Sense of Coherence as a Predictor of Quality of Life in Adolescents With Congenital Heart Defects: A Register-Based 1-Year Follow-Up Study

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ABSTRACT: *Objective:* Sense of coherence (SOC) is a resource for health and quality of life (QoL) in adults. The aim of this investigation was to prospectively evaluate the association between SOC and QoL in adolescents with congenital heart defects (CHDs). *Methods:* This is an observational study among 770 adolescents aged 14 to 17 years from a national CHD register. SOC was measured at baseline with the SOC-L9 questionnaire. QoL was measured at baseline and at a follow-up 12 months later. For this, we used the KINDL-R (revidierter KINDer Lebensqualitätsfragebogen) questionnaire to evaluate overall well-being and 6 subscales (physical well-being, psychological well-being, self-esteem, family-related well-being, friend-related well-being, and school-related well-being). The association between SOC and QoL both in terms of overall well-being and the KINDL-R subscales was evaluated in multilevel linear models. Fully adjusted models accounted for age, gender, behavioral factors, and medical and socioeconomic status. *Results:* Overall well-being, self-esteem, and school-related well-being were significantly higher at follow-up than at baseline. SOC (median: 50 [range: 16–63] points) was positively associated with overall well-being and all KINDL-R subscales at baseline. In overall well-being and the KINDL-R subscales (except in psychological well-being), significant negative interaction terms were observed for SOC at baseline and time to follow-up. However, the associations between SOC at baseline and overall well-being and all KINDL-R subscales at follow-up remained significant even in fully adjusted models. *Conclusion:* SOC is an independent predictor of QoL in adolescents with CHD. In psychological well-being, this prediction remains stable, whereas in total well-being and all other QoL subdimensions, its strength as such wanes over the course of a year but does not entirely dissipate. Further studies should evaluate whether interventions designed to increase SOC in children with CHD would also improve their QoL.

(J Dev Behav Pediatr 32:316–327, 2011) **Index terms:** quality of life, sense of coherence, congenital heart defect, register, observational study.

In the 1970s and 1980s, Antonovsky[1,2] proposed a comprehensive model (the "salutogenic model") to describe the development and maintenance of health. "Salutogenic" and "salutogenesis" are derived from the Latin word salus = health and the Greek word genesis =

origin. The salutogenic theory can complement the primarily pathogenic model of Western medicine with its focus on causes of disease. A core element of the salutogenic model is sense of coherence (SOC). SOC refers to an individual's ability to comprehend internal and external stimuli and stressors, to mobilize appropriate internal and external resources (the so-called generalized resistance resources [GRRs]), and to interpret the resulting demands and efforts as being meaningful, challenging, and worthy of investment.[1,2] Having a higher SOC enables individuals to choose adequate coping strategies, to successfully address the demands and stress of daily life, and to actively move toward promoting their own health.[3] According to Antonovsky, SOC is a significant part of a person's personality. It is formed during

childhood and adolescence and remains stable after the age of 30 years.[2]

Most studies that have investigated the relation between SOC and mental and physical health reported positive associations.[4] A higher SOC is typically conducive to better health partly because it is associated with good preventive health behaviors. People with a high SOC engage less frequently in risky behaviors and use preventive medical services more often. Furthermore, individuals with a high SOC often have more social and educational resources at their disposal.[5-7]

The salutogenic model of development and maintenance of health may be instrumental in identifying contributors to self-rated quality of life (QoL). Measures of self-rated QoL address the subjective nature of health. Taking into account an individual's perception of their own health in addition to measuring it using objective medical and functional parameters gives health professionals a more comprehensive and thus more useful picture to work with.[8] SOC has proven to be a predictor of QoL and life satisfaction for adults in various clinical and population-based settings.[9-13]

Fewer investigations have examined the relationship between SOC and QoL in children and adolescents. Honkinen et al[14] found that the tertile who had the weakest SOC in a group of >1200 12-year-old school children also perceived themselves as being in poor health. Forinder et al[15] discovered a positive association between SOC and QoL in children who had undergone allogeneic stem cell transplantation. Despite the lack of evidence in children with chronic conditions, Moons and Norekval[16] argued that children with diabetes, asthma, or congenital heart defects (CHDs) may develop an even stronger SOC as a result of their illness. Because they go through repeated medical interventions and often receive continued care over the course of their lifetime, it is possible that they acquire coping skills earlier than usual and thus have longer to develop and refine them when growing up and as adults. Although several studies have assessed QoL in children and adolescents with CHD,[17-29] few studies were prospective and none of them focused particularly on the role SOC plays in the development of QoL in adolescents with CHDs' QoL.

Therefore, the Coherence and Quality of Life in Adolescents with Congenital Heart Defects (CoalaH) study aimed to prospectively evaluate the association between SOC and QoL in adolescents with CHD.

METHODS
Study Population

The Coherence and Quality of Life in Adolescents with Congenital Heart Defects (CoalaH) study was conducted within the framework of the Competence Network for Congenital Heart Defects (German: Kompetenznetz Angeborene Herzfehler [KN AHF]).[30] The KN AHF operates a nation-wide congenital heart defect (CHD) register, which was started in 2003. By November 2007, >20,000 patients were registered.[30] Of these, 2339 were between 14 and 17 years old. CHD diagnoses were based on hospital discharge letters, pediatrics' or cardiology specialists' medical reports, or both. CHD diagnoses were grouped according to the first revision of the European Paediatric Cardiac code.[31,32] As per the American College of Cardiology recommendations,[33] study participants were classified into 3 categories according to the complexity of their CHD (simple, moderate, or severe CHD complexity). We defined "underlying medical status" as CHD diagnoses and CHD complexity.

Pilot Study

We conducted a pilot study in April 2007 whereby we sent a 1-page information leaflet with basic information about the objectives of the CoalaH study to a random subsample of 150 individuals chosen from 2339 eligible adolescents. Subsequently, we sent them a draft baseline questionnaire along with a brief form requesting feedback concerning the comprehensibility, length, and layout of both the questionnaire and the accompanying information. Eighteen of the addresses we sent mail to were incorrect and 2 of the patients we tried contacting had died. Seventy-five of the remaining 130 adolescents we contacted (57.7%) returned the material. Two-thirds of the respondents rated the overall design, graphic layout, and the comprehensibility of the questions with either the best or next to best possible score on a 5-point Likert scale. Overall, 63% preferred to receive the 1-page information leaflet together with the questionnaire rather than mailed separately.

Study Cohort

The ethics committee of the Charité–Universitätsmedizin Berlin approved this study. In September 2007, we sent the study documents and a letter requesting participation in the CoalaH study to all 2339 KN AHF-registered adolescents who were between the ages of 14 and 17 years as of November 30, 2007. We obtained written informed consent from all of the adolescents who agreed to take part in the study as well as their parents/guardians. Eighty adolescents were not eligible for participation because they did not have a validated diagnosis, we did not have their current address, or they were no longer living. Nearly half of the 2259 eligible (n = 1072; 47.5%) adolescents did not respond even after receiving a postcard reminder and a phone call. More than 100 adolescents completed the questionnaire but did not enclose the signed informed consent form. A total of 1075 completed baseline questionnaires were returned, and the 12-month follow-up questionnaire had a response rate of 85.5%. Overall, 112 study participants had to be excluded from the prospective analyses due to incomplete baseline or follow-up data. Thus, the final study sample consisted of 770 study participants. Figure 1 shows the flow of participants through the study.
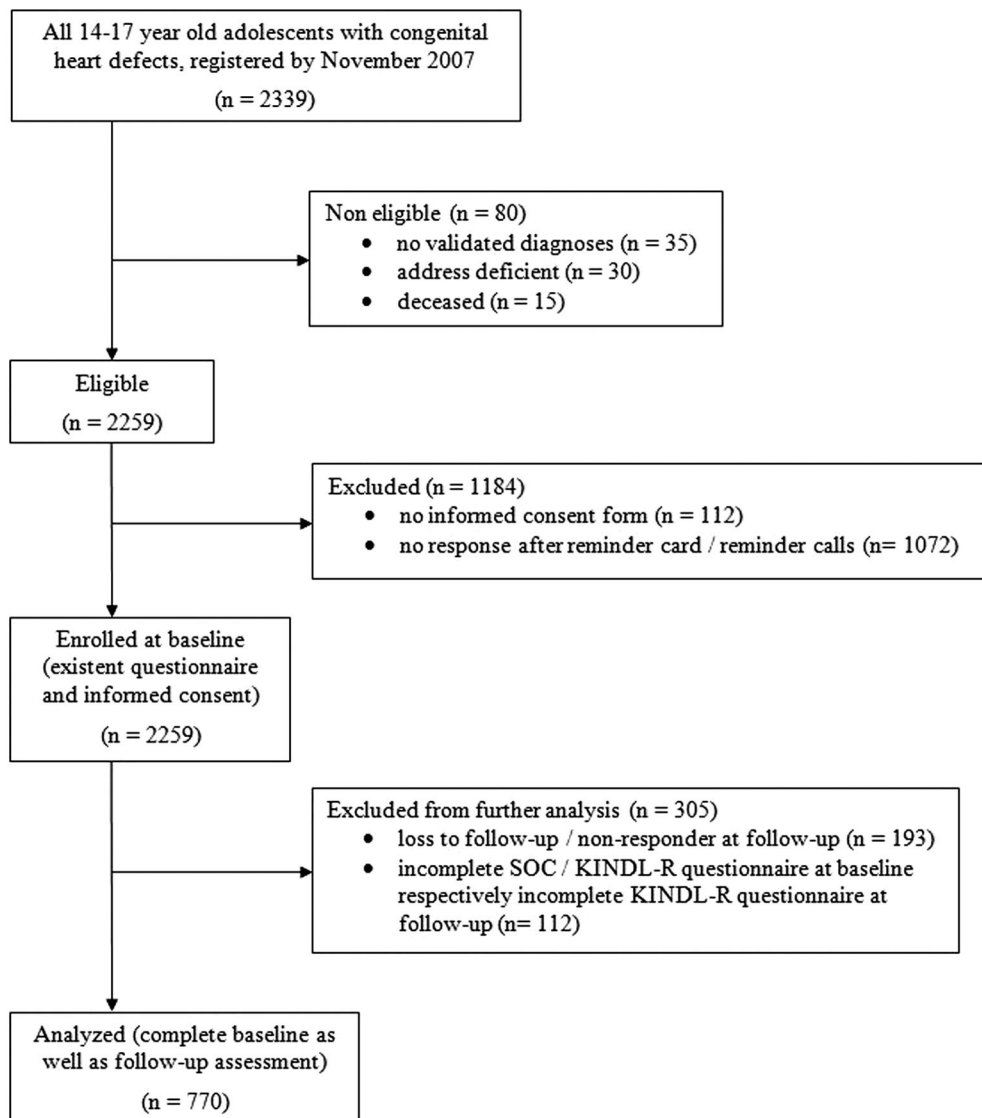
Figure 1. Flow of participants through the study. SOC, sense of coherence; KINDL, KINDer Lebensqualitätsfragebogen.

Questionnaires

At baseline, study participants were asked to provide information on their current medical status (clinical symptoms of CHD, current medication, cyanosis, inpatient treatment during the last 12 months, and deafness). Clinical symptoms of CHD were assessed using 6 questions that measured the presence of dyspnea and arrhythmia at 3 different levels of activity: physical exertion, a state of rest, and at night.

Quality of life (QoL) in this study was defined in terms of patients' perceptions of their physical, mental, social, psychological, and functional well-being.[34] They were assessed using a generic instrument, the "revised children's quality of life" questionnaire (German: revidierter KINDer Lebensqualitätsfragebogen [KINDL-R] questionnaire[35]). The KINDL-R questionnaire is a 24-item self-administered questionnaire that generates a total score (overall well-being) as well as scores for 6 subscales (physical well-being, psychological well-being, self-esteem, family-related well-being, friend-related well-being, and

school-related well-being). Scores range from 0 to 100, with higher values indicating better QoL. In the CoalaH study, the internal consistency of the KINDL-R total scores at baseline and follow-up as assessed by Cronbach's alpha was good (0.84 and 0.85, respectively). Internal consistency of the KINDL-R subscales was 0.67 for physical well-being, 0.49 for psychological well-being, 0.72 for self-esteem, 0.74 for family-related well-being, 0.65 for friend-related well-being, and 0.59 for school-related well-being at baseline. The KINDL-R questionnaire was recently used in the German National Health Interview and Examination Survey for Children and Adolescents (KIGGS), a nation-wide representative population survey of children and adolescents in Germany. KIGGS was conducted between May 2003 and May 2006 in a sample of >17,000 children and adolescents. We used those results to compare the CoalaH study results with German population norms.[36]

Sense of coherence (SOC) was defined according to Antonovsky[1,2] and assessed with the SOC-L9 question-

naire.[37] The SOC-L9 questionnaire is a short form of the original 29-item SOC questionnaire,[38] first published by Antonovsky[39] in 1983. It comprises 9 questions. Each question is answered on a 7-point Likert-scale (e.g., "You anticipate that your personal life in the future will be: (1) 'Totally without meaning or purpose'. . . (7) 'Full of meaning and purpose'"). Ultimately, a summary score between 9 and 63 points is generated whereby higher values indicate a stronger SOC. The questionnaire was validated in a representative German population sample, and population norms for adults are available.[37] It has not been validated in adolescents with CHD in Germany. However, there are a number of investigations of SOC in children and adolescents, which used 13-item SOC questionnaires with satisfactory internal consistency. One of these groups was made of 12-year-old school boys in Finland (Cronbach's alpha = 0.82[40]) and another of 6th- to 10th-grade students in Norway (Cronbach's alpha = 0.85[41]). In the present investigation, the internal consistency (Cronbach's alpha) of the 9-items SOC-L9 questionnaire was 0.84. To evaluate the factorial structure of SOC-L9 in the CoalaH study population, we first calculated the Kaiser-Meyer-Olkin measure of sampling adequacy, which equaled 0.90, thus allowing the application of a factor analysis. After we performed factor analysis extraction using principal axis factoring, the screen test indicated the break point (where the curve of the eigenvalues "flattens out" toward a less steep decline) at 2 factors, indicating that the 1-factor-solution best fits the data. The 1-factor-solution explained 37.6% of the total variance with factor loadings between 0.49 and 0.69. The 2-factor-solution explained 42.9% of the total variance while the 3-factor-solution explained 45.2% of the total variance. In both solutions, the absolute values of factor loadings were found between 0.05 and 0.68.

Socioeconomic status, migration background, and behavioral factors were obtained using relevant questions from the KIGGS questionnaire. Socioeconomic status was defined by taking into account the adolescents' level of education (elementary school/lower grade of secondary school = "10 to 11 years of school education"; higher grade of secondary school/comprehensive school = "12 or 13 years of school education"; "school for handicapped children"), living situation ("with both parents"; "with single mother/father and his/her new partner"; "with single mother/father"; with grandparents or other relatives/with foster parents/in a home for handicapped children/having a flat to themselves = "with neither parents nor a single parent"), whether they have their own room (yes; no), and the amount of pocket money they regularly receive from their parents/ guardians. Information about pocket money could be entered as free text and was categorized as ≤10 €; 11 to 20 €; 21 to 30 €; >30 € per month. Migration background captured information about whether the study participant or either of their parents was born in a different country. The following behavioral factors were

evaluated: alcohol consumption (categories of monthly beer, wine, fruit wine, sparkling wine, and hard liquor consumption were divided as follows: never/<1 unit per month = "<1 unit per month"; "1 to 3 units per month"; 1 unit per week/2 to 4 units per week = "1 to 4 units per week"; 5 to 6 units per week/1 or more units per day = ">5 units per week"), riding with a drunk driver ("never"; "1 time"; 2 or 3 times/4 or more times = "≥2 times"), smoking ("no"; once a week/less than once a week = "once a week or less"; "several times per week," "about daily"), smoking peers (yes; no), environmental tobacco smoke (ETS: "no"; less than once a week/once a week = "up to once a week"; "several times per week," "daily"), and exercise (physical activities such as sports or biking that result in perspiration and shortness of breath: never/1 to 2 times per month = "less than twice per month"; "1 to 2 times per week"; "3 to 5 times per week"; "more or less daily"). After 1 year, we contacted all study participants again and requested that they respond to a version of the baseline questionnaire that had been adapted to account for the 12-month interval since the initial survey.

Statistical Analysis

Categorical variables were analyzed as frequencies. When metric variables were normally distributed, we presented them as arithmetic mean values and their respective SDs. When they were not normally distributed, we presented them as median and Q_1/Q_3 = 25th/ 75th percentiles. Differences between 2 independent groups were evaluated using the Mann-Whithney U test in metric nonnormally distributed variables. Differences among >2 independent groups were evaluated using the Kruskal-Wallis test or the Jonckheere-Terpstra test (in ordered independent groups). Differences between 2 dependent groups were evaluated using the t test for dependent subgroups in normally distributed variables. To answer the main study hypothesis, we used linear multilevel models with QoL (total well-being and KINDL-R subscales, in separate models) as a linear function of SOC at baseline. Measurement of QoL at baseline and at follow-up was nested with individuals. SOC at baseline was entered as a linear continuous variable and centered on its mean. This allowed for interpreting the time to follow-up (further referred to as "time") as the change in QoL in a study participant with an average SOC. Results are presented as regression coefficients and their corresponding 95% confidence intervals (CIs). Two different models for overall well-being as well as all subscales were run. Blockwise adjustments were used to evaluate the independence of the association between SOC and QoL. Independence of the association between SOC and QoL was defined as <10% change in the association between SOC at baseline and QoL at follow-up in the fully adjusted models compared with unadjusted models. The unadjusted models (block 1) entered SOC and the interaction between time and SOC as explanatory variables. The interaction between time and SOC

represents the attenuation over time in the association of SOC and QoL. Models were also (block 2) adjusted for age, gender, underlying and current medical status, behavioral factors, socioeconomic factors, migration background, and assistance of proxies when completing the questionnaire. Complexity of CHD, European Paediatric Cardiac codes, and current medications were entered as categorical variables after having been recoded into dummy variables. "Missing" responses were included in the referent "null"-category for the following variables: cyanosis, deafness, all clinical symptoms variables, inpatient treatment during the last 12 months, current smoking, smoking peers, ETS exposure, and riding with a drunk driver. Missing responses in the "exercise"-variable were included in the first category, i.e., "none or no more than twice a month." No imputation was used for socioeconomic variables and thus missing values in these variables led to a reduced number of observations in the fully adjusted models. Model fit was evaluated using the Bayesian information criterion (BIC) computed as -2 (log likelihood) $+$ number of estimated parameters $\times$ (logarithm [study population size]). A lower BIC indicates a better model fit. The idea of this criterion is to penalize models with a large number of covariates. BIC, with a logarithmic transformation of the number of study participants, penalizes covariates more strongly than, for example, Akaike information criterion and is therefore (especially with large population samples like the one in this investigation) regarded as a more conservative estimate of model fit. Analysis was restricted to study participants with complete data in covariates (n = 758) making it possible to compare BIC between models with different adjustments. All statistical analyses were performed using SAS software version 9.2 (SAS Institute Inc., Cary, NC).[42]

RESULTS

Table 1 shows baseline characteristics of the study participants. The mean age was 15.4 (SD: 0.9) years, and 56% of the participants were female. The most frequent congenital heart defects (CHDs) were ventricular septal defects (16.1%), aortic valve stenosis (13.1%), and Tetralogy of Fallot (12.9%). More than 60% of the study participants had a CHD of moderate complexity; and nearly 1 of 4 study participants was affected by a CHD of severe complexity. Approximately 20% of the 565 study participants who responded to this question had an artificial cardiac valve, a pacemaker, or an implantable cardioverter defibrillator. Three had received a heart transplant. Nearly 1 of 5 took cardiac medications. Every sixth study participant was affected by dyspnea or breathlessness and every seventh by arrhythmia or palpation associated with physical exertion.

The median sense of coherence (SOC) was 50 ($Q_1/Q_3 =$ 44/55) points with a range of 16 to 63 points. The mean SOC was 48.9 (SD: 8.2) points, the skewness equaled -0.68, and the kurtosis equaled 0.44. As shown in Table 2, female gender, more exercise (although not daily),

Table 1. Diagnostic Groups, CHD Complexity, and Current Medical Status at Baseline (n = 770)

Parameter	n (%)
Diagnostic groups	
Ventricular septal defect	124 (16.1)
Atrial septal defect	66 (8.6)
Tetralogy of Fallot	99 (12.9)
Aortic coarctation	65 (8.4)
Aortic valve stenosis	101 (13.1)
Transposition of great arteries	73 (9.5)
Atrioventricular septal defect	34 (4.4)
Pulmonary stenosis	37 (4.8)
Double inlet ventricle	18 (2.3)
Patent ductus arteriosus	18 (2.3)
Patent foramen ovale	1 (0.1)
Double outlet right ventricle	22 (2.9)
Cardiomyopathy	9 (1.2)
Partially anomalous pulmonary venous connection	16 (2.1)
Congenital corrected transposition of great arteries	11 (1.4)
Pulmonary atresia	11 (1.4)
Truncus arteriosus communis	11 (1.4)
Hypoplastic left heart syndrome	1 (0.1)
Totally anomalous pulmonary venous connection	6 (0.8)
Cardiac arrhythmias	5 (0.7)
Marfan syndrome	6 (0.8)
Other	36 (4.7)
CHD complexity according to ACC criteria[30]	
1 (simple)	125 (16.2)
2 (moderate)	468 (60.8)
3 (severe)	177 (23.0)
Implant/heart transplant (n = 565)	
Pacemaker	41 (7.3)
Implantable cardioverter defibrillator	5 (0.9)
Artificial cardiac valve	79 (14.0)
Heart transplant	3 (0.5)
Cyanosis (n = 752)	21 (2.8)
Deafness (n = 754)	16 (2.1)
Clinical symptoms (n = 763)	
Dyspnea or breathlessness on physical exertion	132 (17.3)
Arrhythmia or palpitation on physical exertion	109 (14.3)
Woke up at night with dyspnea or breathlessness	35 (4.6)
Woke up at night with arrhythmia or palpitation	37 (4.8)

(*Table Continues*)

Table 1. Continued

Parameter	n (%)
Dyspnea or breathlessness at rest	7 (0.9)
Arrhythmia or palpitation at rest	12 (1.6)
Current medication (n = 767)	
No medication	619 (80.7)
ACE inhibitors, β-blocker, glycosides	53 (6.9)
Anticoagulants	42 (5.5)
Other medication	53 (6.9)
Inpatient treatment during the last 12 mo (n = 765)	141 (18.4)

CHD, congenital heart defects; ACC, American College of Cardiology; ACE, angiotensin-converting enzyme.

nonsmoking, and nonsmoker peers were associated with a higher SOC. Migration background and higher exposure to environmental tobacco smoke (ETS) were associated with a lower SOC.

Table 3 displays means, SDs, ranges, and Cronbach's alphas of overall well-being and all KINDL-R subscales. These were measured at baseline and at follow-up and compared with published KINDL-R population norms. The overall well-being score was slightly higher than in the representative population sample. However, the overall pattern of the distribution of quality of life (QoL) scores in the KINDL-R subscales was comparable to the German National Health Interview and Examination Survey for Children and Adolescents (KIGGS) results. In both settings, the highest scores were found in family-related well-being, followed by psychological well-being. The lowest scores were found in school-related well-being and self-esteem. The results of the 12-month follow-up indicated a small but significant increase in overall well-being (+0.9 points, $p = .004$) and a significant increase in self-esteem (+2.5 points, $p < .001$) and school-related well-being (+2.0 points, $p = .002$). Physical well-being and family well-being remained nearly the same (mean difference + 0.1 points, $p = .146$), and there was a nonsignificant decrease in mean psychological well-being (-0.8 points, $p = .071$).

Table 4 shows the results of the linear multilevel models. There was a significant positive association between SOC at baseline and overall well-being (per SOC point, regression coefficient = .88, 95% confidence interval [CI] 0.81–0.95). The regression coefficient was only marginally attenuated to .84 (95% CI 0.76–0.91) through further adjustments for covariates. Time showed a positive regression coefficient, whereas the interaction with SOC showed a significant negative effect, per SOC point (-0.16, 95% CI -0.24 to -0.08). Furthermore, there was a significant positive association between SOC and all KINDL-R subscales. Adjustments for covariates reduced the regression coefficient of the association between SOC and KINDL-R subscales by <10% except for physical well-being. This subscale exhibited a nearly 20% decline of the regression coefficient

in fully adjusted models in comparison with unadjusted models. Blockwise adjustments increased the model fit in KINDL-R total scores (overall well-being) and all KINDL-R subscales. A significant positive effect of time was observed on the subscales self-esteem and school-related well-being. Significant negative interaction terms between SOC and time were observed for all KINDL-R subscales except psychological well-being.

DISCUSSION

The main finding of this prospective investigation of the relationship between sense of coherence (SOC) and quality of life (QoL) in adolescents with congenital heart defect (CHD) was that SOC has a positive association with overall well-being and all QoL subdimensions. Except for physical well-being, this association between SOC and QoL was not influenced by age, gender, the underlying and current medical status, behavioral factors, migration background, or socioeconomic factors. The association of SOC with psychological well-being was stable over a 1-year period. However, the association with overall well-being and all other QoL subdimensions attenuated over time.

Findings from a 2006 systematic review on the association between SOC and health suggest a stronger influence of SOC on mental health than on physical health in both cross-sectional and longitudinal investigations.[4] As posited by Antonovsky,[2] several investigations found a positive association between SOC and self-esteem in both cross-sectional and longitudinal investigations.[43-46] Torsheim et al[41] did a cross-sectional investigation in Norway on how SOC and school-related well-being are related. They found a negative association between SOC and both school-related stress and subjective health complaints in ~5000 pupils aged 11 to 15 years. In older pupils, the latter association increased and the former decreased. The authors suggest that pupils are similarly affected by school-related demands as adolescents are by work-related demands. They conclude that SOC may be regarded as a resource useful to children in adapting to age-specific needs. Our findings suggest that, even in adolescents affected by challenging life-long medical conditions, the association between SOC and school-related well-being is only marginally attenuated by further disease-specific, behavioral or social factors. We also saw that SOC is also positively associated with family-related and friend-related well-being. Furthermore, measurements of the association between SOC and both overall well-being and all QoL subdimensions studied, except physical well-being, remained unchanged when entering other covariates into the models. This indicates the independence of the association. Physical well-being measurements were attenuated by >10% when adjusted for functional status indicators (dyspnea, arrhythmia). Adjusting for CHD complexity, as captured by the American College of Cardiology code, did not affect estimates (data not shown). Thus, current functional restraints had an impact on physical well-

Table 2. SOC by Gender, Socioeconomic Factors, Migration Background, and Behavioral Factors at Baseline (n = 770)

	n (%)	SOC, Median (Q₁/Q₃)	p
Gender			
Female	431 (56.0)	51 (45/55)	
Male	339 (44.0)	50 (43/53)	.003[a]
School attendance (n = 768)			
School for handicapped children	71 (9.2)	49 (39/56)	
10–11 years of school education	366 (47.7)	50 (44/55)	
12 or 13 years of school education	331 (43.1)	50 (45/55)	.295[b]
Migration background (n = 768)			
Yes	76 (9.9)	47 (39/53)	
No	692 (90.1)	50 (44/55)	.003[a]
Living situation (n = 766)			
With both parents	584 (76.2)	51 (44/55)	
With single mother/father	95 (12.4)	49 (40/54)	
With mother/father and his/her new partner	71 (9.3)	48 (42/52)	
With neither parents nor a single parent	16 (2.1)	52 (46/58)	.008[c]
Own room (n = 769)			
Yes	735 (95.6)	50 (44/55)	
No	34 (4.4)	51 (43/56)	.673[a]
Pocket money (n = 716)			
≤10 € per month	83 (11.6)	50 (43/54)	
11–20 € per month	290 (40.5)	50 (43/55)	
21–30 € per month	187 (26.1)	51 (44/56)	
>30 € per month	156 (21.8)	50 (44/54)	.567[b]
Exercise (n = 766)			
Less than twice per month	104 (13.6)	47.5 (38.5/53)	
Once or twice per week	307 (40.1)	50 (44/54)	
3–5 times per week	252 (32.9)	52 (47/56)	
About daily	103 (13.5)[d]	49 (43/55)	<.001[b]
Current smoker (n = 769)			
No	736 (95.7)	50 (44/55)	
Yes, once a week or less	12 (1.6)	43 (40.5/47)	
Yes, several times per week	7 (0.9)	45 (41/51)	
About daily	14 (1.8)	45 (39/50)	<.001[b]
Smoking peers (n = 755)			
Yes	246 (32.6)	49 (42/54)	
No	509 (67.4)	51 (44/55)	0.029[a]
ETS (n = 768)			
No	173 (22.5)	50 (45/55)	
Up to once a week	441 (57.4)	50 (45/55)	
Several times per week	75 (9.8)	49 (43/52)	
Daily	79 (10.3)	48 (40/54)	.013[b]
Alcohol consumption (n = 768)			
Never	252 (32.9)	51 (44.5/55.5)	
<1 unit per month	291 (37.9)	50 (44/55)	
1–3 units per month	121 (15.8)	49 (43/53)	
1–4 units per week	91 (11.9)	51 (45/55)	
>5 units per week	12 (1.6)[d]	49 (39/55)	.145[b]

(*Table Continues*)

Table 2. Continued

	n (%)	SOC, Median (Q₁/Q₃)	p
Riding with a drunk driver (n = 739)			
Never	704 (95.3)	50 (44/55)	
1 time	24 (3.3)	47.5 (43.5/51.5)	
≥2 times	11 (1.5)[d]	48 (42/49)	.059[b]
Completed questionnaire (n = 769)			
Without assistance of parents/guardians	328 (42.7)	50 (43/54.5)	
With assistance of parents/guardians	441 (57.3)	50 (44/55)	.169[a]

SOC, sense of coherence; Q₁, 25th percentile; Q₃, 75th percentile; ETS, environmental tobacco smoke. [a]Mann-Whitney U test. [b]Jockheere-Terpstra test for trend. [c]Kruskal-Wallis test. [d]Does not sum up to 100% because of rounding error.

being beyond the influence of long-term underlying medical conditions or psychological traits such as SOC.[47]

Because we used multilevel models with blockwise adjustments, we were able to evaluate the impact of SOC on QoL, taking into account changes of QoL over time and several covariates. By centering SOC around its mean, our approach allowed for interpreting the measurement of the time variable, independent of all covariates in the model, as change in QoL in adolescents with a mean SOC. The increase in overall well-being in this study population was mainly driven by increases in self-esteem and school-related well-being. This probably reflected age-specific socialization phenomena. Our results clearly show that the predictive value of SOC concerning psychological well-being is quite stable over time. It must also be emphasized that the associations between SOC and QoL concerning overall well-being and all further subdimensions studied remain positive over the course of a year. These can be calculated by adding the measurements of SOC (at baseline) and the (negative) interaction terms of SOC × time. In the Coherence and Quality of Life in Adolescents with Congenital Heart Defects (CoalaH) data fully adjusted models, the measurement for the association between SOC and overall well-being at follow-up equals 0.68 (95% confidence interval [CI] 0.60–0.75) per SOC point; in physical well-being at follow-up 0.46 (95% CI 0.32–0.60) per SOC point; in psychological well-being at follow-up 0.72 (95% CI 0.62–0.83) per SOC point; in self-esteem at follow-up 0.92 (95% CI 0.79–1.05) per SOC point; in family-related well-being 0.61 (95% CI 0.48–0.74) per SOC point; in friend-related well-being 0.62 (95% CI 0.49–0.76) per SOC point; and in school-related well-being 0.74 (95% CI 0.60–0.88) per SOC point. Adjusting for covariates increased the model fit as captured by the Bayesian information criterion (BIC), an established criterion for model selection. This speaks for choosing the fully adjusted models as the final models.

Consistent with recent interpretations of SOC as a preventive health orientation,[4] in this specific group of adolescents, a higher SOC was associated with moderate exercise (although not daily), nonsmoking, nonexposure to environmental tobacco smoke (ETS), and with having peers who do not smoke. Apart from migration background, there were no associations with socioeconomic factors in univariate cross-sectional analysis. Although some authors have criticized the concept of SOC in adults as mainly reflecting social inequalities,[48] recent large-scale longitudinal observational studies showed associations independent of social position between SOC and health behaviors (such as physical activity, fruit and fiber intake, and smoking) and mortality in adults.[49,50]

Table 3. Quality of Life as Measured With the KINDL-R Questionnaire at Baseline and at Follow-Up in CoalaH Participants and in 14- to 17-Year-Old KIGGS Participants[36]

KINDL-R Scores	All CoalaH Participants (n = 770)						KIGGS Participants (n = 1153) Mean (SD)
	Baseline		Cronbach's Alpha	Follow-Up		Cronbach's Alpha	
	Mean (SD)	Range		Mean (SD)	Range		
Total score (overall well-being)	72.5 (10.4)	37.5–97.9	0.84	73.4 (10.9)*	33.3–95.8	0.85	71.5 (10.6)
Physical well-being	68.8 (17.3)	12.5–100.0	0.67	69.9 (17.6)	6.25–100.0	0.71	68.5 (16.9)
Psychological well-being	79.8 (11.9)	25.0–100.0	0.49	79.0 (14.0)	18.8–100.0	0.64	80.5 (13.7)
Self-esteem	62.9 (17.4)	0.0–100.0	0.72	65.4 (16.7)**	0.0–100.0	0.70	59.9 (18.1)
Family-related well-being	83.8 (14.8)	12.5–100.0	0.74	83.9 (15.8)	6.25–100.0	0.79	81.1 (16.4)
Friend-related well-being	72.5 (17.2)	0.0–100.0	0.65	73.3 (16.2)	0.0–100.0	0.59	75.2 (15.0)
School-related well-being	67.0 (16.7)	6.25–100.0	0.59	69.0 (16.7)*	0.0–100.0	0.64	64.2 (16.4)

KINDL-R, revidierter KINDer Lebensqualitätsfragebogen; CoalaH, Coherence and quality of life in adolescents with congenital heart defects; KIGGS, German National Health Interview and Examination Survey for Children and Adolescents. *$p < .05$ (t test for dependent variables). **$p < .001$ (t test for dependent variables).

Table 4. Multilevel Model Estimates for Quality of Life at Follow-Up (KINDL-R Overall Well-Being and All Subscales), as a Function of Sense of Coherence at Baseline, Time to Follow-Up and Their Interaction and Further Explanatory Variables, Results of Blockwise Adjustments, and Overall Model Fit for All Participants of the CoalaH Study With Complete Covariates Dataset (n = 758)

Dependent Variable	Explanatory Variables	Block 1		Block 2	
		Estimate (95% CI)	BIC	Estimate (95% CI)	BIC
Overall well-being	SOC (per point)	0.88 (0.81 to 0.95)**		0.84 (0.76 to 0.91)**	
	Time (follow-up vs baseline)	0.87 (0.24 to 1.50)*		0.87 (0.24 to 1.50)*	
	SOC (per point)* time	−0.16 (−0.24 to −0.08)**	10610.3	−0.16 (−0.24 to −0.08)**	10338.7
Physical well-being	SOC (per point)	0.77 (0.62 to 0.91)**		0.64 (0.49 to 0.78)**	
	Time (follow-up vs baseline)	0.86 (−0.40 to 2.12)		0.85 (−0.41 to 2.11)	
	SOC (per point)* time	−0.17 (−0.32 to −0.01)*	12605.8	−0.17 (−0.32 to −0.01)*	12166.9
Psychological well-being	SOC (per point)	0.74 (0.64 to 0.84)**		0.72 (0.61 to 0.82)**	
	Time (follow-up vs baseline)	−0.86 (−1.78 to 0.07)		−0.86 (−1.79 to 0.06)	
	SOC (per point)* time	−0.001 (−0.12 to 0.11)	11600.7	0.00003 (−0.11 to 0.11)	11331.3
Self-esteem	SOC (per point)	1.19 (1.06 to 1.32)**		1.16 (1.03 to 1.30)**	
	Time (follow-up vs baseline)	2.49 (1.35 to 3.62)**		2.50 (1.36 to 3.63)**	
	SOC (per point)* time	−0.23 (−0.37 to −0.09)*	12272.0	−0.23 (−0.37 to −0.09)*	11977.9
Family-related well-being	SOC (per point)	0.75 (0.63 to 0.88)**		0.74 (0.60 to 0.87)**	
	Time (follow-up vs baseline)	−0.007 (−1.08 to 1.06)		0.006 (−1.07 to 1.08)	
	SOC (per point)* time	−0.15 (−0.28 to −0.01)*	12172.4	−0.15 (−0.28 to −0.02)*	11880.5
Friend-related well-being	SOC (per point)	0.90 (0.77 to 1.04)**		0.88 (0.74 to 1.01)**	
	Time (follow-up vs baseline)	0.68 (−0.37 to 1.73)		0.68 (−0.79 to 2.14)	
	SOC (per point)* time	−0.23 (−0.36 to −0.10)**	12320.5	−0.23 (−0.41 to −0.04)*	12136.8
School-related well-being	SOC (per point)	0.94 (0.80 to 1.07)**		0.91 (0.77 to 1.05)**	
	Time (follow-up vs baseline)	1.99 (0.77 to 3.22)*		2.01 (0.79 to 3.23)*	
	SOC (per point)* time	−0.18 (−0.34 to −0.03)*	12364.0	−0.19 (−0.34 to −0.04)*	12029.6

KINDL-R, revidierter KINDer Lebensqualitätsfragebogen; CoalaH, coherence and quality of life in adolescents with congenital heart defects; CI, confidence interval; BIC, Bayesian information criterion; SOC, sense of coherence. SOC was centered. Unadjusted models (block 1) include only SOC at baseline, time to follow-up, and their interaction as explanatory variables; adjusted models (block 2) included additionally gender, age at baseline, diagnosis group, congenital heart defect complexity, current medical status (clinical symptoms, current medication, cyanosis, inpatient treatment during the last 12 months, and deafness), behavioral factors (alcohol consumption, riding with drunk driver, smoking, smoking peers, environmental tobacco smoke, and exercise), socioeconomic factors (education, living situation, and pocket money), migration background, and assistance of proxies when completing the questionnaire. *p < .05. **p < .001.

Regardless of the social context, SOC seems to be a health resource that adolescents can make good use of, and its effect on health and QoL may, even at this young age, be partly mediated by preventive health behaviors. In Finland, a recent randomized controlled trial in 13-year-old healthy boys showed that a physical intervention program benefited both their cardiorespiratory fitness as well as their SOC.[51] Future studies should evaluate whether a similar program adapted to the needs of adolescents with CHD could have a positive affect on their SOC. Furthermore, a very recent study done over a period of 5 years in adults aged 20 to 54 years showed that a high SOC at entrance was associated with stability of or even growth in SOC over time. This was even true in young adults aged 20 to 24 years.[52]

In the CoalaH study, QoL in adolescents with CHD was better than in an age-matched representative population sample. Latal et al[22] did a systematic review on psychological adjustment and QoL in children and adolescents after open-heart surgery for CHD. They identified 12 studies reporting on QoL in this population. In 4 of these studies, QoL in children with operated CHD was comparable to normative samples. Four studies reported impaired QoL in self- and most proxy-reported dimensions. The other studies either compared QoL in children with CHD with QoL in children with other chronic conditions or did not report overall QoL. A Hungarian study of children with CHD of mild and severe complexity being treated in a cardiology outpatient unit found significant lower physical functioning and impaired psychosocial functioning in comparison with the general population.[17] In another study, 404 adults with CHD had a higher QoL than their healthy counterparts after matching for age, gender, educational level, and employ-

ment status.[53] Because it is difficult to judge how representative these study populations are, no conclusive comparisons can currently be made between CHD survivors' QoL and population norms.

Study Limitations

Although the investigation is based on a sufficient number of study participants, it is questionable whether the data is representative. The KN AHF register is an opportunistic register and done purely on a voluntary basis. A recent study estimated a prevalence of ~6000 newborns with CHD in Germany annually.[54] As the CoalaH study captured the 3 birth years 1991–1993, ~4% (770 of an expected 18,000 adolescents with CHD) of all adolescents with CHD in Germany in this age range were enrolled. Because the parents who enrolled their children in the KN AHF may have been more highly motivated or educated than the average, the composition of the sample may have been affected. This may partly explain why the overall good QoL we observed in this population exceeded that of the German National Health Interview and Examination Survey for Children and Adolescents (KIGGS) representative population sample of adolescents in Germany. More than 40% of the CoalaH participants were preparing for secondary school examinations (the German "Abitur"). In KIGGS, the proportion was 35% in the age group 11 to 17 years.[55] Unfortunately, there are no data available to characterize the participants' parents/guardians and their households. However, it is possible that the CoalaH population was more socially advantaged and characterized by more generalized resistance resources (GRRs) than were the adolescents not registered with the KN AHF and those who declined participation in the study. If CoalaH-study participants were able to resort to greater GRRs, the effect of SOC on QoL was probably overestimated. Thus, the results of the CoalaH study population may not be representative of all adolescents with CHD in that specific age group. However, the KN AHF register is the only available large-scale database for persons with CHD in Germany.

Although we were able to compare CoalaH study results of the KINDL-R questionnaire with findings from the KIGGS survey, data on the internal consistency of the KINDL-R questionnaire (Cronbach's alpha) were solely published in the age group 11 to 17 years and thus not directly comparable with our findings.[56]

Three KINDL-R subscales (psychological well-being and school-related well-being at baseline as well as friend-related well-being at follow-up) showed a Cronbach's alpha beyond 0.6. A cutoff of 0.6 is sometimes regarded as the lower limit of an acceptable internal consistency. However, removing 1 item from 1 of these 3 subscales did not substantially increase the internal consistency. In the case of psychological well-being at baseline (Cronbach's alpha = 0.49), the Cronbach's alphas of subscales with 1 item removed ranged from 0.28 to 0.46. Thus removing single items from this specific KINDL-R-subscale even deteriorated the internal consis-

tency. In the case of school-related well-being (Cronbach's alpha = 0.59), removing an item led to solutions with internal consistencies between 0.45 and 0.61 and thus no sufficient increase. In the case of friend-related well-being at follow-up (Cronbach's alpha = 0.59), 1 solution with 1 item removed showed a borderline increase (Cronbach's alpha = 0.64), whereas the other solutions ranged from 0.46 till 0.49. But, as the CoalaH study was not a validation study, we decided to present the estimates deriving from analyzing the original scales. It must be emphasized that results based on scales with less than acceptable internal consistency may be prone to measurement errors and thus biased results.

The follow-up period in the CoalaH study was 12 months. Other studies on the influence of SOC on QoL had similar follow-up periods.[10,11,57–60] Studies with longer follow-up periods, younger study entry age, and an emphasis on functional and clinical outcomes would strengthen the Public Health implications of these prospective findings.

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Book Review

The Down Syndrome Transition Handbook: Charting Your Child's Course to Adulthood

by Jo Ann Simons, Bethesda, MD, Woodbine House, 2010, 292 pp, Paperback, $24.95.

"What happens when my child with Down syndrome leaves school? And, what happens when I am no longer here?" Author Jo Ann Simons addresses these universal questions of parents of older children with Down syndrome in the book *The Down Syndrome Transition Handbook*. She describes the transition period for these individuals and their families as an "Ironman Triathlon": "It takes gathering information, training, endurance, perseverance, resolve, and resources." She draws from her personal experiences as a parent of an adult son with Down syndrome and as a social worker in the field of developmental disabilities to guide other families on the journey to adulthood.

Simons begins with an overview of the transition period and encourages parents to have a vision for their child's future and, most importantly, to include the child with the disability in formulating that vision. She then takes readers through the steps and processes involved in making their vision a reality, from high school individualized educational plan goals to postsecondary opportunities to job options. She provides guidance for the many decisions facing families of transition-age individuals. For example, should our son graduate with his class or continue in high school as long as he is eligible under Individuals with Disabilities Education Act? Should we pursue guardianship for our adult daughter? How can we plan financially for our child's future? After presenting the decisions that need to be made, Simons describes the various options in detailed but easy-to-read explanations and discusses their advantages and disadvantages. Lists of questions to consider aid families in deciding what skills to focus on in high school, what types of jobs their child might pursue, and in what living environment he or she would be most successful. Throughout the book, she includes vignettes from her own and other families' experiences.

This comprehensive volume also covers topics that may not immediately come to mind when thinking about the transition period such as voting, use of leisure time, and communicating with an adult child's employer or service providers. In the final chapter, Simons advises parents to create a document such as a "Letter of Intent" to record important information about their child to share with those who provide support now and in the future.

Families whose children are in the midst of the transition process will likely benefit from reading this entire book. However, it is divided into chapters by topic and indexed for easy reference. The book also includes a resource guide of organizations, books, and Web sites.

The Down Syndrome Transition Handbook is directed toward parents of individuals with Down syndrome and other developmental disabilities. Its focus is on the transition period and adulthood, but much of the information is useful for parents of younger children with disabilities to begin considering as well. Professionals in various fields who work with these individuals will find it an excellent resource. As a pediatrician, I found the explanations of government funding sources and legal matters such as guardianship and estate planning particularly helpful in understanding some of the complex issues families must navigate. The only downside to this book is that the specification of Down syndrome in the title may lead to families of individuals with other intellectual disabilities missing out on the wealth of information it provides.

Simons includes her son's perspective on transitioning to adulthood: "I want to tell you my side because she is not so good sometimes at letting go. … Now, I am an adult and live farther away. If I fall down, I have to pick myself up. I am not her little boy anymore. She's getting used to it." She shares these final words of advice for parents, "If you don't teach your child to cross the street, she will never know what's on the other side. Neither will you."

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