TÜRK PEDIATRI ARŞIVI
TURKISH ARCHIVES of PEDIATRICS

Original Article

Life quality of children with congenital heart diseases

Tamay Sertçelik[1], Fatoş Alkan[2], Şermin Yalın Sapmaz[3], Şenol Coşkun[2], Erhan Eser[4]

[1]Department of Pediatrics, Celal Bayar University School of Medicine, Manisa, Turkey
[2]Department of Pediatrics, Division of Pediatric Cardiology, Celal Bayar University School of Medicine, Manisa, Turkey
[3]Department of Child Psychiatry, Celal Bayar University School of Medicine, Manisa, Turkey
[4]Department of Public Health, Celal Bayar University School of Medicine, Manisa, Turkey

Cite this article as: Sertçelik T, Alkan F, Yalın Sapmaz Ş, Coşkun Ş, Eser E. Life quality of children with congenital heart diseases. Turk Pediatri Ars 2018; 53: 78-86.

Abstract

Aim: We aimed to evaluate the effects of the severity and symptoms of congenital heart disease and the emotional and behavioral problems of affected children on their quality of life.

Material and Methods: The study was performed by interviewing 80 children aged between 6 and 16 years (40 with cyanotic heart disease and 40 with acyanotic disease) and their mothers. A sociodemographic data form, quality of life questionnaire, strength and difficulties questionnaire, and family life and parenting attitudes scale were used in the research. Life quality was the dependent variable of this research.

Results: No significant relation was found between age, sex, and education level of the parents and all quality of life subscale scores ($p>0.05$). In terms of quality of life, total quality of life subscale, emotional well-being and self-esteem subscales were significantly lower in children with cyanotic congenital heart disease ($p=0.02$, $p=0.007$, $p=0.006$, respectively). The total quality of life subscale was significantly lower in children with a medical treatment and surgical history. In terms of clinical symptoms, self-esteem, friendship and school life quality subscales were affected in the presence of dyspnea. As scores from strength and difficulties questionnaire increased, which is used for the assessment of children's psychological symptoms, all quality of life scores were significantly lowered except for school and family subscales.

Conclusion: It was found that symptoms of congenital heart disease affected the psychosocial quality of life subscales rather than the physical subscales. In addition, it was observed that mental symptoms in both the mother and child negatively affected quality of life rather than disease-related parameters.

Keywords: Congenital, heart disease, quality of life

Introduction

Quality of life (QoL) is defined as the individual's perception related with their state in life in terms of the cultural structure and system of values in which they live, their objectives, expectations, standards, and concerns, whereas health-related quality of life is defined as the patient's subjective perception of the impact of their disease or its treatment. The concept of QoL involves the individual's specific physical and psychological health, level of independence, social relations, environmental factors, and personal beliefs. When evaluating QoL, the individual is asked what they feel about their own life, and the aim is to grade the individual's physical, psychological, and social well-being by addressing the individual as a whole with all their characteristics (1).

The prevalence of congenital heart disease (CHD) is known to be approximately 0.91% in all live births (2). The signs and symptoms of congenital heart diseases are substantially variable. Life expectancy has been increased to a great extent in adolescents and children with CHD as a result of advances in cardiac surgery and early diagnosis. With this new situation, the importance of assessment of health-related QoL in all age groups as significant health data has increased further (3). Mellion et al. (4) reported lower QoL scores in children and adolescents with CHD and other chronic diseases compared with a control group. In a study by Uzark et al. (5),

Address for Correspondence: Fatoş Alkan E-mail: fatos.alkan@hotmail.com

Received: 20.11.2017 **Accepted:** 21.02.2018

DOI: 10.5152/TurkPediatriArs.2018.6428

QoL scores in terms of physical and psychosocial functionality were found to be significantly lower in children with heart disease compared with normal healthy children. Again, the same study even showed significant disruption in psychosocial QoL in 19.2% of children with less severe cardiovascular disease. In contrast to the studies in which QoL was found to be disrupted in children and adolescents with CHD, some investigators reported surprising results. In a study in which Teixeira et al. (6) evaluated adolescents and young adults with CHD, higher QoL levels were reported especially in environmental and social relation dimensions compared with the general population. Culbert et al. (7) evaluated QoL levels of 306 children who were diagnosed as having transposition of the great arteries and found that the QoL scores were higher compared with the general population, except for the self-esteem dimension. Evaluation of QoL levels and factors that affect QoL in children with CHD is important because it enables physicians to obtain information in terms of defining risk groups and elucidating intervention strategies that focus on the health needs of these children.

In this study, we aimed to specify the disease-related variables and psychosocial factors that would lead to negativity in QoL in children with CHD.

Material and Method

The study was conducted in Celal Bayar University S of Medicine, Division of Pediatric Cardiology. The sample of the study was composed of a total of 80 children, 40 of whom had cyanotic CHD and 40 had acyanotic CHD. The children had been diagnosed in our center previously and were being routinely followed up. The children and their families were informed about the study by the responsible research fellow and written informed consent was obtained from the families. Ethics committee approval was obtained from Celal Bayar University, Faculty of Medicine Ethics Committee for this study (28/08/2015:297).

Data collection tool

1) Sociodemographic data form

This form, which was developed by the investigators, contained questions that assessed personal characteristics including age, sex, maternal and paternal education level, maternal and paternal employment, and relationship between parents (consanguinity), and clinical characteristics including disease type, disease duration, age at the time of diagnosis, medical treatments, history of surgery, and symptoms.

2) Quality of Life Questionnaire for Children (QoL-C)

The QoL-C [“KINDer Lebensqualitätsfragebogen, Children Quality of Life-Questionnaire” (KIND)] has six dimensions including physical well-being, emotional well-being, self-esteem, family, friends and school (school or day nursery/kindergarden where daily activities are performed). The scores belonging to these dimensions were calculated independently and the total QoL score was obtained by adding the scores of these six dimensions. QoL-C can be used both in healthy children and in children with chronic disease in both clinical and non-clinical areas. It is rated from 1 (never) to 5 (Always) using a 5-point Likert type scale. The score is calculated by counting the points given to the items for each dimension, converting such that it is scaled between 0 and 100 and summarizing. A high score indicates good QoL. The QoL-C has three versions, which were constructed based on self-report and which are used in different age groups. These include: Kiddy-KINDL for children aged between 4 and 7 years (the version that is applied by way of interview, the child responds to questions), Kid-KINDL for children aged between 8 and 12 years and Kiddo-KINDL for adolescents aged between 13 and 16 years. In this study, questionnaires were completed by the children in all age groups. In previous studies, the Turkish KINDL was shown to be valid and reliable for measurement of QoL (8, 9).

3) Strengths and Difficulties Questionnaire (SDQ)

This SDQ was developed to be used to screen for emotional and behavioral problems in children. It includes 25 questions, some of which interrogate positive behavioral characteristics and others interrogate negative behavioral characteristics. These questions are collected under five subtitles, each containing five questions; attention deficit and hyperactivity, behavioral problems, emotional problems, peer problems, and social behaviors. Each subtitle may be evaluated in itself and a separate score may be obtained for each subtitle or a “total difficulty score” may be calculated with the sum of the first four titles. This questionnaire has a parent and teacher form for children aged between 4 and 16 years, and a form for adolescents aged between 11 and 16 years, which is competed by the adolescent themselves. The validity and reliability of its Turkish version has been shown (10, 11). It was applied to evaluate the psychological symptoms of the children and mothers completed the questionnaire on behalf of their children.

4) Parental Attitude Research Instrument

This scale was adapted to Turkish in 1978 by Le Compte et al. (12). The test, which was rearranged according to the conditions of Turkey, contains 60 items and 5 subscales. The answers given by mothers to the Parental Attitude Research Instrument (PARI) are evaluated in five different dimensions. These dimensions include attitude of over-parenting, democratic attitude and recognition of equality, attitude of hostility and rejection, marital discordance, and authoritarian attitude. Increased scores in the dimensions excluding democratic attitude and equality dimension indicate negative parental attitudes (13). It was used to evaluate the effect of parental attitudes on the QoL of the children. The mothers completed the form and assessed their own attitudes.

5) Hospital anxiety and depression scale (HADS)

The original HADS form was developed by Zigmond and Snaith (14) and the validity and reliability of its Turkish version was studied by Aydemir et al (15). This is a self-assessment scale that is used to determine the severity of anxiety and depression and to evaluate the change in severity level in healthy individuals and other patient groups excluding psychiatry patients. An increased total score indicates that the severity of the symptoms has increased. It was used to evaluate the effect of parental psychological symptoms on the QoL of the children. It was used to determine anxiety and depression levels of the mothers and was completed by the mothers for themselves.

Statistical analysis

The Statistical Package for the Social Sciences (SPSS)" for Windows version 15.0 (SPSS Inc.; Chicago, IL, USA) software was used for statistical analyses in the evaluation of the results obtained in this study.

Single and multivariable statistical analyses were applied to the data. Independent variables included sociodemographic characteristics, clinical findings, treatment history, psychological symptom level of the child, maternal psychological symptom levels, and PARI subscale scores.

In single-variable analyses, the relationship of the children's QoL scores with the sociodemographic characteristics, disease variables, the child's psychological symptoms, maternal psychological symptoms, and parental attitudes was evaluated. Student's t-test was used for the comparison of two mean values and Pearson correlations were used to compare two continuous variables. Type 1 error (critical p value) was considered as <0.05 in statistical analyses.

Variables that were found to be statistically significant in single-variable analyses were included in multivariable models. Multilinear regression models were used in multivariable models. A model was constituted for each of the Child QoL dimensions that were dependent variables. In stepwise models, reduced final model projections are presented.

Results

The study group included a total of 80 children, 40 of whom had cyanotic CHD [Fallot tetralogy n=27, transposition of the great arteries n=9, Ebstein anomaly n=1, total anomalous pulmonary venous return (TAPVR) n=3], and 40 had acyanotic CHD [aortic stenosis (mild-moderate) n=3, coarctation of the aorta (mild) n=1, pulmonary stenosis (mild-moderate) n=4, patent ductus arteriosus n=2, atrial septal defect n=12, ventricular septal defect n=18], and their mothers. Thirty-five (43.8%) of the children in the study group were female and 45 (56.3%) were male. The youngest child included in the study was aged 6 years and the oldest was aged 16 years; mean age was 9.9± 2.9 years. No statistically significant correlation was found between the patient's age, sex, and parental education level and any QoL subdimension scores (p>0.05).

The distribution of the children's QoL dimension scores by disease diagnosis, treatment history, and clinical symptoms is shown in Table 1. It was found that the total score of QoL dimension and the scores of emotional well-being and self-esteem were significantly lower in the children with cyanotic CHD. The total score for the QoL dimension was found to be significantly low in the subjects who received medical treatment and had a history of surgery. When evaluated in terms of clinical symptoms, all QoL subdimensions were affected excluding physical well-being, emotional well-being, and family subdimension in the presence of dyspnea. The relationship of the children's QoL scores with the mothers' and children's psychological symptoms is shown in Table 2. It was found that the scores of all QoL dimensions, excluding school and family subdimensions, significantly decreased as the scores of the SDQ increased.

The relationship of the children's scores of QoL dimensions with the parental attitudes is shown in Table 3.

QoL subdimension scores were affected negatively in the children of the parents who reported higher scores in over parenting, authoritarian attitude and attitude of hostility and rejection subdimensions. Only the school subdimension was not affected by parental attitudes.

In the multilinear regression analysis, a separate model was constituted for QoL total dimension score and subdimension scores. The variables that were found to be statistically significantly correlated with the dependent variable in single variable analyses were included in these models. The models that were constituted are presented in Table 4. All models were found to be significant (p<0.05).

In the model in which the total QoL dimension was considered a dependent variable, presence of parents who applied authoritarian attitude., increased levels of psychological symptoms of children, presence of cyanotic CHD, and presence of symptoms of dyspnea significantly affected the change in total QoL score (p<0.05). In the model in which physical well-being was considered a dependent variable, increased levels of psychological symptoms in the children and increased levels of maternal anxiety significantly negatively affected physical well-being (p<0.05). In the model in which emotional well-being and self-esteem dimensions were considered as dependent variables, emotional well-being and self-esteem decreased significantly in the presence of cyanotic CHD when negative parental attitudes, as evaluated using PARI, over parenting subdimension scores and psychological symptom levels of children increased. In addition, the presence of the symptoms of dyspnea also negatively affected the self-esteem subdimension (p<0.05). In the model in which the family dimension was considered a dependent variable, it was observed that negative parental attitudes that caused application of authoritarian attitude. led to a significant change in the scores of the QoL family dimension (p<0.05). In the model in which the friendship dimension was considered a dependent variable, it was found that the friendship dimension was affected by negative

Table 1. Distribution of quality of life scores of the children by the type of congenital heart disease and clinical characteristics

Quality of life subdimensions		Total Mean±sd	Physical well-being mean±sd	Emo-tional well-being mean±sd	Self-esteem Mean±sd	Family mean±sd	Friend-ship mean±sd	School mean±sd
Disease type	Cyanotic	70.4±15.1	78.7±18.4	70.9±16.7	62.7±19.9	67.6±19.2	74.4±19.4	52.4±13.4
	Acyanotic	80.2±11.9	83.5±14.1	82.2±13.9	76.6±17.7	72.7±19.3	81.9±18.1	56.0±13.6
P[a]		0.002	0.259	0.007	0.006	0.314	0.129	0.301
Medical treatment	Yes	67.1±13.9	81.7±16.1	73.3±16.3	61.7±20.6	71.3±20.8	72.5±21.4	50.4±9.6
	No	77.4±13.8	80.6±17.0	76.8±16.6	71.2±19.6	68.4±18.9	79.5±18.2	55.2±14.5
P[a]		0.009	0.827	0.486	0.112	0.753	0.221	0.240
History of surgery	Yes	72.1±13.9	80.9±16.5	73.0±16.3	65.7±20.9	68.8±19.4	78.4±18.1	58.8±12.9
	No	78.8±14.2	80.8±17.2	79.8±16.0	73.1±18.6	69.9±19.4	76.9±20.7	54.3±14.4
P[a]		0.037	0.977	0.112	0.159	0.979	0.769	0.871769
Dyspnea	Yes	56.3±9.0	65.6±23.1	62.5±17.7	53.1±3.6	59.4±6.3	46.9±14.9	50.0±0.0
	No	76.3±13.9	81.9±15.9	76.9±16.1	69.9±20.3	70.6±19.7	79.9±17.5	54.3±13.9
P[a]		0.006	0.059	0.091	<0.001	0.262	<0.001	0.0241
Chest pain	Yes	70.1±15.3	75.5±16.8	75.9±15.3	69.7±19.4	71.6±17.8	72.6±22.5	56.7±12.1
	No	76.4±14.0	82.3±16.5	75.9±16.9	68.6±20.5	69.4±19.8	79.2±18.1	53.3±13.9
P[a]		0,175	0.194	0.992	0.864	0.714	0.274	0.415
Getting exhausted quickly	Yes	73.3±12.8	79.6±16.7	77.0±14.2	66.9±19.9	72.2±17.6	77.9±19.2	55.9±12.6
	No	77.4±15.7	82.4±16.9	74.5±18.9	71.3±20.5	66.9±21.1	77.5±19.3	51.6±14.5
P[a]	0,197	0.518	0.561	0.402	0.285	0.937	0.224	
Palp-itation	Yes	68.8±18.9	77.5±17.2	69.3±19.9	66.9±23.9	69.4±21.3	71.3±20.9	45.0±16.1
	No	76.6±13.1	81.5±16.7	77.2±15.6	69.2±19.5	69.9±19.0	79.0±18.7	55.8±12.4
P[a]		0.179	0.493	0.170	0.737	0.929	0.241	0.020

[a]Student's t-test

Table 2. Relationship between quality of life dimension scores of the children and psychological symptoms [a]

	KINDL boyutları						
Psychological symptom levels	**Total**	**Physical well-being**	**Emotional well-being**	**Self-esteem**	**Family**	**Friendship**	**School**
SDQ total score (child)	-0.553[b]	-0.467[b]	-0.426[b]	-0.348[b]	-0.216	-0.429[b]	-0.029
HAD-A (mother)	-0.277[c]	-0.345[b]	-0.241	-0.190	-0.106	-0.152	0.173
HAD-D (mother)	-0.278[c]	-0.171	-0.070	-0.212	-0.009	0.034	0.045

[a]Pearson Correlation; [b]p<0.01 [c]p<0.05

SDQ: strength and difficulties questionnaire; HAD-A: hospital anxiety depression scale–anxiety subscale; HAD-D: hospital anxiety depression scale–depression subscale; KINDL: Quality of Life Questionnaire for Children

Table 3. Relationship between quality of life scores of children and PARI subdimensions[a]

	KINDL dimensions						
PARI dimensions	**Total QoL**	**Physical well-being**	**Emotional well-being**	**Self-esteem**	**Family**	**Friend-ship**	**School**
Over parenting	-0.220b	-0.237	-0.396c	0.377b	-0.217	-0.191	-0.121
Democratic attitude and equality	0.151	-0.114	-0.130	-0.018	-0.171	0.020	-0.036
attitude of hostility and rejection	-0.143	-0.326b	-0.326b	-0.378b	-0.298b	-0.165	0.037
Marital discordance	0.015	0.119	0.074	-0.145	-0.176	-0.060	-0.079
authoritarian attitude	-0.336c	-0.187	-0.323b	-0.408c	-0.327b	-0.277b	-0.062

[a]Pearson correlation; [b]p<0.05; [c]p<0.01

KINDL: Quality of Life Questionnaire for Children; PARI: Parental Attitude Research Instrument; QoL: quality of life

parental attitudes of applying authoritarian attitude., increased psychological symptom levels in children, and symptoms of dyspnea (p<0.05).

Discussion

In this study, the effect of psychosocial factors and disease-related variables on QoL of children with CHD was evaluated. When the QoL scores of the children with - CHD were evaluated in our study, it was observed that these children had poorer QoL in terms of total QoL and emotional well-being and self-esteem subdimensions in presence of cyanotic CHD. In a study conducted in Portugal, it was reported that QoL perception was better in adolescents and young adults with CHD compared with a healthy community sample, but poorer in cyanotic patients, in patients who underwent surgery, and in patients who had physical limitations (16). Tahirovic et al. (17) grouped 114 children according to the severity of CHD and found that QoL perception was poorer in children with cyanotic heart disease compared with children who had left-to-right shunt anomalies and obstructive anomalies. Freitas et al. (18) reported that QoL was affected negatively in children who had cyanotic CHD and a history of surgery. It was thought that this could be related with severe symptoms, a higher number of operations, a higher rate of drug use, and limitations in daily life in cyanotic CHD. Latal et al. (19) showed that QoL was disrupted in children and adolescents who underwent cardiac surgery, especially in the presence of complex CHD. Janiec et al. (20) showed that the frequency of clinical symptoms had a greater impact on QoL in their study in which QoL was examined in patients with mitral valve prolapsus using KIDSCREEN. In studies by Landolt et al. (21) and Spijkerboer et al. (22) in which similar measurements were used, it was shown that QoL in terms of motor, cognitive, social, and emotional functions became poorer in children and adolescents following cardiac surgery and/or invasive treatment for CHD by way of catheterization compared with healthy children. Another notable finding of that study was that disease-related variables had no significant effect on the physical QoL subdimension and affected psychosocial dimensions. It was thought that challenging treatment processes and disease-related limitations caused this situation, though present treatments (surgical and medical) caused improvement in clinical symptoms.

In the present study, QoL total score and physical well-being, emotional well-being, self-esteem, and friendship scores were found to be decreased with an increase in psychological symptom levels, and it was also found that psychological symptom levels significantly affected dimension scores in multivariable models. Studies have reported that psychological symptoms were found with a

Table 4. Final models of the variables affecting quality of life in children reduced with multilinear regression

KINDL dimensions		B	Std B	p
Total quality of life	Constant	107.480		<0.001
	Type of congenital disease	5.412	0.189	0.034
	Dyspnea	-14.887	-0.227	0.011
	SDQ total score	-1.105	-0.431	0.000
	authoritarian attitude	-0.571	-0.282	0.002
	R2=0.459 p<0.0001			
Physical well-being	Constant	99.565		<0.001
	SDQ total score	-1.021	-0.404	0.001
	HAD-A	-1.994	-0.237	0.046
	R2=0.270 p<0.0001			
Emotional well-being	Constant	136.167		<0.001
	Over parenting	-1.141	-0.364	0.001
	SDQ total score			
	Type of congenital disease	-1.240	-0.406	0.000
		8.257	0.252	0.018
	R2=0.403 p<0.0001			
Self-esteem	Constant	146.082		<0.001
	SDQ total score	-1.084	-0.290	0.009
	Over perenting	-1.529	-0.398	0.001
	Type of congenital disease			
	Dyspnea	9.621	0.240	0.030
		-18.125	-0.225	0.047
	R2=0.381 p<0.0001			
Family	Constant	115.741		<0.001
	authoritarian attitude	-0.949	-0.327	0.010
	R2=0.107 p<0.010			
Friendship	Constant	121.483		<0.001
	authoritarian attitude	-0.889	-0.312	0.003
	SDQ total score			
	Dyspnea	-1.248	-0.351	0.001
		-27.723	-0.363	0.001
	R2=0.445 p<0.0001			
School	Constant	55.760		<0.001
	Palpitation	-10.760	-0.297	0.020
	R2=0.088 p=0.020			

SDQ: strengths and difficulties questionnaire; HAD-A: hospital anxiety depression scale–anxiety subscale; KINDL: Quality of Life Questionnaire for Children

higher rate in children with CHD compared with healthy children and the presence of psychological symptoms affected QoL negatively (23-28). In the study by Müller et al. (29) in which 767 patients with CHD were evaluated, the prevalence of depression was found as 6.6% and symptoms of depression affected QoL at a higher level compared with limited exercise capacity. The results of our study are also compatible with the literature. It is especially notable that the physical QoL dimension was affected by psychological symptoms belonging to the child and mother rather than disease-related variables. It has been reported that treatment compatibility was disrupted, symptoms were reflected with a higher rate, the prognosis was poorer, and rates of outpatient referrals and hospitalizations were higher in conditions where psychological disorders accompanied in individuals with physical illness (30-32). In the treatment guidelines published by the American Society of Cardiology in 2008, it was recommended that psychiatric disorders should be screened in patients with CHD (33). It has been shown that physical health outcomes were affected positively and hospital referrals decreased with evaluation of these patients in terms of psychological health and with adjustment of treatment, if necessary (34).

Over parenting encompasses issues including excessive anxiety, control, intrusiveness, and demanding the child to be dependent. Excessively protective parents are anxious, they have difficulty in separating and do not support their children's independent behaviors. High scores obtained in the attitude of hostility and rejection dimension indicate that the mother is unsatisfied, strained, and displeased in terms of the issues related with the care of the child. The authoritarian attitude dimension includes items that encompass issues including believing in stern discipline, forcing the child, and believing in absolute parental domination (35). Luyckx et al. (36) reported that symptoms of depression increased and QoL decreased in children in the presence of parental attitudes that applied pressure and discipline and in the presence of increased psychological control. In this study, QoL subdimension scores were affected negatively in the children of parents who reported higher scores in the subscales of overprotectiveness, authoritarian attitude, andattitude of hostility and rejection. It is notable that the child's QoL decreased as parental dissatisfaction and displeasure related with the child's care increased. As a result of multivariate analyses, it was found that overprotective motherhood behavior significantly decreased QoL score in emotional well-being and self-esteem subdimensions and parental behaviors that applied authoritarian attitude significantly decreased QoL scores in friendship and family subdimensions. Our study is also compatible with the literature. Studies have reported that parents of children with chronic diseases behaved overprotectively, they were less close and less warm in their relationships with their children, and the severity level of the chronic disease had an effective role in the more protective and controlling behavior of parents (37-39). It was found that behavioral problems of children decreased and compatibility behaviors increased and even QoL of both children and families increased and parental anxiety decreased when more efficient parenting was practiced (40).

In conclusion, QoL is a very complex phenomenon in which many factors are involved. Therefore, it requires multi-directional analyses. Assessment of QoL of children with CHD will provide valuable information for defining risk groups and elaborating intervention tactics that focus on their health requirements. These assessments will be directive for objectives including planning of new health policies, social and psychological support, selection of individually appropriate interventions, decreasing hospitalization periods and treatment costs, and bringing patients and their relatives into the labor force thereby increasing their productivity. Therefore, more studies need to be conducted.

Ethics Committee Approval: Ethics committee approval was received for this study from the local ethics committee of Faculty of Medicine, Celal Bayar University (2015- 337).

Informed Consent: Written informed consent was obtained from the parents of the patients who participated in this study.

Peer-review: Externally peer-reviewed

Author Contributions: Concept - F.A., T.S.; Design - T.S., Ş.Y.S.; Supervision - Ş.C., E.E.; Funding - T.S.; Materials - F.A., T.S.; Data Collection and/or Processing - F.A., T.S.; Analysis and/or Interpretation - E.E., Ş.YS.; Literature Review - F.A., T.S.; Writing - F.A.; Critical Review - E.E., Ş.C.

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study has received no financial support.

References

1. Üneri Ö, Memik Çakın N. Çocuklarda yaşam kalitesi kavramı ve yaşam kalitesi ölçeklerinin gözden geçirilmesi. Çocuk ve Gençlik Ruh Sağlığı Dergisi 2007; 14: 48-56.
2. Van Der Linde D, Konings EE, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. J Am Coll Cardiol 2011; 58: 2241-7. [CrossRef]
3. Huber J, Peres VC, Santos TJ, et al. Congenital heart diseases in a reference service: clinical evolution and associated illnesses. Arq Bras Cardiol 2010; 94: 313-8.
4. Mellion K, Uzark K, Cassedy A, et al. Health-related quality of life outcomes in children and adolescents with congenital heart disease. J Pediatr 2014; 164: 781-9. [CrossRef]
5. Uzark K, Jones K, Slusher J, Limbers CA, Burwinkle TM, Varni JW. Quality of life in children with heart disease as perceived by children and parents. Pediatrics 2008; 121: e1060-7. [CrossRef]

6. Teixeira FM, Coelho RM, Proenca C, et al. Quality of life experienced by adolescents and young adults with congenital heart disease. Pediatr Cardiol 2011; 32: 1132-8. [CrossRef]
7. Culbert EL, Ashburn DA, Cullen-Dean G, et al. Congenital Heart Surgeons Society Quality of life of children after repair of transposition of the great arteries. Circulation 2003; 108: 857-62. [CrossRef]
8. Eser E, Yüksel H, Baydur H, ve ark. KID-KINDL yaşam kalitesi ölçeği çocuk formu Türkçe sürümü geçerlilik ve güvenirlik sonuçları. (Poster Bildiri). 1. Sağlıkta Yaşam Kalitesi Sempozyumu Program ve Özet Kitabı, 2004.p.79.
9. Eser E, Yüksel H, Baydur H, ve ark. KIDDOKINDL (KINDL ergen formu) yaşam kalitesi ölçeği Türkçe sürümü geçerlilik ve güvenirlik sonuçları. (Poster Bildiri). 1. Sağlıkta Yaşam Kalitesi Sempozyumu Program ve Özet Kitabı, 2004.p.78.
10. Goodman R. The strengths and difficulties questionnaire: a research note. J Child Psychol Psychiatry 1997; 38: 581-6. [CrossRef]
11. Yalın Ş, Özbek A, Güvenir T, ve ark. Tükçe güçler ve güçlükler anketinin ileri psikometrik özellikleri. Çocuk ve Gençlik Ruh Sağlığı Dergisi 2013; 20: 23-32.
12. Le Comple G, Le Compte A, Özer S. Üç sosyo-ekonomik düzeyde, Ankaralı annelerin çocuk yetiştirme tutumları: Bir ölçek uyarlaması. Psikoloji dergisi 1978; 1: 5-8.
13. Öner N. Türkiye'de kullanılan psikolojik testler. İstanbul: Boğaziçi Üniv. Yayınları 1994; 3: 538-42.
14. Zigmond AS, Snaith PR. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983; 67: 361-70. [CrossRef]
15. Aydemir Ö, Güvenir T, Küey L, Kültür S. Hastane Anksiyete ve Depresyon Ölçeği Türkçe formunun geçerlilik ve güvenilirliği. Türk Psikiyatri Dergisi 1997; 8: 280-7.
16. Areias ME, Pinto CI, Vieira PF, et al. Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults. Transl Pediatr 2013; 2: 90-8.
17. Tahirović E, Begić H, Nurkić M, Tahirović H, Varni JW. Does the severity of congenital heart defects affect disease-specific health-related quality of life in children in Bosnia and Herzegovina? Eur J Pediatr 2010; 169: 349-53. [CrossRef]
18. Freitas IR, Castro M, Sarmento SL, et al. A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease. BMJ Open 2013; 3: e001138. [CrossRef]
19. Latal B, Helfricht S, Fischer JE, Bauersfeld U, Landolt MA. 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. [CrossRef]
20. Janiec I, Werner B, Sieminska J, Ravens-Sieberer U. Quality of life of children with mitral valve prolapse. Qual Life Res 2011; 20: 537-41. [CrossRef]
21. Landolt MA, Valsangiacomo Buechel ER, Latal B. Health-related quality of life in children and adolescents after open-heart surgery. J Pediatr 2008; 152: 349-55. [CrossRef]
22. Spijkerboer AW, Utens EM, De Koning WB, Bogers AJ, Helbing WA, Verhulst FC. Health-related quality of life in children and adolescents after invasive treatment for congenital heart disease. Qual Life Res 2006; 15: 663-73. [CrossRef]
23. Utens EM, Verhulst FC, Meijboom FJ, et al. Behavioural and emotional problems in children and adolescents with congenital heart disease. Psychol Med 1993; 23: 415-24. [CrossRef]
24. Gupta S, Giuffre RM, Crawford S, Waters J. Covert fears, anxiety and depression in congenital heart disease. Cardiol Young 1998; 8: 491-9. [CrossRef]
25. Fredriksen PM, Mengshoel AM, Frydenlund A, Sørbye Ø, Thaulow E. Follow-up in patients with congenital cardiac disease more complex than haemodynamic assessment. Cardiol Young 2004; 14: 373-9. [CrossRef]
26. Luyckx K, Goossens E, Rassart J, Apers S, Vanhalst J, Moons P. Parental support, internalizing symptoms, perceived health status and quality of life in adolescents with congenital heart disease: influences and reciprocal effects. J Behav Med 2014; 37: 145-55. [CrossRef]
27. Wang Q, Hay M, Clarke D, Menahem S. Associations between knowledge of disease, depression and anxiety, social support, sense of coherence and optimism with health-related quality of life in an ambulatory sample of adolescents with heart disease. Cardiol Young 2014; 24: 126-33. [CrossRef]
28. Drakouli M, Petsios K, Giannakopoulou M, Patiraki E, Voutoufianaki I, Matziou V. Determinants of quality of life in children and adolescents with CHD: a systematic review. Cardiol Young 2015; 25: 1027-36. [CrossRef]
29. Müller J, Hess J, Hager A. Minor symptoms of depression in patients with congenital heart disease have a larger impact on quality of life than limited exercise capacity. Int J Cardiol 2012; 154: 265-9. [CrossRef]
30. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. Arch Intern Med 2000; 160: 2101-27. [CrossRef]
31. Whooley MA, de Jonge P, Vittinghoff E, et al. Depressive symptoms, health behaviors, and risk of cardiovascular events in patients with coronary heart disease. JAMA 2008; 300: 2379-88. [CrossRef]
32. Vamos EP, Mucsi I, Keszei A, Kopp MS, Novak M. Comorbid depression is associated with increased healthcare utilization and lost productivity in persons with diabetes: a large nationally representative Hungarian population survey. Psychosom Med 2009; 71: 501-7. [CrossRef]
33. Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital

heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines. Circulation 2008; 118: e714-e833. [CrossRef]

34. Katon W, Russo J, Lin EH, et al. Costeffectiveness of a multicondition collaborative care intervention: a randomized controlled trial. Arch Gen Psychiatry 2012; 69: 506-14. [CrossRef]
35. Kucuk S. The validity of The Turkish form of PARI subscales. Doktora Tezi, Boğazici Universitesi İstanbul; 1987.
36. Luyckx K, Goossens E, Missotten L, Moons P, i-DETACH investigators adolescents with congenital heart disease: the ımportance of perceived parenting for psychosocial and health outcomes. J Dev Behav Pediatr 2001; 32: 651-9. [CrossRef]
37. Pinquart M. Do the parent–child relationship and parenting behaviors differ between families with a child with and without chronic ıllness? A meta-analysis. J Pediatr Psychol 2013; 38: 708-21. [CrossRef]
38. Holmbeck G, Johnson SZ, Wills KE, et al. Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: the mediational role of behavioral autonomy. J Consult Clin Psychol 2002: 70; 96-110. [CrossRef]
39. Power TG, Dahlquist LM, Thompson SM, Warren R. Interactions between children with juvenile rheumatoid arthritis and their mothers. J Pediatr Psychol 2003; 28: 213-21. [CrossRef]
40. Morawska A, Calam R, Fraser J. Parenting interventions for childhood chronic illness: a review and recommendations for intervention design and delivery. J Child Health Care 2015; 19: 5-17.[CrossRef]