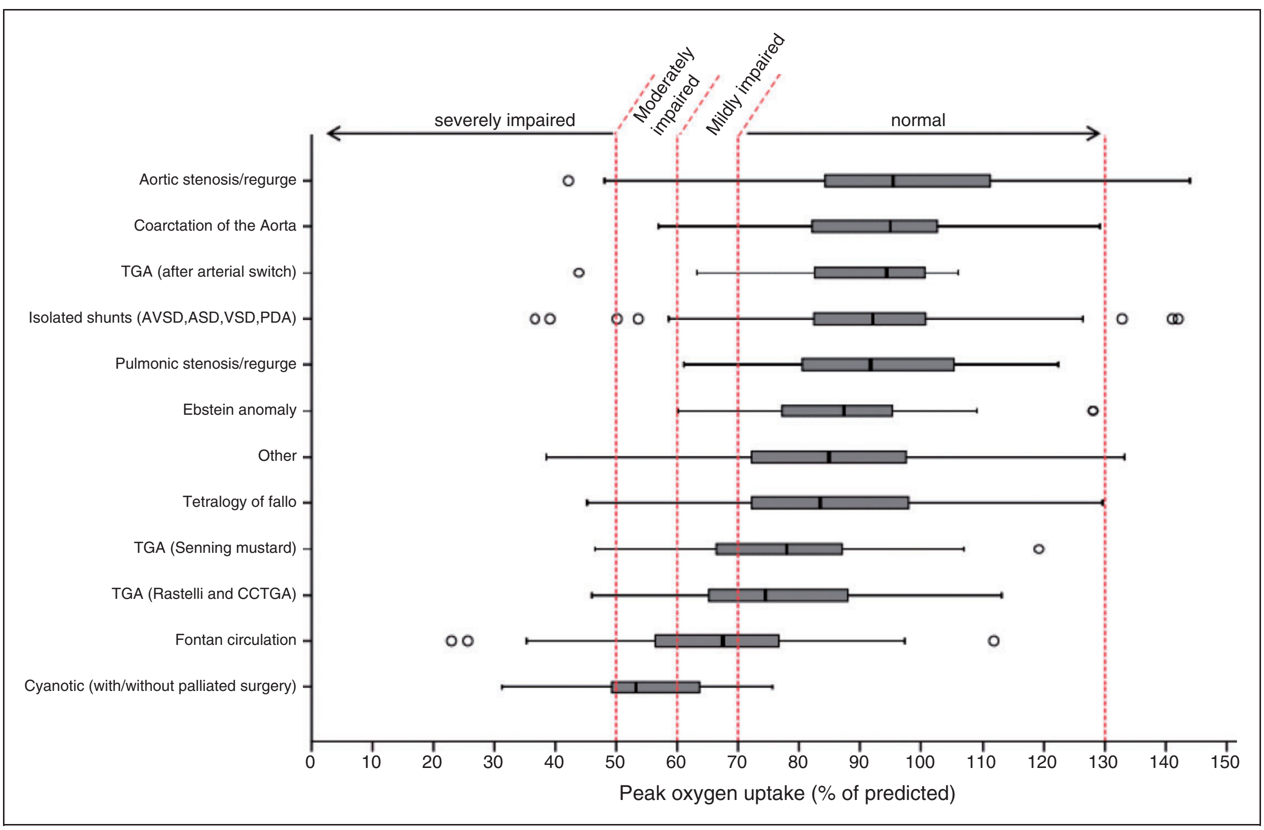

Figure 1. Peak oxygen uptake according to diagnostic subgroups.

responsible for the increase. It might be the result of a higher comprehensibility as a result of more family enrolment as patients discuss their concerns more often with their parents or health care professionals. This is supported by findings that SOC was positively associated with family-related and friend-related well-being.[14] Another explanation might be a higher manageability. Patients with CHD have to cope from birth onwards with concerns regarding their heart defect and obviously have not experienced or could not remember substantial restrictions. But finally, it might also be a higher meaningfulness. It was suggested that all components act in concert to obtain this strong SOC in patients with CHD.[12]

As previously reported in younger study groups of patients with CHD,[14,15] there was no association of SOC to the type or severity of the heart defect. This is in accordance to numerous other reports showing that psychological issues, health-related QoL or anxiety are not linked to heart defect type or severity.[1–4,6,25–27]

Based on theoretical considerations, SOC develops during childhood and early adulthood and is fully developed by the age of 30 years.[11] Unfortunately, our data cannot be compared in detail with the data from Neuner,[14] who used the SOC-9 questionnaire, nor with the data from Nio,[15] who used a five-point Likert scale. But the higher SOC values in our study group show that also adults with CHD still show favourable results in comparison to reference values. In addition, no correlation of SOC to age could be found. So it can be assumed that the favourable SOC and its impact on life quality is sustained at least into the fifth decade of life, at which our investigated patient group tapered off.

Regarding gender difference, there are inconsistent findings. As reported from Neuner[14] and our study group, females obtained higher SOC values than males. However, this gender aspect is contradictory to Nio,[15] in which males scored higher.

All studies support the initial concept of Antonovsky that SOC has an important impact on health and well-being. SOC was moderately linked to QoL in adolescents with CHD[14] as well as in adults in our study. As in adolescents,[14] SOC seems to mediate especially the mental components of health-related QoL. It seems important to select the right coping strategy. On the other hand, associations to the more physical components were rather weak. The objectively measured peak oxygen uptake at CPET as the most global variable of physical functioning and cardiovascular fitness shows only a weak association to SOC. This is in accordance to various reports, all showing that there is inconsistency of any psychological tests to objectively measured exercise capacity in patients with CHD.[3,26] Furthermore, this study again confirmed that patients with CHD do not obtain their QoL from the physical point of view. A patient's focus on family and psychological issues in life is one resource of a good quality of life. However, it is also an important task in the medical management of patients with congenital heart disease to explain the defect to the patient and to make the defect and the current situation understandable.

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Conflict of interest

None declared.

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