Original Article

Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults

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Background: Congenital heart disease (CHD) is a chronic illness with a high frequency in the worldwide population, and is normally diagnosed at birth or in uterus. Because of better conditions in diagnosis and early medical and surgical treatment, patients have survival rates of 90% and go further and further in life, facing different challenges in life cycle. In this study, we tested the effects of different demographic, clinical and psychosocial variables on the perception of quality of life (QOL), on psychosocial adjustment (PSA) and psychiatric morbidity (PM) of adolescents and young adults with CHD.

Objectives: We aimed to evaluate QOL, PM and PSA of adolescents and young adults with CHD and to determine which variables (demographic, clinical, and psychosocial) play a role in buffering stress and promoting resilience and which ones have a detrimental effect.

Methods: The study enrolled 150 CHD patients (87 males and 63 females), 12 to 26 years (M: 17.45± 3.373 years). The participants were interviewed regarding social support, family educational style, self-image, demographic information and physical limitations. They responded to questions in a standardized psychiatric interview (SADS-L) and completed self-reports questionnaires for assessment of QOL (WHOQOL-BREF) and PSA (YSR/ASR).

Results: We found an 18.7% lifetime prevalence of psychopathology in our participants (25.4% in females and 13.8% in males). 57.1% had retentions in school (M: 1.53±0.804 year). The perception of QOL of CHD patients is better compared to the Portuguese population in the Social Relationships, Environmental, Physical and General Dimensions. However, it is worse in complex forms of CHD, in cyanotic patients, in moderate-to-severe residual lesions, in patients submitted to surgery and in patients with physical limitations. All of these variables, except presence of cyanosis, are also associated to a worse PSA. Social Support is very important in improving QOL of patients in all dimensions as well as academic performance.

Conclusions: Female patients and patients with poor academic performance and poor social support refer worse PSA and QOL.

Keywords: Congenital heart disease (CHD); risk factor; quality of life (QOL); psychosocial adjustment (PSA); psychiatric morbidity (PM)

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Introduction

Congenital heart disease (CHD) is defined as a malformation of the heart or the large blood vessels that develops during the fetal period. Clinically, it is classified as cyanotic or acyanotic based on the percentage of oxygen saturation in the blood (1,2).

CHD, comprising a wide spectrum of simple, moderate, and complex heart lesions, is the most common birth defect (3).

Because of advances in pediatric cardiology and cardiac surgery, the life expectancy of these children has increased substantially over the past decades (4,5). Today, 90% of newborns diagnosed with CHD live to adulthood, resulted in an increasing number of adults with CHD being followed up in tertiary care centers, fact that is generating interest in adult CHD on the standpoint of a new subspecialty of cardiology (6).

The prevalence of CHD is changing all over the world and nowadays there are more adults affected with CHD than children (6).

As survival rates improve, psychosocial issues have emerged as a critical research area.

A prominent clinical concern is patient perception of quality of life (QOL) (7), psychosocial adjustment (PSA) (8) and PM to allow a more effective intervention along this population (8,9).

The evaluation of QOL provides a comprehensive description of the health of the individual, may result in the identification of physical, functional and psychosocial dysfunctions and is an important component in assessing the long-term impact of chronic conditions (10).

QOL is defined as a multi-dimensional construct integrating physical, emotional, and social well-being and functioning as perceived by the individual (11,12) and as the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain important aspects of life, both related and unrelated to health (13).

To date, studies on QOL in CHD patients have reported contradictory findings. Some studies reported that poorer QOL is related to cardiac instability (14), disease severity (15,16), motor functioning and autonomy (17), although no differences were found for the variables of gender, age or marital status (14). Some studies found poorer psychological well-being and QOL in CHD patients compared to healthy controls (18,19), while others claimed there was no difference between the two groups. Some researchers have reported that the congenital nature of the disease leads CHD patients to have better QOL than healthy people (13,20).

Studies indicate that patients with CHD have persistent cardiac defects, a poor QOL and PSA problems (21). Moreover, patients with CHD are considered to be at increased risk of psychological and emotional difficulties (20,22).

Many studies have been conducted assessing the impact of CHD in psychosocial and cognitive functioning. Despite the lack of a consensus, in some studies, it is reported that parents and partners tend to emphasize more behavior and emotional problems than the patient which tends to classify their behavior as similar to that of peers (8,16,23-27). Another study reports socioeconomic status and cardiac disease severity significantly associated with parent proxy-reported cognitive problems (28).

Moreover, studies including patients with different types of congenital heart diseases, after a surgical correction, with recourse to scales of PSA, showed associations between heart disease and hyperactivity disorder, impulsivity, feelings of anxiety and depression, and other emotional problems (internalizing problems, limitations in socialization and feelings of inferiority) (24,25,29-32). Poor academic performance, low self-esteem and self-concept are also associated with these problems (27,33).

Thus, it is very important to understand which variables have a detrimental effect in PSA and well-being of patients and which ones increase resilience and ability to adapt (34).

In our research, we aimed to systematically address the question of which demographic or clinical variables have an impact over quality of life, psychosocial adjustment, or PM in grown up patients with CHD.

Materials and methods

Participants

The study enrolled 150 CHD patients (87 males and 63 females) with a mean age: 17.45±3.373 years old (range: 12-26 years old) followed in the pediatric cardiology or adult cardiology outpatient clinic of a tertiary hospital in Portugal, and 141 of their relatives. The patients that had not achieved a basic educational level to understand and complete the written questionnaires were excluded.

At the time of the study, two participants were married, one was divorced, two were living in a marital union and all other participants [145] were single. 21 were employed full- or part-time, 7 were unemployed, and the others, 122, were students.

With regard to educational level, one completed the

4 first years in school, twenty-three the 6 first years, sixty-three the 9 first years, fifty-seven completed the whole secondary education and six an university degree.

Complete medical records were available for all the patients, the clinical files being provided by the department of Cardiology or Pediatric Cardiology. The diagnosis was determined during the neonatal period for 81 of the participants, before the first birthday for 33, between the ages of 1 and 3 years for 6, between the ages of 3 and 6 years for 9 of the them, between the ages of 6 and 12 years for 11 of the participants, and between the ages of 12 and 18 years for the remaining 10. For 77 individuals, the primary congenital cardiac malformation was cyanotic, and for 73 patients, it was acyanotic. According to clinical files, at the time of diagnosis, 41 participants exhibited a severe form of CHD, 32 had a moderate form, and 77 had a mild form. 59 patients were on pharmacological therapy while 91 were not. 49 patients had some physical limitations while 101 did not. As far as the residual lesions are concerned, 6 participants had severe residual lesions, 30 had moderate residual lesions, and 114 had mild residual lesions.

In several participants, the main CHD was combined with other heart diseases. Individuals with associated extra cardiac malformations or chromosomopathies were excluded from the study.

Participants exhibited the following distribution of pathologies: Transposition of the Great Arteries (15 participants, 2 with Ventricular Septal Defect, 1 with Aortic Stenosis, 3 with Pulmonary Stenosis, and 2 with also Coarctation of the Aorta), Tetralogy of Fallot (37 participants), Coarctation of the Aorta (16 participants: 1 also had Ventricular Septal Defect, and another had Aortic Stenosis), Ventricular Septal Defect (21 participants: 1 also had Interrupted Aortic Arch, 1 also had Mitral Insufficiency, 1 had also Aortic Stenosis, 2 had also Pulmonary Stenosis, and another had also Atrial Spetal Defect), Atrial Septal Defect (12 participants: 1 had also Mitral Atresia and Pulmonary Hypertension), 5 had Atrioventricular Septal Defect, 10 had Aortic Stenosis, Pulmonary Stenosis (16 participants: 1 also had Ventricular Septal Defect, and another had also Atrial Spetal Defect), Single Ventricle (2 participants, one had also Pulmonary Stenosis, and another have Pulmonary Atresia), 2 had also Patent Ductus Arteriosus, 1 had Double Outlet Right Ventricle, Ebstein Anomaly (4 participants: 1 had also Atrial Septal Defect), Pulmonary Atresia (4 participants: 2 also had Ventricular Septal Defect), 2 had Mitral Valve Prolapse, 1 had Tricuspid Valve Regurgitation, and finally 2 had Bicuspid Aortic Valve.

In total, 36 patients were never submitted to any kind of surgical procedure, while 61 had one surgery, 31 had two, 12 had three, 6 had four, 3 had five and 1 had 9 surgeries. For 114 participants who underwent surgery, the first surgery was performed during the neonatal period for 8, before the first birthday for 35, between the ages of 1 and 3 years for 23, between the ages of 3 and 6 years for 23, between the ages of 6 and 12 years for 12 of the participants, between the ages of 12 and 18 years for 12 of the participants, and after of 18 years for 1 of the participants.

Assessment instruments

The patients were interviewed on only one occasion where a complete clinical history (e.g., diagnosis, severity and category of CHD, course of illness, surgeries, presence of residual lesions, and pharmacological therapy) and demographic information (e.g., marital status, educational level, and occupation) were collected in a questionnaire.

The participants also responded to a semi-structured interview that included 38 multiple-choice or short-answer questions focused on different topics such as social support, family educational style, environment, self-image, functional limitations, educational background, and emotional adjustment.

A standardized psychiatric interview (SADS-L) was administered to obtain a clinical diagnosis of any psychopathologic disorders that may have existed prior to the interview (35).

The participants completed self-report questionnaires like WHOQOL-BREF for assessment of their QOL, and YSR or ASR (according to the age of patients) for assessment of PSA. One of the patients' caregivers completed an observational version of the same questionnaires (CBCL or ABCL, according to the age of patients).

The WHOQOL-BREF (36) is a self-report questionnaire that assesses subjective QOL in both healthy individuals and those with wide range of psychological and physical disorders. It is a 26-item Likert-type scale with ratings from 1 to 5. For almost all the scale items, higher scores reflect a higher QOL. However, for three items (questions 3, 4, and 26), higher scores reflect a lower QOL. The first two questions of the instrument assess general QOL. The WHOQOL-BREF also assesses four dimensions of QOL: physical (questions 3, 4, 10, 15, 16, 17, and 18), psychological (questions 5, 6, 7, 11, 19, and 26), social (questions 20, 21, and 22), and environmental (questions 8, 9, 12, 13, 14, 23, 24, and 25). For each dimension, the average score is calculated and

transformed into a scale value that ranges from 0 to 100.

YSR (Youth Self-Report) and ASR (Adult Self-Report) are self-report questionnaires that assess behavior problems of youth or adults in the last 6 months. It is a 112-item Likert-type scale for youth (YSR) and 123-item for adults (ASR) with ratings from 0 to 2. Items on the scale of youth are grouped into eight syndromes: Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior. It also allows the measurement on two scales: internalization (results from the sum of scores on Withdrawn Behavior, Somatic Complaints, Feelings of Anxiety/Depression and the subtraction of item 103) and externalization (results from the sum of scores on Delinquent Behavior and Aggressive Behavior). Items on the scale of adults are grouped into eight syndromes: Feelings of Anxiety/Depression, Withdrawn Behavior, Somatic Complaints Thought Problems, Attention Problems, Aggressive Behavior, Rule-Breaking and Intrusive Behavior. It can also be grouped in the same two scales of internalization and externalization. The CBCL (Child Behavior Check List) and ABCL (Adult Behavior Check List) are observational versions of the same questionnaires and intend to assess the perception of caregivers about possible behavior problems in the patients. For their similarities and to have a better representative sample, the results of the YSR and ASR were pooled, such as the results of the CBCL and the ABCL (37,38).

Procedure

Prospective participants were contacted before or after scheduled hospital appointments. The subjects were asked to participate after being fully informed of the objectives and procedures of the investigation. The parents (when they were under 18 years old) or the patients who agreed completed an informed consent form approved by the hospital's ethical committee, which followed international conventions guaranteeing the rights of the patients. The interview happened on the spot.

Design

All the assessment measures were obtained on a single occasion. Clinical data were collected retrospectively using each patient's clinical record, with assistance from hospital medical staff.

Methods of statistical analysis

Statistical analyses of the data were performed using the IBM Social Package for the Social Sciences (SPSS), version 20.0 (SPSS, Chicago, IL, USA). The distribution of all the variables was tested. Differences for parametric variables were established using Student's t-tests, and differences for nonparametric variables were established using Mann–Whitney U tests and Chi-square tests of association. Finally, several independent regression analyses were conducted to determine the relationship between the independent variables (gender, kind of congenital heart disease, severity of illness, severity of residual lesions, amount of social support presence/absence of psychopathology, being or not submitted to surgery, number of surgeries) and the dimensions of QOL and those of psychosocial adjustment.

Results

One or more of the following psychiatric disorders had been diagnosed for 28 of the participants before the interview: minor or major depressive syndrome (n=14), panic disorder (n=3), anxiety disorder (n=7), or manic syndrome (n=3), and cyclothymic personality (n=1). Thus, we found a 18.7% lifetime prevalence of psychopathology (25.4% in females and 13.8% in males). However, there were no significant differences in QOL for presence/ absence of psychiatric diagnosis.

Female patients refer also more somatic complaints (u=750.000; P=0.002), more feelings of anxiety/depression (u=1,866.000; P=0.001), thought problems (u=1,881.500; P=0.001), aggressive behaviors (u=1,877.500; P=0.001), and internalization problems (u=1,548.500; P=0.000) in PSA scales. The females also show worse QOL on environmental dimension (t=2.590; P= 0.011).

Patients aged 12 to 18 (N=102) compared to patients aged 19 to 26 (N=48) have higher scores in withdrawn behavior (u=1,768.500; P=0.006). However, those aged 19 to 26 showed more feelings of anxiety/depression (u=1,272.500; P=0.000), thought problems (u=1,911.000; P=0.027), attention problems (u=1,432.500; P=0.000), and externalization problems (u=724.000; P=0.000) than those aged 12-18. Regarding the quality of life, patients aged 12-18 years showed better QOL in the physical dimension (t=4.225; P=0.000) than the other age-group.

We found that 57.1% of our participants had at least one retention in school (M=1.53±0.804 year). The participants with poor academic performance showed

Table 1 Comparison between reference values and those presented by our participants in quality of life

Dimensions	Reference values*	Participants of our study	T	P
Physical	M=77.49	M=67.96	–8.281	0.000
	DP=12.27	DP=14.095		
Psychological	M=72.38	M=71.05	–1.365	0.174
	DP=13.50	DP=11.967		
Social relationships	M=70.42	M=74.75	3.493	0.001
	DP=14.54	SD=15.196		
Environmental	M=64.89	M=73.26	7.910	0.000
	DP=12.24	SD=12.965		
General QOL	M=71.51	M=74.11	2.305	0.023
	DP=13.30	DP=13.834		

* For the Portuguese population as a whole.

worse psychosocial adjustment, with more feelings of anxiety/depression (u=1,563.000; P=0.014), more attention problems (u=1,380.000; P=0.001), more aggressive behavior (u=1,652.000; P=0.039), and more externalization problems (u=1,386.000; P=0.002). However, the participants with better academic performance showed better QOL on Psychological (t=2.583; P=0.011), Environmental (t=2.569; P=0.011) and General dimensions (u=1592.500; P=0.014).

The perception of QOL of CHD patients was better when compared to the Portuguese population as a whole in the Social Relationships, Environmental, Physical and General Dimensions, but not in the Psychological Dimension (*Table 1*).

The QOL was worse in complex than in moderate-to-mild forms of CHD in Physical (t=–3.813; P=0.000), Environmental (t=–2.472; P=0.015) and General (u=1,764.000; P=0.048) dimensions. As well as PSA, with patients exhibiting more social problems (u=1,544.500; P=0.037). Moreover, relatives referred more somatic complains (u=1,380.500; P=0.021), and internalization problems (u=1,264.500; P=0.006) for the most complex forms of CHD.

Cyanotic patients, compared to acyanotic, had worse QOL on Physical (t=–3.021; P=0.003) and Environmental (t=–3.289; P=0.001) dimensions. However, there were no significant differences in QOL for patients who were medicated or not. In PSA scales no differences were found for these two variables.

Patients submitted to surgery (N=114) showed higher scores in attention problems (u=1,538.000; P=0.016) and externalization problems (u=1,560.000; P=0.024). Those submitted to more than two surgeries had also higher scores in withdrawn behavior (u=1,752.000; P=0.001), anxiety/depression (u=1,971.500; P=0.018), social problems (u=1,866.000; P=0.033), delinquent behavior (u=2,044.500; P=0.036), aggressive behavior (u=1,929.500; P=0.011), internalization (u=1,864.500; P=0.007), and externalization problems (u=1,974.500; P=0.024). The perception of QOL, in patients submitted to surgery, was also worse in all dimensions, when compared to those not operated (N=34) (*Table 2*).

Those submitted to more than two surgeries had also worse QOL, on Physical (t=4.785; P=0.000) Psychological (t=2.850; P=0.005), Environmental (t=3.379; P=0.001) and general dimensions (u=1,907.000; P=0.005).

Patients with moderate-to-severe residual lesions had worse perception on QOL than those with mild lesions, in the Physical dimension (t=–2.187; P=0.030). These patients also showed worse psychosocial adjustment, with more somatic complaints (u=752.000; P=0.045). The relatives also referred more withdrawn behavior (u=1,401.000; P=0.029), feelings of anxiety/depression (u=1,392.500; P=0.026), social problems (u=498.000; P=0.001), attention problems (u=1,263.000; P=0.005), aggressive behaviors (u=1,396.500; P=0.028), and internalization problems (u=976.500; P=0.000) for the moderate-to-severe residual lesions.

Patients with physical limitations (N=49) showed more withdrawn behavior (u=1,810.500; P=0.007), anxiety/depression (u=1,898.000; P=0.020), attention problems (u=1,962.000; P=0.039) and internalization problems (u=1,880.500; P=0.027). They had also a worse perception in Physical (t=–3.148; P=0.002), Psychological (t=–2.874; P=0.005) and General QOL (u=1,938.500; P=0.022) than those without physical limitations (N=101).

Table 2 Comparison between patients who were or were not submitted to surgical intervention on quality of life

Dimensions	With surgery (N=114)		Without surgery (N=36)		T	P
	M	SD	M	SD		
Physical	25.44	3.875	27.81	3.658	–3.270	0.001
Psychological	22.65	2.934	24.27	2.305	–3.069	0.003
Social relationships	11.79	1.830	12.51	1.710	–2.128	0.035
Environmental	31.05	4.381	32.62	3.094	–2.396	0.019
	M		M		U	P
General QOL	7.80		8.32		1,505.000	0.006

Table 3 Comparison between patients with good social support with those with poor support on quality of life

Dimensions	Good SS (N=117)		Poor SS (N=33)		T	P
	M	SD	M	SD		
Physical	26.39	3.893	24.73	3.915	2.168	0.032
Psychological	23.37	2.797	21.91	2.887	2.627	0.010
Social relationships	12.26	1.647	10.91	2.037	3.956	0.000
Environmental	32.00	3.991	29.45	4.139	3.210	0.002
	M		M		U	P
General QOL	8.09		7.33		1,233.000	0.001

Social support seemed to be very important in improving QOL of patients in all dimensions (*Table 3*). Participants with poorer social support showed also more withdrawn behavior (u=1,210.500; P=0.001) and more social problems (u=1,209.500; P=0.015) in PSA scales.

Finally, as we conducted the independent regression analyses, we could confirm some of these tendencies. The variables that could predict a worse general perception of QOL (R2=0.158; F=3.306; P=0.002) were a poor social support (Beta=0.275; P=0.001) and a bigger number of surgeries (Beta=–0.186; P=0.056); the variable that could predict a worse QOL on physical dimension (R^2=0.191; F=4.166; P=0.000) was a bigger number of surgeries (Beta=–0.214; P=0.026); being submitted to surgery (Beta=-0.200; P=0.025) and having a poor social support network (Beta=0.207; P=0.012) predicted a worse QOL on psychological dimension (R^2=0.143; F=2.938; P=0.005); the last (Beta=–0.336;P=0.000) also predicted worse QOL on social relationships dimension (R^2=0.158; F=3.302; P=0.002); for the environmental dimension (R^2=0.212; F=4.733; P=0.000), besides poor social support , being submitted to a greater number of surgeries (Beta=–0.196; P=0.038), being a female patient (Beta=–0.245; P=0.002) and having a cyanotic CHD (Beta=0.170; P=0.048) were good predictors

The predictors of poor PSA for young adults (18-26 years old) were being a female patient, for internalization (R^2=0.303; F=2.613; P=0.019)(Beta=0.438; P=0.002), feelings of anxiety and depression (R^2=0.331; F=2.966; P=0.009) (Beta=0.488; P=0.000) and aggressive behavior (R^2=0.387; F=3.790; P=0.002) (Beta=0.458; P=0.001), but for the last, also being submitted to a greater number of surgeries (Beta=0.292; P=0.037) is a predictor; poor social support predicts more withdrawn behavior (R^2=0.249; F=1.993;P=0.068) (Beta=–0.388; P=0.006). For younger patients (12-17 years old), being a female only predicts more somatic complaints (R2=0.208; F=2.765; P=0.009) (Beta=0.291; P=0.005) and more problems of internalization (R^2=0.262;F=3.722; P=0.001) (Beta=0.267; P=0.008); being submitted to a greater number of surgeries predicts more withdrawn behavior (R^2=0.231; F=3.152; P=0.004) (Beta=0.369; P=0.005), more feelings of anxiety and depression (R^2=0.187; F=2.414; P=0.021) (Beta=0.291; P=0.029) and more internalization (Beta=0.317; P=0.013); withdrawn behavior can also be predicted by a poor social support (Beta=–0.305; P=0.004). Finally, having a cyanotic CHD is a good predictor of reporting social problems (R^2= 0.185; F=2.386; P=0.023) (Beta=0.248; P=0.046)

Discussion

In our study, we analyzed the impact of different clinical

(severity of illness, number of surgeries, presence of residual lesions, presence of cyanosis, physical limitations), demographic (gender, age, education and school achievement) and psychosocial variables (performance in school, size and functioning of the social support network, family educational styles) in the prevalence of psychopathologic disorders, in social adjustment and in perception of QOL of patients. To our knowledge, no other study was previously published with our variables number.

An intriguing finding of our study, however confirming data from other authors, is that CHD patients in the whole perceive in a better way their QOL than the healthy population (20,35). That fact may be explained by the presence of some buffer variables, like family environment and cohesion, and social support.

However, when we look at different subgroups, we find that patients submitted to surgery show a worse perception on their QOL than the whole group. These facts, more expected, may be explained by the daily life restrictions and residual side effects that limit physical performance and activity, and by the feeling of life threat and fragility, after a surgical treatment. The comparison between cyanotic and acyanotic patients and those with moderate-to-severe or those with mild residual injuries show for the first ones a worse perception on quality of life.

In the literature, the predictors of behavioral and emotional problems include the female gender, low exercise capacity, restrictions imposed by physicians, a severe heart lesion, a surgical treatment, and a greater number of heart operations (16,39-41). In our study, we found that being female, having poor academic performance, poor social support, having a complex form of CHD, moderate-to-severe residual lesions, having been submitted to surgery and having physical limitations is associated to worse psychosocial adjustment.

The participants of our study showed 18.7% lifetime prevalence of psychopathology, with almost the double rate in female than in male patients. Also, when we look at social adjustment, the same tendency is revealed, with women showing more feelings of anxiety and depression, more somatic complaints and other signs of poorer adjustment. That tendency encompasses the international higher prevalence of women at least in the subtypes of "affective disorders" and "anxiety disorders".

We also found more adjustment problems in older patients (19-26 years). In the others studies, the younger patients showed more psychopathology than the older patients (22,28,42). On the other hand, studies on the level of psychopathology in CHD adults show conflicting results, varying from elevated levels of psychopathology to levels similar to those of peers (43,44).

When we looked at good predictors of bad perception of QOL, we came to the conclusion that social support, being submitted to surgery and to a greater number of surgeries were the best predictors. Being a female patient is a strong predictor of worse PSA overall.

In Portugal, there are no final data on PM nationwide, although some estimation on the prevalence of psychiatric disorders in the general population could be made on the basis of partial studies (45). Referring to those findings, we may say that CHD patients seem to show a slightly increased proneness to psychopathology.

In short, our research is important because we tested the effects of different demographic, clinical, and psychosocial variables on the perception of QOL, on PSA and on PM of CHD patients.

As other published data, our study has limitations. First of all, the number of patients is not large enough for some intra-group comparisons. We believe that a greater sample size will allow us to investigate the impact of the time of surgery in patients' quality of life. Another interesting variable to study in a future research is the personality of patients and its impact on QOL independently of the CHD severity.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

References

1. Karsdorp PA, Everaerd W, Kindt M, et al. Psychological and cognitive functioning in children and adolescents with congenital heart disease: a meta-analysis. J Pediatr Psychol 2007;32:527-41.
2. Nousi D, Christou A. Factors affecting the quality of life in children with congenital heart disease. Health Science Journal 2010:4;94-100.
3. Hoffman JI, Kaplan S. The incidence of congenital heart disease. J Am Coll Cardiol 2002;39:1890-900.

4. Luyckx K, Missotten L, Goossens E, et al. Individual and contextual determinants of quality of life in adolescents with congenital heart disease. J Adolesc Health 2012;51:122-8.
5. Apers S, Luyckx K, Rassart J, et al. Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease: A cross-lagged prospective study. Int J Nurs Stud 2013;50:776-85.
6. Marelli AJ, Mackie AS, Ionescu-Ittu R, et al. Congenital heart disease in the general population: changing prevalence and age distribution. Circulation 2007;115:163-72.
7. Loup O, von Weissenfluh C, Gahl B, et al. Quality of life of grown-up congenital heart disease patients after congenital cardiac surgery. Eur J Cardiothorac Surg 2009;36:105-11; discussion 111.
8. Fredriksen PM, Mengshoel AM, Frydenlund A, et al. Follow-up in patients with congenital cardiac disease more complex than haemodynamic assessment. Cardiol Young 2004;14:373-9.
9. Baumeister H, Härter M. Prevalence of mental disorders based on general population surveys. Soc Psychiatry Psychiatr Epidemiol 2007;42:537-46.
10. Marino BS, Uzark K, Ittenbach R, et al. Evaluation of quality of life in children with heart disease. Prog Pediatr Cardiol 2010:29;131-8.
11. Goldbeck L, Melches J. Quality of life in families of children with congenital heart disease. Qual Life Res 2005;14:1915-24.
12. Gortmaker SL, Walker DK, Weitzman M, et al. Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. Pediatrics 1990;85:267-76.
13. Moons P, Van Deyk K, Marquet K, et al. Individual quality of life in adults with congenital heart disease: a paradigm shift. Eur Heart J 2005;26:298-307.
14. Moons P, Van Deyk K, Marquet K, et al. Profile of adults with congenital heart disease having a good, moderate, or poor quality of life: a cluster analytic study. Eur J Cardiovasc Nurs 2009;8:151-7.
15. Goldbeck L, Melches J. The impact of the severity of disease and social disadvantage on quality of life in families with congenital cardiac disease. Cardiol Young 2006;16:67-75.
16. Latal B, Helfricht S, Fischer JE, et al. Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review. BMC Pediatr 2009;9:6.
17. Krol Y, Grootenhuis MA, DestrÉe-Vonk A, et al. Health Related Quality of Life in Children with Congenital Heart Disease. Psychology & Health 2003;18:251-60.
18. Rose M, Köhler K, Köhler F, et al. Determinants of the quality of life of patients with congenital heart disease. Qual Life Res 2005;14:35-43.
19. Spijkerboer AW, Utens EM, De Koning WB, et al. Health-related Quality of Life in children and adolescents after invasive treatment for congenital heart disease. Qual Life Res 2006;15:663-73.
20. Fekkes M, Kamphuis RP, Ottenkamp J, et al. Health-related quality of life in young adults with minor congenital heart disease. Psychology & Health 2001;16:239-50.
21. Rietveld S, Mulder BJ, van Beest I, et al. Negative thoughts in adults with congenital heart disease. Int J Cardiol 2002;86:19-26.
22. Kovacs AH, Saidi AS, Kuhl EA, et al. Depression and anxiety in adult congenital heart disease: predictors and prevalence. Int J Cardiol 2009;137:158-64.
23. Bellinger DC, Newburger JW. Neuropsychological, psychosocial, and quality-of-life outcomes in children and adolescents with congenital heart disease. Progress in Pediatric Cardiology 2010;29:87-92.
24. Gaynor JW, Nord AS, Wernovsky G, et al. Apolipoprotein E genotype modifies the risk of behavior problems after infant cardiac surgery. Pediatrics 2009;124:241-50.
25. van Rijen EH, Utens EM, Roos-Hesselink JW, et al. Longitudinal development of psychopathology in an adult congenital heart disease cohort. Int J Cardiol 2005;99:315-23.
26. Spijkerboer AW, Utens EM, Bogers AJ, et al. Long-term behavioural and emotional problems in four cardiac diagnostic groups of children and adolescents after invasive treatment for congenital heart disease. Int J Cardiol 2008;125:66-73.
27. Majnemer A, Limperopoulos C, Shevell M, et al. Developmental and functional outcomes at school entry in children with congenital heart defects. J Pediatr 2008;153:55-60.
28. Limbers CA, Emery K, Uzark K. Factors Associated with Perceived Cognitive Problems in Children and Adolescents with Congenital Heart Disease. J Clin Psychol Med Settings 2013;20:192-8.
29. Spijkerboer AW, Utens EM, Bogers AJ, et al. Long-term behavioural and emotional problems in four cardiac diagnostic groups of children and adolescents after invasive treatment for congenital heart disease. Int J Cardiol 2008;125:66-73.
30. Casey FA, Sykes DH, Craig BG, et al. Behavioral adjustment of children with surgically palliated complex

congenital heart disease. J Pediatr Psychol 1996;21:335-52.
31. Shillingford AJ, Glanzman MM, Ittenbach RF, et al. Inattention, hyperactivity, and school performance in a population of school-age children with complex congenital heart disease. Pediatrics 2008;121:e759-67.
32. Kovacs AH, Sears SF, Saidi AS. Biopsychosocial experiences of adults with congenital heart disease: review of the literature. Am Heart J 2005;150:193-201.
33. Hövels-Gürich HH, Konrad K, Skorzenski D, et al. Long-term behavior and quality of life after corrective cardiac surgery in infancy for tetralogy of Fallot or ventricular septal defect. Pediatr Cardiol 2007;28:346-54.
34. McCusker CG, Doherty NN, Molloy B, et al. A randomized controlled trial of interventions to promote adjustment in children with congenital heart disease entering school and their families. J Pediatr Psychol 2012;37:1089-103.
35. Hesselbrock V, Stabenau J, Hesselbrock M, et al. A comparison of two interview schedules. The Schedule for Affective Disorders and Schizophrenia-Lifetime and the National Institute for Mental Health Diagnostic Interview Schedule. Arch Gen Psychiatry 1982;39:674-7.
36. Canavarro M, Simões M, Vaz Serra A, et al. Instrumento de avaliação da qualidade de vida da Organização Mundial de Saúde: WHOQOL-Bref. In: Simões CM, Gonçalves M, Almeida L, et al. eds. Avaliação psicológica: Instrumentos validados para a população portuguesa. III. Coimbra: Quarteto Editora, 2007:77-100.
37. Achenbach T, Rescorla L. Manual for the ASEBA Adult Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families; 2003.
38. Achenbach TM, Rescorla LA. Manual for the ASEBA School-Age Forms & Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families; 2001.
39. van Rijen EH, Utens EM, Roos-Hesselink JW, et al. Medical predictors for psychopathology in adults with operated congenital heart disease. Eur Heart J 2004;25:1605-13.
40. Birkeland AL, Rydberg A, Hägglöf B. The complexity of the psychosocial situation in children and adolescents with heart disease. Acta Paediatr 2005;94:1495-501.
41. Hülser K, Dubowy KO, Knobl H, et al. Developmental outcome and psychosocial adjustment in children after surgery for congenital heart disease during infancy. J Repro Infant Psycho 2007;25:139-51.
42. Olsen M, Sørensen HT, Hjortdal VE, et al. Congenital heart defects and developmental and other psychiatric disorders: a Danish nationwide cohort study. Circulation 2011;124:1706-12.
43. Utens EM, Bieman HJ, Verhulst FC, et al. Psychopathology in young adults with congenital heart disease. Follow-up results. Eur Heart J 1998;19:647-51.
44. Cox D, Lewis G, Stuart G, et al. A cross-sectional study of the prevalence of psychopathology in adults with congenital heart disease. J Psychosom Res 2002;52:65-8.
45. Ministério da Saúde (2004). Plano Nacional de Saúde 2004-2010, Saúde mental e doenças psiquiátricas, Available online: http://www.dgsaude.min-saude.pt/pns/vol2_227.html (acessed 11 Jun 2012).

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