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Sense of coherence and perceived physical health explain the better quality of life in adolescents with congenital heart disease

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Abstract

Background: Since survival rates of patients with congenital heart disease (CHD) have improved, issues beyond the quantity of life have become more important. Quality of life (QOL) has mainly been investigated in adults with CHD. Hence, research about QOL among adolescents with CHD is much needed.

Aim: To compare the QOL of adolescents with CHD with that of control subjects from the general population and to explore whether sense of coherence (SOC) explains differences in QOL between patients and controls.

Methods: In this cross-sectional, comparative study, we included 429 patients (229 boys; 200 girls) aged 14-18 years, who were matched to control subjects for age and sex. QOL was measured with a Linear Analogue Scale; SOC was measured using the SOC-13.

Results: Median QOL score in patients was 82 (Q1=75; Q3=90). The QOL of patients was significantly ($Z=-5.888$; $p<0.001$) better than that of controls (median=80; Q1=70; Q3=85.5). Adjusted for other potentially confounding factors, linear mixed modelling showed that the better QOL in patients was explained by a higher SOC (mean=61.4±12.0 vs. 53.6±10.4) and better perceived physical health (mean=87.0±13.8 vs. 85.3±13.2).

Conclusions: This study found that adolescents with CHD have a good QOL, one that is better than that of control subjects from the general population. A stronger SOC and a better perceived physical health are potential resources for better QOL in patients.

Keywords

Quality of life, heart defects congenital, adolescent, transition, nursing, sense of coherence

Implications for practice

- Sense of coherence (SOC) is an independent determinant of quality of life (QOL) in adolescents with congenital heart disease (CHD) and should therefore be considered as a target for interventions in childhood to improve patients' QOL during adulthood.
- Healthcare workers can help children with CHD to develop a strong SOC by educating them about their illness, by helping them balance the stresses of their disease, and by encouraging them to participate in decision making.
- Further longitudinal research is needed to draw conclusions in terms of the direction of associations between SOC and QOL.

Introduction

The life expectancy of children with congenital heart disease (CHD) has improved significantly over the past decades. Currently, about 90% of the children born with a cardiac anomaly can survive into adulthood (1). Hence, issues beyond the quantity of life have become more important. As a result, numerous quality-of-life (QOL) studies in patients with CHD have been published (2;3).

Research on QOL in adolescents with CHD is of particular interest. Adolescence is viewed as an important transitional period with major changes occurring in biological, psychological, and social functioning. Further, this life phase is characterized by different developmental challenges partially depending on age and maturational stage. This phase is also characterized by experimenting behaviours (e.g. drugs and alcohol), the increasing importance of friends and group belongingness, and the formation of a personalized sense of identity (4). In addition, an adolescent is assumed to develop from a dependent child into an independent adult, who is able to take up the responsibility for his or her life and good health (5). While adolescence can be a stressful period in itself, it can be even more stressful for adolescents with CHD. Indeed, a meta-analysis revealed that adolescents with CHD displayed an increased risk for internalizing and externalizing behaviour problems (6). Gaining an insight into these adolescents' subjective experiences may help professionals when confronted with treatment decisions. Hence, research on their QOL offers an evidence base for the provision of patient-oriented care in the increasing number of transition programmes (7-9). Depending on age and maturation adolescents with a chronic illness may experience certain aspects of life differently. For instance, from early adolescence onwards the importance of increasing peer integration comes to the fore, whereas from middle adolescence onwards issues of personal identity formation gain in importance and

need to be addressed. Such differential developmental challenges can influence their perception of QOL (10;11).

Based on a prior study in adults with CHD (12), it was hypothesized that growing up with CHD results in the development of a stronger sense of coherence (SOC), which in turn yields a better QOL in patients than in controls (13). SOC represents an individual's generalized world view and is enhanced by a feeling of high comprehensibility, manageability, and meaningfulness (14). SOC may be stronger in individuals with CHD because they have learnt to discuss concerns with their parents and healthcare professionals (comprehensibility) and have learnt to cope with their disease (manageability), and living with a cardiac condition often has a high existential meaning (meaningfulness) (13). This hypothesis is worthwhile to investigate, because an extensive review of the literature confirmed the relation between SOC and QOL in several patient populations and the general population (15). Therefore, SOC has been put forward as a meaningful concept for cardiovascular nursing and as an important target for nursing interventions in order to improve patients' psychosocial functioning (16).

Research on SOC in patients with CHD is scarce. Only two studies investigated SOC in adolescents with CHD (17;18). One study, performed in 172 Japanese patients, found that adolescents with CHD scored higher for SOC than did healthy students, but did not evaluate the relationship between SOC and QOL (17). Another study, conducted in 770 German adolescent patients, found that SOC was an independent predictor of QOL after 1 year (18). However, this study did not include data on SOC in adolescents from the general population.

Research concerning QOL in patients with CHD has focused mainly on adults (2). Studies that focused on children and/or adolescents with CHD often evaluated QOL in patients with a specific heart defect (19-22) or after a specific treatment (3;23;24), or assessed both adolescents

and adults simultaneously (20;25;26). Only one study included an unselected group of adolescents with CHD (18). Some of these studies found that adolescents with CHD had a higher QOL in comparison with the general population (18;25;26). On the other hand, other studies in children and adults with CHD have found a lower level of QOL in patients compared with controls (24;27-29). However, these latter studies have assessed QOL in terms of functional status. The appropriateness of defining QOL as functional status is questionable (30). Previous in-depth conceptual research concluded that overall satisfaction with life is the most suitable approach for defining QOL in patients with CHD (12). Thus, research on QOL in patients with CHD is not characterized by scarcity, but by methodological shortcomings and inconsistencies in the findings (2).

Therefore, the present study aimed to compare QOL in adolescents with CHD directly with that of matched control subjects from the general population and to investigate whether SOC could explain differences in QOL between patients and controls, adjusted for other potentially influencing factors.

Methods

Study population and procedure

This cross-sectional study is part of a large, longitudinal project on transfer and transition of adolescents with CHD (www.kuleuven.be/switch2/i-DETACH), investigating developmental tasks in these patients.

Two separate samples were recruited for this study. First, patients were selected from the database of the Department of Paediatric Cardiology and the Adult Congenital Heart Disease programme at the University Hospitals Leuven, Belgium. A description of this database is provided elsewhere (1). Patients were eligible to participate in the study if they met the following

inclusion criteria: aged 14-18 years; confirmed CHD, defined as structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance (31); last cardiac consult at the University Hospitals Leuven ≤ 5 years ago; Dutch-speaking; and valid contact details available. Exclusion criteria were: cognitive and/or physical limitations that would affect filling out questionnaires; prior heart transplantation; and absence of consent to participate by patients or parents. Patient selection is detailed in Figure 1. Overall, 498 patients were selected based on these criteria. Eligible patients received a package by mail, containing an information letter, an informed consent form, the questionnaires and a pre-stamped and addressed return envelope. Respondents were asked to complete and return the questionnaires within 3 weeks. Completing the entire set of questionnaires lasted approximately 60 minutes. To increase the response rate, we applied a modified Dillman's approach (32). This approach entails two written reminders and one telephone reminder. Patients who completed the questionnaires received a movie ticket as an incentive. Data collection ran from November 2009 to April 2010.

Second, for each patient with CHD, a control subject was sought, to be matched for sex and age (1:1 matching). Controls were enrolled from secondary schools distributed over Flanders. Students were asked to complete questionnaires during regular class hours, supervised by two psychology students. We did not ask controls about the presence of medical conditions. Hence, our control group cannot be seen as healthy controls, but rather as controls from the general population.

The study was approved by the Institutional Review Board of the University Hospitals Leuven (Belgian number B32220096259). In addition, the procedures followed were in accordance with the Helsinki Declaration of 1964.

Variables and measurement

Demographic and clinical information was collected from the programme's database. To categorize patients according to their primary cardiac defect, we used a modified version of the classification of heart defects that was previously developed for the Dutch CONCOR (CONgenitale CORvitia) project (33). Modifications were based on its use in an epidemiological study in Belgium (34). To classify patients by the complexity of their heart defect, we used the categories outlined by Task Force 1 of the 32nd Bethesda Conference: simple, moderate, or complex heart lesions (35).

We used established instruments to evaluate patients' QOL and SOC. To adjust for potentially influencing factors, we also assessed psychosocial variables (i.e. perceived health and depressive symptoms) and health behaviour. Indeed, perceived health and depressive symptoms have been found to predict QOL over time in adolescents with CHD (36;37). Furthermore, a known pathway through which SOC enhances health, and thus possibly QOL, is adaptive health behaviour (14). The following instruments were used.

Quality of life. Relying on prior conceptual work (30), we defined QOL as 'the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain aspects of life important to them, including matters both related and unrelated to health' (38). Hence, we measured overall QOL for which life satisfaction is an indicator (30). For this purpose, we used a Linear Analogue Scale (LAS). This is a vertically oriented, 10-centimetre line, graded with indicators from 0 (worst imaginable QOL) to 100 (best imaginable QOL). Participants were asked to rate their overall QOL by marking a point on this scale that best corresponded to their situation. A prior study in adults with CHD demonstrated that the LAS has good psychometric properties (12).

Sense of coherence. The 13-item version of Antonovsky's SOC scale (SOC-13) was used (39). The SOC-13 assesses three components (comprehensibility, manageability, and meaningfulness) and comprises 13 items that are scored on a seven-point Likert scale. After reversing the scores of five items, a total score can be calculated that ranges from 13 to 91. Higher scores indicate a higher SOC. This is a valid instrument to use in adolescents with CHD (40).

Perceived health status. Self-perceived health was measured using the self-report version for adolescents aged 13-18 years of the Pediatric Quality of Life Inventory (PedsQL 4.0) generic module (41). This instrument covers four dimensions and consists of 23 items that are scored on a five-point rating scale, ranging from 0 (never a problem) to 4 (almost always a problem). After transformation of the item scores to a scale of 0 to 100, summary scores can be calculated for the entire scale and for subscales: physical health summary score and psychosocial health summary score. A higher score reflects a better situation in the patient. While the PedsQL was initially developed to measure health-related QOL, it more likely expresses perceived health status (42).

Health behaviour. Based on an existing survey instrument in the Netherlands (43), we developed the Health Behaviour Scale-CHD for this project. This instrument includes health behaviour items that are particularly relevant for patients with CHD: alcohol consumption, smoking, illicit drug use, and dental care (44). Habitual physical activity was measured using the Baecke questionnaire (45). This is a self-report instrument that consists of three open questions, 18 five-point rating items, and one dichotomous item. To be used in adolescents, only items on sport and leisure were included, leaving the work-related items unaddressed.

The Health Behaviour Scale-CHD and the Baecke questionnaire allow the calculation of a 'substance abuse score' (binge drinking; smoking; illicit drug use), a 'dental hygiene score' (no dental visits; not brushing the teeth; not flossing the teeth) and a 'health risk score' (binge

drinking; smoking; drug use; no dental visits; not brushing the teeth; not flossing the teeth; no sport activities) by applying a specifically developed algorithm (44). These scores are expressed on the scale from 0 (no substance abuse/dental risks/health risks) to 100 (maximum substance abuse/dental risks/health risks). Because of the overlap between the scores, only the health risk score was used in the present study. A psychometric evaluation of the Health Behavior Scale-CHD showed that this instrument is valid and responsive to be used in adolescents with CHD (44).

Depressive symptoms. We measured depressive symptoms with the 20-item Center for Epidemiologic Studies Depression Scale (CES-D) (46). Each item pertains to the frequency with which respondents have experienced symptoms of depression during the past week. Items were scored on a four-point Likert-type rating scale, ranging from 0 (seldom) to 3 (most of the time or always). An overall score is calculated by summing all item scores, after reversing the scores of four items. This overall score ranges from 0 to 60. A higher score expresses more depressive symptoms.

Statistical analyses

The data were analysed using SPSS version 12.0 (SPSS Inc., Chicago, Illinois). Nominal level data were expressed in absolute numbers and percentages. Medians and quartiles (Q1 and Q3) were calculated for non-normally distributed continuous variables.

The difference in QOL between patients and matched controls was univariately investigated using the Wilcoxon Signed Rank test. To explore the relative difference in scores between these two groups, a mean standardized difference was calculated. For each patient, the score of the corresponding control subject was subtracted from the patient's score and this was divided by the standard deviation of the control group, generating a standardized difference for

that patient. Averaging this difference over all patients resulted in a mean standardized difference (12). Values greater than zero indicate that the QOL of patients was higher than that of the control participants. Cut-off values as proposed by Cohen were used: small difference (0.2–0.5); moderate difference (0.5–0.8); large difference (>0.8) (47).

To evaluate whether SOC explains the difference in QOL between patients and controls, a linear mixed model was used, adjusting for other potentially influencing factors (i.e. educational level, romantic relationships, perceived health status, health risk behaviour, and depressive symptomatology). Group belonging (patients or controls) and all other variables were entered as fixed effects (enter method), and matching pair was entered as a random effect. Because patients and controls were matched for sex and age, these variables were excluded from the model. Clinical variables were also excluded, because they were not relevant, and, thus, not measured in the control group. All tests were two-tailed and the level of significance was set at 0.05.

Results

Sample characteristics

In total, 429 patients with CHD provided written informed consent to participate (response rate: 86%). The patient sample consisted of 229 boys and 200 girls, with a median age of 16.3 years. Ventricular septal defect was the most prevalent congenital heart defect (18.1%). Demographic and clinical characteristics of the participating patients with CHD are detailed in Table 1.

In all, 403 (94.0%) patients could be matched to a control person. No significant differences in terms of educational level ($\chi^2=0.52$; $p=0.972$) or presence of romantic relationships (i.e. having a partner) ($\chi^2=1.266$; $p=0.26$) were observed between patients with CHD and matched controls.

Quality of life in adolescents with congenital heart disease

The median QOL score of adolescents with CHD was 82 (Q1=75; Q3=90) on a scale from 0 to 100, representing a good QOL. Scores in our sample range from 30 to 100, suggesting that some patients have a very poor QOL, whereas others have the best imaginable QOL. Figure 2 represents a histogram of the QOL scores in this patient cohort.

Comparison with adolescents from the general population

The median score of controls on the LAS for QOL was 80 (Q1=70; Q3=85.5) on a scale from 0 to 100. This score was significantly lower than that of adolescents with CHD ($Z=-5.888$; $p<0.001$). Although the scores of patients and control subjects differed significantly, the difference was small according to Cohen's cut off values (47), as the mean standardized difference was 0.40 (95% confidence interval 0.27-0.53).

Sense of coherence as determinant of quality of life

Adjusted for other potentially confounding factors (i.e. educational level, romantic relationships, perceived health status, health risk behaviour, and depressive symptomatology), linear mixed modelling showed that the better QOL in patients with CHD was partly explained by a higher SOC (Table 2). Indeed, the mean score of SOC in adolescents with CHD was 61.4 (standard deviation 12.0), which was substantially higher than the mean score of 53.6 (SD 10.4) in controls. Another factor that explained the better QOL of adolescents with CHD in the linear mixed modelling was the higher perceived physical health status (mean 87.0 (SD 13.8) vs. 85.3 (SD 13.2)). The difference in QOL between patients and controls was not completely explained by the demographic, behavioural and psychosocial variables measured, because group belonging remained a significant factor.

Discussion

QOL in adolescent patients with CHD is an important, yet understudied, area. In the present study, we found that adolescents with CHD have a good QOL, even better than that of their counterparts from the general population. Correspondingly, SOC in our patients is higher than in adolescents of the general population. Moreover, SOC is an independent factor in explaining the better QOL in adolescents with CHD.

The results might be counterintuitive for CHD clinicians, but they are in line with the results of studies in adults with CHD that used the same method to assess QOL (12;48). It should be noted, however, that the mean standardized difference between the scores of the patients and controls is small. This means that this difference is not clinically significant.

Our findings concerning SOC in patients with CHD are also in line with recent reports, though the scores on SOC that we have found cannot be directly compared with these studies (17;18). Neuner et al. used the SOC-9, a nine-item version of the instrument with a possible score range from 9 to 63 (18). Nio, on the other hand, used an adapted version of the SOC-13 scale, in which SOC was measured on a five-point scale (17) instead of the original seven-point scale that we have used.

Clinical implications

The fact that SOC is generally higher in patients than in controls, and the observation that it is an independent determinant of QOL, can greatly broaden healthcare professionals' roles in caring for youngsters with CHD, provided that the results are confirmed in longitudinal studies. To help these children to developing a strong SOC, healthcare workers ought to educate children about their illness, help children balance the stresses of their diseases, and encourage children to participate in any decisions dealing with the management of their disease (13). Parents should be

encouraged to do the same. In other words, SOC should be considered as a target for interventions in childhood to improve patients' QOL during adulthood (13).

A first possible step for health professionals in supporting patients with CHD to maintain or improve their SOC is to identify vulnerable patients by evaluating their level of SOC. A second step could be to put emphasis on potential resources to support the patient, besides focusing on potential barriers to a successful disease adaptation process or recovery (49). More specifically, lifestyle interventions, talk-therapy, patient empowerment, and case management have proved to be effective strategies to enhance SOC (50-52). Finally, health professionals caring for adolescent patients with CHD need to tailor their support to match the developmental stage and challenges these youngsters are facing (10).

Methodological issues

This study has several strengths and, consequently, expands the current knowledge base on the importance of SOC in developing a good QOL in patients with CHD. First, the methods applied to assess QOL were built on a thorough conceptual basis (30). The definition used in this study precludes interchanging QOL with functional health status and stresses a subjective approach. Previous research revealed that there is a lack of instruments tapping adolescents' general perceptions and that most instruments to measure QOL in adolescents focus on functional health status (53). Nevertheless, QOL is a subjective experience and it is essential that adolescents themselves can define items important to their individual QOL. Research has proved that adolescents are indeed capable of articulating their own views on QOL (53) and that they perceive QOL and health as related, but separate, concepts (54). Hence, there is evidence supporting the use of this definition among adolescents. Second, the report was congruent with the current standards for QOL reporting (55): QOL was defined in terms of life satisfaction;

overall QOL was measured using a LAS; patients from the entire spectrum of heart defects were included; and a direct comparison was made with controls of the general population (12). Third, the present study was conducted in a large sample of adolescents with CHD. The use of Dillman's approach (32) and the movie ticket that was given to the respondents yielded a high response rate. Hence, the questionnaire burden did not prevent patients from participating in the study. The distribution of simple, moderate, and complex defects in our study was in line with recent epidemiological data on CHD in Belgium (1;34). In addition, patients were recruited from the database of one university hospital, but received follow-up in different hospitals across the country. Fourth, a control group that was comparable in terms of sociodemographic characteristics was recruited.

However, there were some methodological limitations in this study. First, questionnaires were sent by post to the patient's home address. Hence, we did not have in-depth information on the clinical condition of the patients at the time of completing the questionnaires. Previous research has found that the course of illness does not influence patients' QOL (56). Therefore, we assume that the lack of clinical information did not have a significant effect on our results. Furthermore, we do not know whether the patients completed the set of questionnaires at one time or over more than one session. Nonetheless, if patients did not complete the questionnaires at the same time, it is unlikely that it would have affected our results, because the variables that we measured do not greatly fluctuate over time. Second, we were unable to adjust our findings for sex, as patients and controls were matched for sex, although we previously found that boys with CHD had a significantly higher SOC compared with girls (57). Consequently, we recommend future studies to further explore the role of sex. Third, previous research revealed that QOL is subject to changes in adolescents' perceptions and experiences according to

developmental stage and maturation (10). The method used to measure QOL in this study, however, did not allow adolescents' subjective maturation and the potentially differential developmental challenges they were confronted with to be taken into account. As such, it remained unclear how specific developmental tasks may influence QOL in adolescents with CHD. Fourth, the cross-sectional design of this study does not allow conclusions to be drawn in terms of the direction of associations. Indeed, we cannot state whether QOL is influenced by SOC, whether QOL influences SOC, or both. Because the present study is part of a longitudinal research project, in which adolescents are asked to complete the questionnaires four times over a period of 3 years, we will be able to chart evolutions of QOL over time, and to investigate how such evolutions transact and influence one another. Fifth, as in all QOL studies, patients with cognitive deficiencies were debarred from inclusion in the study. Indeed, self-report by questionnaires requires intact intellectual abilities (48). Hence, the results of this study only apply to adolescent patients who have normal cognitive functions. Sixth, our findings are not generalizable until they have been confirmed in replication research. Indeed, cross-testing in other settings, countries, and cultures is needed to verify whether SOC is really key in promoting the QOL of individuals with CHD. There are other factors that could explain these patients' QOL. Personality, for example, plays a role, as patients with CHD with a type D personality report poorer QOL (58). Besides taking into account other explanatory factors, it is required to investigate to what extent SOC explains QOL over and above other related concepts, such as resilience or hardiness. An integration of these insights with existing coping theories is needed. There are avenues for future research.

Conclusion

We investigated QOL in adolescents with CHD in the transition to adulthood. These adolescents had a good QOL, one that was slightly better than that of control subjects from the general population. The better QOL in patients was explained in part by a higher SOC. This study corroborated previous findings that patients with CHD have a good QOL, and provided evidence that SOC potentially plays an important role in this respect.

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Conflict of interest

None declared.

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Table 1. Demographic and clinical characteristics of adolescents with congenital heart disease (n=429).

	<i>n (%)</i>
Male subjects	229 (53.4%)
Median age (years)	16.3 (Q1=15.3; Q3=17.3)
Educational level (n=413)	
General secondary/university/university college	194 (47.0%)
Technical secondary	135 (32.7%)
Vocational secondary/special education	84 (20.3%)
In a romantic relationship (n=423)	70 (16.5%)
Primary CHD diagnosis	
Hypoplastic left heart syndrome	2 (0.5%)
Univentricular physiology	4 (0.9%)
Tetralogy of Fallot	11 (2.6%)
Double outflow right ventricle	12 (2.8%)
Double inlet left ventricle	1 (0.2%)
Truncus arteriosus	1 (0.2%)
Transposition of great arteries (TGA)	26 (6.1%)
Congenitally corrected TGA	5 (1.2%)
Coarctation of the aorta	43 (10.0%)
Atrioventricular septal defect	6 (1.4%)
Atrial septal defect type I	4 (0.9%)
Ebstein malformation	2 (0.5%)
Pulmonary valve abnormality	38 (8.9%)
Aortic valve abnormality	69 (16.0%)
Aortic abnormality	9 (2.1%)
Left ventricle outflow tract obstruction	5 (1.2%)
Atrial septal defect type II	56 (13.1%)
Ventricular septal defect	78 (18.1%)
Mitral valve abnormality	37 (8.6%)
Pulmonary vein abnormality	9 (2.1%)
Other	11 (2.6%)
Complexity of heart defect	
Simple	174 (40.6%)
Moderate	204 (47.6%)
Complex	51 (11.9%)
Underwent prior heart surgery for CHD	200 (46.6%)
Pulmonary arterial hypertension	20 (4.7%)

CHD: congenital heart disease.

Table 2. Correlates of the difference in quality of life between patients and controls using linear mixed modelling (n=806).

Variable	Estimate	Standard error	95% CI	<i>p</i> Value
Intercept	49.12	5.61	38.11-60.14	<0.001
Patient vs. control	4.61	1.21	2.23-6.98	0.001
Demographic variables				
Educational level	0.02	0.63	-1.22-1.25	0.979
Romantic relationship	-0.57	1.15	-2.82-1.68	0.618
Patient-reported outcomes				
Sense of coherence	0.15	0.06	0.04-0.26	0.006
Perceived health status: physical health	0.14	0.04	0.06-0.23	0.001
Perceived health status: psychosocial health	0.10	0.06	-0.01-0.21	0.072
Health risk behaviour	-0.02	0.03	-0.08-0.04	0.480
Depressive symptomatology	-0.02	0.07	-0.16-0.12	0.742

95% CI: 95% confidence interval.

Figure 1. Flow-chart of patient selection.

Figure 2. Histogram of quality-of-life scores in 429 adolescents with congenital heart disease.