Cardiology in the Young

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Assessment of quality of life and psychosocial problems in children with Congenital Heart Disease

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Abstract

Objective: Congenital heart disease (CHD) is a condition that can significantly impact health-related quality of life due to the need for long-term follow-up and treatment. The purpose of this study was to analyse the quality of life of children diagnosed with CHD and to assess the relationship between the disease and their physical and mental well-being. *Materials and Methods:* The study involved 180 patients and 180 healthy controls. Both groups were divided into three age categories (5–7 years, 8–12 years, and 13–18 years), with 60 children in each age group. The researchers administered the Pediatric Quality of Life Inventory (PedsQL) to the participants, taking into account their age. *Results:* Comparisons between the patient and control groups showed that the patient group had significantly lower scores than the control group in terms of total quality of life scale score, physical health score, and psychosocial health score of the Pediatric Quality of Life Inventory ($p < 0.001$, $p < 0.001$, and $p < 0.001$). Quality of life was also compared between patients receiving and not receiving medication treatment. Patients receiving medication treatment had lower scores for total quality of life score, physical health score, and psychosocial health score of the Pediatric Quality of Life Inventory compared to the control group ($p < 0.001$, $p = 0.005$, and $p < 0.001$). *Conclusion:* Children with CHD experience a negative impact on their quality of life. Given the extended life expectancy resulting from new treatment options, it is important to monitor these children both physically and psychosocially and to implement activities aimed at improving their quality of life.

Introduction

The World Health Organisation defines health as encompassing not only physical well-being but also mental and social well-being.[1] This definition highlights the significance of the concept of quality of life. Quality of life is defined as an individual's perception of their own situation within their culture and system of values.[2] The term quality of life was first mentioned in Long's article "On the Quantity and Quality of Life" published in 1960.[3] The term quality of life related to health first emerged in the 1990s.[4] This term evaluates the impact of the disease and its treatment on the patient from the patient's point of view.[5]

Congenital heart disease is a group of structural and functional heart pathologies that result from abnormal heart development during the prenatal period. The prevalence of CHD is reported to be 0.8% in all live births.[6] The definition of CHD encompasses a range of pathologies, whose severity is dependent on the location and size of the cardiac defect. This variability in severity results in different symptoms in children. Many patients with mild to moderate CHD are asymptomatic. In patients with severe and especially cyanotic CHD may experience reduced ability to perform daily activities, increased frequency of hospitalisations, and daily medications. These symptoms may affect the quality of life especially in children with severe CHD. In recent years, life expectancy for adolescents and children with CHD has increased due to advances in interventional cardiology and cardiac surgery. It is also important to assess the quality of life of these patients, as they grow up and become more aware of their condition.[7–8]

In a study conducted at a single centre, 347 children with cardiovascular disease were compared to 478 healthy children. The study found that the quality of life of children with cardiovascular disease was significantly lower than that of healthy children.[9] Another study examined the relationship between CHD diagnosis severity and health-related quality of life outcomes in children diagnosed with CHD. The Pediatric Cardiac Quality of Life Inventory was used in the study by including 1482 patients and their parents between the ages of 8–18. Study results found that increased CHD severity was associated with higher disease burden and worse patient- and parent-reported health-related quality of life outcomes.[10] In the literature, there are various studies showing that the quality of life in children diagnosed with CHD is significantly lower than healthy children.[11–12]

Limited data exist in Turkey evaluating the quality of life of children diagnosed with CHD. Previous studies have focused solely on the physical sequelae caused by the disease, without evaluating its impact on quality of life. This study, to the best of our knowledge, is the first in Turkey to evaluate the quality of life of children diagnosed with CHD using a large patient population. In this study, we aimed to see what effect CHDs have on the quality of life in children between the ages of 5–18.

Material and method

Study characteristics and patient selection

The study included children and their families who presented to the pediatric cardiology outpatient clinic of our hospital between 1 July, 2018 and 31 March, 2019. The patient group of the study consisted of patients diagnosed with CHD. All patients underwent echocardiography and were evaluated by a pediatric cardiologist, in addition to clinical symptoms and physical examination findings, to confirm the diagnosis of CHD based on the detection of cardiac pathology. The study included patients between the ages of 5 and 18 who had been diagnosed with CHD. Patients with psychiatric comorbidity, a history of other medical or neurological diseases, alcohol or substance abuse and those aged 0–4 years were excluded. The families included in the study were required to meet specific criteria. They had to be the primary caregivers of the patient, without any organic or systemic disease affecting personality or mental status, no alcohol or substance abuse and no history of active psychotic disorder.

The control group of the study was randomly selected among children who presented to the healthy children follow-up outpatient clinic of our hospital and did not have any known chronic or cardiac disease. The purpose of our study was explained to the families who applied to the healthy child clinic. Families who wanted to participate in our study signed the informed voluntary consent form. Children underwent echocardiography only as part of the study procedures. Children without any pathological findings on echocardiography were included in the control group.

Study sample

The study was designed as a cross-sectional study. Patients and their families were informed about the study, and those who provided voluntary consent were included. Thirty-four families were excluded from the study for not providing informed consent. The patient group (n = 180) consisted of children diagnosed with CHD, while the control group (n = 180) consisted of children who attended the outpatient clinic for healthy children and had no pathology detected after echocardiography. The study aimed to include a large number of patients and was terminated once the number of patients and control group were equalised.

The study categorised patient and control groups into three age groups: 5–7 years, 8–12 years, and 13–18 years, with 60 children in each group. Quality of life was assessed using the Pediatric Quality of Life Inventory scale for young children (5–7 years), children (8–12 years), and adolescents (13–18 years). The questionnaires were administered on the day of the echocardiography. If children under the age of 7 experience difficulty reading and comprehending the Pediatric Quality of Life Inventory form, they may receive assistance from their parents.

Pediatric Quality of Life Inventory

Pediatric Quality of Life Inventory is a scale developed by Varni *et al.* in 1999 to measure the health-related quality of life of children and adolescents aged 2–18 years. It comprises four sub-forms: physical health, emotional functioning, social functioning, and school functioning. Scoring is performed in three areas. The scale calculates three total scores: the overall score, the physical health score, and the psychosocial health score which evaluates emotional, social, and school functioning. The scale is evaluated out of 100, with a higher score indicating a better perceived health-related quality of life.

Statistical analysis

The data were evaluated in the statistical package program IBM SPSS Statistics 25.0 (IBM Corp., Armonk, New York, USA). The normal distribution of the data of numerical variables was evaluated with the Shapiro–Wilk normality test and *Q-Q* graphs. Categorical variables were given as frequency and percentage. Descriptive statistics are given as mean ± standard deviation and median (interquartile range) values. Mann–Whitney *U* test was used to compare two independent groups of continuous variables for which the assumption of normal distribution was not met.

The Mann–Whitney *U* test was used to compare two independent groups of continuous variables where the assumption of normal distribution was not met, and the Kruskal–Wallis test was used for comparisons of more than two independent groups. In case of a difference as a result of the Kruskal–Wallis analysis, the Dunn–Bonferroni test was used as a multiple comparison test. The relationship between categorical variables was evaluated with the continuity correction test in *2* x *2* tables and the Pearson Chi-square test in *r* x *c* tables. A value of $p < 0.05$ was considered statistically significant.

Results

Socio-demographic and group characteristics

The study included 360 children. The number of male (n = 178 % 49.4) and female (n = 182 %50.6) participants in our study was similar. Gender distribution was not significantly different between the patient and control groups ($p > 0.05$). The data indicate that mothers were the most common caregivers in both the CHD cases (n = 91 %50.6) and control groups (n = 82 %45.6). The educational status of the caregivers was analysed, and a significant difference was observed between the patient and control groups ($p = 0.002$). A significant difference was found in the comparison between the patient and control groups in the non-student and literate groups ($p < 0.05$). There was no significant difference between the patient and control groups in caregivers whose

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Table 1. Demographic and characteristics of the patient and control groups

	Groups		
	Control	Patient	*p* value
Variables	*n* (%)	*n* (%)	
Gender			0.527[+]
Female	88 (48.9)	94 (52.2)	
Male	92 (51.1)	86 (47.8)	
Caregiver closeness			0.615[+]
Mother	82 (45.6)	91 (50.6)	
Father	70 (38.9)	62 (34.4)	
Others	28 (15.6)	27 (15.0)	
Caregiver education level			**0.002**[+]
Non-student	12 (6.7)[a]	32 (17.8)[b]	
Literate	26 (14.4)[a]	13 (7.2)[b]	
Primary school	49 (27.2)[a]	64 (35.6)[a]	
Middle school	25 (13.9)[a]	24 (13.3)[a]	
High school	39 (21.7)[a]	26 (14.4)[a]	
University	29 (16.1)[a]	21 (11.7)[a]	
Mother's working status			0.213*
Working	16 (8.9)	9 (5.0)	
Not working	164 (91.1)	171 (95.0)	
Father's working status			0.325[+]
Working	146 (81.1)	153 (85.0)	
Not working	34 (18.9)	27 (15.0)	

Superscripts *a* and *b* indicate the difference between groups distributions in the same caregiver education levels. The distributions of the same letter are similar.
[+] Pearson Chi-square test.
* Continuity correction test.

Table 2. Characteristics of the patient group

Variables	*n* (%)
Age at CHD diagnosis (day)	
0-30	60 (33.3)
30-365	43 (23.9)
>365	77 (42.8)
ECHO findings	
Mild CHD not requiring treatment	82 (45.6)
CHD to which curative treatment applied	29 (16.1)
Mild residual CHD after treatment	25 (13.9)
Moderate residual CHD after treatment	15 (8.3)
Severe CHD that cannot be fully corrected	29 (16.1)
Receiving medication treatment	
Yes	128 (71.1)
No	52 (28.9)

CHD = congenital heart disease; ECHO = echocardiography.

Table 3. Comparison of PedsQL and sub-dimension scores according to the medical treatment status

	Not receiving medication treatment ($n = 128$)	Receiving medication treatment ($n = 52$)	
Scales	*Mean* ± *SD* or *Median* (*IQR*)	*Mean* ± *SD* or *Median* (*IQR*)	*p* value[+]
PedsQL total	74.74 ± 14.66 76.09 (19.57)	62.37 ± 18.68 60.87 (25.00)	<**0.001**
Physical health	73.31 ± 19.22 75.00 (25.00)	61.42 ± 25.56 62.50 (41.41)	**0.005**
Psychosocial health	75.49 ± 16.06 79.17 (21.67)	62.88 ± 20.39 63.33 (30.83)	<**0.001**

SD = standard deviation; IQR = interquartile range; PedsQL = Pediatric Quality of Life Inventory.
[+] Mann–Whitney *U* test.

educational level was primary school, secondary school, high school, and university ($p > 0.05$). Fathers were the most common working parents in both patient and control groups (Table 1).

Patients' demographics

No significant difference was found in total quality of life scale score, physical health scale score, and psychosocial health scale scores in the comparison made according to gender in the patient group ($p > 0.05$). One-third of the patients were diagnosed with CHD in the neonatal period. In children in the CHD group, the many common finding on echocardiography was mild CHD not requiring treatment (45.6%). The group with moderate residual CHD after treatment constituted the smallest number of CHD cases according to echocardiography findings (8.3%) (Table 2).

Most patients were not receiving medication treatment (71.1%). In total, 52 patients received drug treatment for CHD (%28.9) (Table 2). Among those who received medication treatment, the majority (57.7%) received multiple cardiac medications.

The study compared the quality of life of patients who received medication treatment with those who did not. The Pediatric Quality of Life Inventory total scale score was lower in patients who receive medication treatment. There was a significant difference in Pediatric Quality of Life Inventory total scale score ($p < 0.001$), physical health total score ($p = 0.005$), and psychosocial health total score ($p < 0.001$) compared to the control group in the medication group (Table 3).

Among patients diagnosed with CHD, those with multiple pathologies (n = 80, 44.4%) were the many common. In patients diagnosed with CHD with a single pathology, atrial septal defect (n = 33, 19.4%) was the many common, followed by ventricular septal defect (n = 10, 5.6%), mitral regurgitation (n = 10, 5.6%), and tetralogy of Fallot (n = 10, 5.6%). All patients diagnosed with CHD with multiple pathologies had atrial septal defect.

Comparison of patients and controls Pediatric Quality of Life Inventory scores

The study compared the quality of life scale scores of the patient and control groups. The patient group had a significantly lower Pediatric Quality of Life Inventory total scale score ($p < 0.001$), physical health total score ($p < 0.001$), and psychosocial health total score ($p < 0.001$) compared to the control group (Table 4).

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Table 4. Comparisons of the PedsQL total score, physical health, and psychosocial health scores of the patient and the control group

	Groups		
	Control ($n = 180$)	Patient ($n = 180$)	
Variables	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*p* value[+]
PedsQL total score	81.56 ± 12.74 83.69 (16.30)	71.16 ± 16.84 73.37 (24.46)	<**0.001**
Physical health score	82.29 ± 16.04 87.50 (21.09)	69.88 ± 21.85 68.75 (31.25)	<**0.001**
Psychosocial health score	81.17 ± 13.32 83.33 (16.67)	71.85 ± 18.28 75.00 (23.33)	<**0.001**

SD = standard deviation; IQR = interquartile range; PedsQL = Pediatric Quality of Life Inventory.
[+] Mann–Whitney *U* test.

Table 5. Comparison results of scale scores according to six age groups

	Groups						
	Patient ($n = 180$)			Control ($n = 180$)			
	5-7 years ($n = 60$)[1]	8-12 years ($n = 60$)[2]	13-18 years ($n = 60$)[3]	5-7 years ($n = 60$)[4]	8-12 years ($n = 60$)[5]	13-18 years ($n = 60$)[6]	
Scales	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*Mean ± SD* or *Median (IQR)*	*p* value[+]
PedsQL total	70.96 ± 17.40 73.91 (23.37)^{a}	72.63 ± 14.97 73.91 (25.92)^{a}	69.91 ± 18.15 71.74 (24.46)^{a}	83.93 ± 11.70 84.78 (19.57)^{b}	79.00 ± 14.15 81.52 (20.65)$^{a, b}$	81.76 ± 11.96 84.78 (13.04)^{b}	<**0,001**
Physical health	73.02 ± 21.66 75.00 (31.25)$^{a, b}$	69.48 ± 21.43 73.44 (21.43)^{a}	67.13 ± 22.40 65.62 (37.50)^{a}	85.41 ± 15.03 87.50 (18.75)^{c}	78.12 ± 16.06 81.25 (21.88)$^{a, b, c}$	83.33 ± 16.38 89.06 (20.31)$^{b, c}$	<**0,001**
Psychosocial health	69.86 ± 20.14 70.00 (33.33)^{a}	74.30 ± 14.97 75.83 (18.33)$^{a, b}$	71.39 ± 19.33 75.83 (26.67)$^{a, b}$	83.14 ± 13.91 86.67 (20.00)^{c}	79.47 ± 14.33 83.33 (21.25)$^{a, b, c}$	80.92 ± 11.51 83.33 (16.25)$^{b, c}$	<**0,001**

SD = standard deviation; IQR = interquartile range; PedsQL = Pediatric Quality of Life Inventory.
Superscripts a, b, and c indicate the difference between groups distributions. The distributions of the same letter are similar.
[+] Independent-samples Kruskal–Wallis test.

The results of comparing the scale scores according to six age groups are given in Table 5. When the pairwise comparison results for Pediatric Quality of Life Inventory total scale score are examined, the same age control group as the 13–18 years age patient group ($p = 0.002$), 5–7 years age control group ($p < 0.001$); 5–7 years age patient group and 13–18 years age control group ($p = 0.004$), 5–7 years age control group ($p < 0.001$); 8–12 years age patient group, 13–18 years age control group ($p = 0.010$), and 5–7 years age control group ($p < 0.001$). For the physical health sub-dimension, the 13–18 years age patient group and the same age control group ($p < 0.001$), the 5–7 years age control group ($p < 0.001$); 8–12 years age patient group and 5–7 years age control group ($p < 0.001$); 5–7 years age control group and the 5–7 years age patient group ($p = 0.014$). For the psychosocial health sub-dimension, 5–7 years age patient group and 13–18 years age control group ($p = 0.05$), 5–7 years age control group ($p < 0.001$); 13–18 years age patient group and 5–7 years age control group ($p = 0.004$); 8–12 years age patient group and the 5–7 years age control group ($p = 0.013$). A statistically significant difference was found between their distributions. In the six-group comparison, it was observed that the group with the lowest Pediatric Quality of Life Inventory total scale score and physical health score was the 13–18-year-old patient group (Table 5). In the six-group comparison, the psychosocial health score was lowest in the 5–7-year-old patient group (Table 5).

Pairwise comparison analyses were conducted between the patient and control groups based on age groups. A significant difference was observed in the Pediatric Quality of Life Inventory total scale score for the 5–7 years ($p < 0.001$), 8–12 years ($p = 0.017$), and 13–18 years ($p < 0.001$) age groups. When analysing the physical health score, a significant difference was found in the 5–7 age ($p < 0.001$), 8–12 age group ($p = 0.038$), and 13–18 age ($p < 0.001$) groups. A significant difference in the score of psychosocial health was found in the 5–7 years ($p < 0.001$), 8–12 age group ($p = 0.041$), and 13–18 years ($p < 0.010$) age groups (Table 6).

Discussion

In recent years, advances in surgical and interventional treatment methods for CHDs have significantly increased the life expectancy and quality of life in these patients. However, there is a need to minimise the long-term complications caused by treated CHD and their impact on quality of life. This study revealed that the total scale score, physical health total score, and psychosocial health total score were significantly lower in the patient group than in healthy controls. Although most of the children with CHD included in our study were asymptomatic, it is also important that the scale scores were low.

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Table 6. Comparison of PedsQL and sub-dimension scores in 5–7 years, 8–12 years and 13–18 years age groups compared to patient control groups

		Control ($n = 60$)	Patient ($n = 60$)	
		Mean ± *SD* or *Median* (*IQR*)	*Mean* ± *SD* or *Median* (*IQR*)	*p* value[+]
Scales				
PedsQL total	5–7 years	83.93 ± 11.70 84.78 (19.57)	70.96 ± 17.40 73.91 (23.37)	**<0.001**
	8–12 years	79.00 ± 14.15 81.52 (20.65)	72.63 ± 14.96 73.91 (25.82)	**0.017**
	13–18 years	81.75 ± 11.96 84.78 (13.04)	69.91 ± 18.15 71.74 (24.46)	**<0.001**
Physical health	5–7 years	85.42 ± 15.03 87.50 (18.75)	73.02 ± 21.66 75.00 (31.25)	**0.001**
	8–12 years	78.12 ± 16.06 81.25 (21.88)	69.48 ± 21.43 73.44 (31.25)	**0.038**
	13–18 years	83.33 ± 16.38 89.06 (20.31)	67.13 ± 22.40 65.62 (37.50)	**<0.001**
Psychosocial health	5–7 years	83.14 ± 13.91 86.67 (20.00)	69.86 ± 20.14 70.00 (33.33)	**<0.001**
	8–12 years	79.47 ± 14.33 83.33 (21.25)	74.30 ± 14.97 75.83 (18.33)	**0.041**
	13–18 years	80.92 ± 11.51 83.33 (16.25)	71.39 ± 19.33 75.83 (26.67)	**0.010**

SD = standard deviation; IQR = interquartile range; PedsQL = Pediatric Quality of Life Inventory.
[+] Mann–Whitney *U* test.

Assessment of quality of life in children and adolescents with CHD is important to identify patients at risk. Various data collection methods are used in the assessment of quality of life. Among these, one of the most accepted in terms of validity and reliability is the Pediatric Quality of Life Inventory scale.[13] There are various studies in the literature using Pediatric Quality of Life Inventory.[14–17] Examination of Pediatric Quality of Life Inventory scores in children diagnosed with CHD is a guide in the evaluation of the quality of life in children with the disease. Gao *et al.*[18] conducted a study to evaluate the quality of life in children with chronic diseases, including CHDs. The study included 651 children aged between 2 and 18 years, diagnosed with 11 chronic diseases, including patent ductus arteriosus (n = 40). The patients diagnosed with patent ductus arteriosus had the lowest physical health total score among all children. The situation highlighted the necessity for a comprehensive assessment of the quality of life of children diagnosed with CHD, using a variety of data collection methods.

In a study by Moure *et al.*,[19] 317 patients aged 6-18 years were evaluated using KINDL. At the beginning of the study, the quality of life scores of older children with CHD was significantly lower, but reassessments made during the 2-year follow-up showed that the scores changed for the better over time. This situation reveals that patients should be re-evaluated in terms of quality of life not only at the time of admission but also at regular intervals as long as their follow-up continues.

In a study by Berkes *et al.*,[20] 195 patients aged 5–18 years and 373 healthy controls aged 5–18 years were evaluated. Similar to our findings, the physical health total score of children with cardiological disease was significantly lower than healthy controls. Different from our findings, the total scale score and psychosocial health total score of the patients in this study were found to be similar to those of the controls. However, the questionnaire used to evaluate the participants in this study was not analysed under outpatient clinic conditions, unlike our study. Instead, it was delivered to them by mail.

In a study conducted by Amodeo *et al.*[21] in Italy, 498 patients aged 2–18 years were included in the study using the Pediatric Quality of Life Inventory cardiac-specific module. As a result of the study, the total scale score was found to be significantly lower in the patient group aged 5–7 years. In the pairwise comparison analyses performed in our study, total scale score, physical health score, and psychosocial health score were found to be significantly lower in patients aged 5–7 years compared to healthy controls. In the multiple comparison of the six groups, the group with the lowest psychosocial health score was the 5–7-year-old patient group.

In a meta-analysis of thirty-two studies, impaired quality of life in children with CHD was associated with the severity of the cardiac lesion. This meta-analysis also reported that physical, psychosocial, emotional, and school functioning-related quality of life decreased after cardiac surgery.[22] Sertçelik *et al.*[23] evaluated a total of 80 children, 40 cyanotic and 40 acyanotic, who were followed up in the pediatric cardiology clinic with a diagnosis of CHD. As a result of the study, it was observed that total quality of life, emotional well-being, and self-esteem sub-dimensions were significantly lower in cyanotic children than in acyanotic children.

In this study, patients were analysed based on their medication status. When the findings were evaluated, all scores were found to be significantly lower in those on continuous medication. In a study conducted by Özdemir *et al.*[24] in Turkey, 63 patients aged 2–7 years and their parents were evaluated using Pediatric Quality of Life Inventory. As a result of the study, scale scores were found to be significantly lower in patients receiving continuous drug treatment compared to those who did not receive drug treatment. In a study by Yuan *et al.*[25] involving 199 children with atrial septal defect and ventricular septal defect who underwent interventional

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treatment, the pre-treatment and post-treatment 3rd month and 6th month scale scores of the children were analysed. In the comparison, it was observed that total scale scores increased significantly after interventional treatment. When compared with our study and the study of Özdemir *et al.*, this study shows that cardiac surgery or interventional treatments improve quality of life more than continuous drug therapy. In conclusion, these data indicate that the quality of life of children with CHD will improve with appropriate treatment and follow-up.

Saavedra *et al.*[26] conducted a cross-sectional observational study to evaluate the health-related quality of life using Pediatric Quality of Life Inventory in 31 patients aged between 2 and 4 years with a diagnosis of CHD who underwent cardiac surgery in the first year of life and 62 healthy controls. The total scale scores analysis did not reveal any statistically significant difference between children diagnosed with CHD and healthy children. However, the sick group had statistically significantly lower social and school scale scores within the psychosocial scale score. Saavedra *et al.* attributed the lower social and school scale scores in sick children compared to healthy children to an increase in the frequency of school absenteeism due to disease or planned health controls.

In the literature, there are various studies showing that chronic diseases other than CHD also affect health-related quality of life in a similar way. Bai *et al.*[27] conducted a study to evaluate the health-related quality of life in children aged 4–11 years (n = 5301) with chronic diseases such as asthma, eczema, dyslexia, attention deficit hyperactivity disorder, or migraine. The study found that the quality of life scores of children with chronic diseases were lower compared to those without any chronic disease. A study by Cadman *et al.*[28] examined 3294 Canadian children aged 4–16 years with chronic diseases. The study found that those with chronic diseases and disabilities had the highest risk of developing psychiatric disorders and social adjustment problems. In a prospective study conducted by Sawyer *et al.*,[29] the quality of life of 123 children with asthma (n = 40), cystic fibrosis (n = 39), and type 1 diabetes (n = 44) was evaluated over time. In this study, the course of these chronic diseases on quality of life over time was examined. After 6, 12, 18, and 24 months, all children were re-evaluated based on their previous conditions, and it was found that their quality of life had significantly improved. Durualp *et al.*[30] evaluated the quality of life in children with various chronic diseases, including asthma, acute rheumatic fever, chronic kidney disease, familial Mediterranean fever, diabetes, and chronic sinusitis. The study compared 154 children aged 8–18 years with chronic diseases to 154 healthy children. The study found that the physical and psychosocial health total scores of healthy children were significantly higher than those of children with chronic diseases.

The study has some limitations. We used the Pediatric Quality of Life Inventory general basic scale as a data collection tool, but did not use the cardiac-specific module. Past interventional or surgical treatment histories of the children diagnosed with CHD included in the study could not be evaluated. The study was designed as a cross-sectional research. Changes in the findings over time could not be fully addressed. The effect of CHD on the quality of life in children can be better understood with the findings obtained as a result of studies in which the data to be analysed are collected again.

In conclusion, it is important to note that CHD has a negative impact on the quality of life of children. Early recognition of this condition and prompt treatment are necessary to improve physical health. Furthermore, it is recommended that psychological health symptoms are also screened for in these children at the time of diagnosis, and appropriate psychosocial support should be provided upon early detection.

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Ethical standard. This study was conducted with the approval of Dicle University Non-Interventional Clinical Research Ethics Committee (Date: 06/06/2018 and Decision No: 238).

References

1. World Health Organization. The constitution of the WHO. Who Chron 1947; 1: 29.
2. Topçu B, Saraçlı S, Dursun P, Gazeloğlu C. Akademisyenlerin yaşam kaliteleri üzerine bir çalışma: Afyon kocatepe üniversitesi örneği. Düzce Üniversitesi Sağlık Bilimleri Enstitüsü Dergisi 2012; 2 *(1)*: 15–19.
3. Long PH. On the quantity and quality of life. Med Times 1960; 88: 613–619.
4. Varni JW, Seid M, Rode CA. The pedsQL: measurement model for the pediatric quality of life inventory. Med Care 1999; 37 *(2)*: 126–139.
5. Fitzpatrick R, Davey C, Bucton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Healt Technol Assess 1998; 2 *(14)*: 1–74.
6. Bernstein D. Congenital heart disease. In: Behrman RE, Kliegman RM, Jenson HB (eds). Nelson textbook of pediatrics, 18th. Saunders, Philadelphia, 2007, pp1878–1942.
7. Virani SS, Alonso A, Aparicio HJ, et al. Heart disease and stroke statistics—2021 update. Circulation 2021; 143 *(8)*: e254–e743.
8. Tsao CW, Aday AW, Almarzooq ZI, et al. Heart disease and stroke statistics 2014; 2022 update: a report from the American heart association. Circulation 2022; 145 *(8)*: e153–e639.
9. Uzark K, Jones K, Slusher J, et al. Quality of life in children with heart disease as perceived by children and parents. Pediatrics 2008; 121 *(5)*: e1060–e1067.
10. O'Connor AM, Cassedy A, Wray J, et al. Differences in quality of life in children across the spectrum of congenital heart disease. J Pediatr 2023; 263: 113701. DOI: 10.1016/j.jpeds.2023.113701.
11. Mellion K, Uzark K, Cassedy A, et al. Pediatric cardiac quality of life inventory testing study consortium. Health-related quality of life outcomes in children and adolescents with congenital heart disease. J Pediatr 2014; 164 *(4)*: 781–788.e1.
12. Ruggiero KM, Hickey PA, Leger RR, Vessey JA, Hayman LL. Parental perceptions of disease-severity and health-related quality of life in school-age children with congenital heart disease. J Spec Pediatr Nurs 2018; 23 *(1)*: e12204.
13. Çakın M, Ağaoğlu N, Coşkun B, Karakaya A. Çocuklar İçin Yaşam Kalitesi Ölçeğinin 8-12 Yaş Çocuk Formunun geçerlik ve güvenirliği. Çocuk ve Gençlik Ruh Sağlığı Dergisi 2008; 15 *(2)*: 87–98.
14. Kalaycı E, Çalışkan Z. The quality of life and influencing factors in turkish children receiving cancer treatment. J Pediatr Nurs 2021; 61: 213–218.
15. Dewi SP, Gondhowiardjo SA, Mangunatmadja I, et al. Quality of life in children with brain tumors post radiotherapy in a lower-middle income country. Pediatr Hematol Oncol 2022; 29: 1–10.
16. Handisides JC, Hollenbeck-Pringle D, Uzark K, et al. Pediatric heart network investigators. Health-related quality of life in children and young adults with marfan syndrome. J Pediatr 2019; 204: 250–255.e1. DOI: 10.1016/j.jpeds.2018.08.061.
17. Baygani S, Zieles K, Jea A. PedsQL for prediction of postoperative patient-reported outcomes following Chiari decompression surgery. J Neurosurg Pediatr 2019; 6 *(1)*: 1–6.
18. Gao Q, Wang S, Ren J, Wen X. Measuring parent proxy-reported quality of life of 11 rare diseases in children in Zhejiang, China. Health Qual Life Outcomes 2020; 18 *(1)*: 372.

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19. Fuertes-Moure A, Meyer M, Häcker A, Reiner B, Brudy L, et al. Longitudinal health-related quality of life assessment in children with congenital heart disease. Congenit Heart Dis 2020; 15 *(4)*: 217–227.
20. Berkes A, Varni JW, Pataki I, et al. Measuring health-related quality of life in Hungarian children attending a cardiology clinic with the pediatric quality of life inventory. Eur J Pediatr 2010; 169 *(3)*: 333–347.
21. Amodeo G, Ragni B, Calcagni G, et al. Health-related quality of life in Italian children and adolescents with congenital heart diseases. BMC Cardiovasc Disord 2022; 22 *(1)*: 173. DOI: 10.1186/s12872-022-02611-y.
22. Drakouli M, Petsios K, Giannakopoulou M, et al. Determinants of quality of life in children and adolescents with CHD: a systematic review. Cardiol Young 2015; 25 *(6)*: 1027–1036.
23. Sertçelik T, Alkan F, Sapmaz Ş.Y, Coşkun Ş., Eser E. Doğuştan kalp hastalığı olan çocuklarda yaşam kalitesi. Türk Pediatri Arşivi 2018; 53 *(2)*: 78–86.
24. Ozdemir R, Kutlu A, Mese T, et al. Quality of life among children aged 2 to 7 years with congenital or acquired heart disease in Turkey. Bulletin of Clinical Psychopharmacology 2015; 25 *(1)*: 96.
25. Yuan Y, Pan B, Liang X, Lv T, Tian J. Health-related quality of life in children with congenital heart disease following interventional closure versus minimally invasive closure. Front Cardiovasc Med 2022; 9: 974720.
26. Saavedra MJ, Eymann A, Pérez L, et al. Health related quality of life in children with congenital heart disease that undergo cardiac surgery during their first year of life. Arch Argent Pediatr 2020; 118 *(3)*: 166–172.
27. Bai G, Herten MH, Landgraf JM, Korfage IJ, Raat H. Childhood chronic conditions and health-related quality of life: findings from a large population-based study. PLoS One 2017; 12 *(6)*: e0178539.
28. Cadman D, Boyle M, Szatmari P, Offord DR. Chronic illness, disability, and mental and social well-being: findings of the Ontario child health study. Pediatrics 1987; 79 *(5)*: 805–813.
29. Sawyer MG, Reynolds KE, Couper JJ, et al. Health-related quality of life of children and adolescents with chronic illness–a two year prospective study. Qual Life Res 2004; 13 *(7)*: 1309–1319.
30. Durualp E, Kara FN, Yılmaz V, Alabeyoğlu K. Kronik Hastalığı Olan ve Olmayan Çocukların ve Ebeveynlerinin Görüşlerine Göre Yaşam Kalitelerinin Karşılaştırılması. Ankara Üniversitesi Tıp Fakültesi Mecmuası 2010; 63 *(2)*: 55–63.

https://doi.org/10.1017/S1047951124026155 Published online by Cambridge University Press