

# The Quality of Life in Children with Congenital Heart Disease Who Underwent an Intervention

## Konjenital Kalp Hastalığı Tanılı ve Girişim Uygulanmış Olan Çocuklarda Hayat Kalitesi

Havva Yazıcı<sup>1</sup>, Timur Meşe<sup>2</sup>

<sup>1</sup>Ege University Faculty of Medicine, Department of Inborn Errors of Metabolism, Izmir, Turkey

<sup>2</sup>Dr. Behçet Uz Children's Diseases and Surgery Training and Research Hospital, Department of Pediatric Cardiology, Izmir, Turkey

### Öz

Konjenital kalp hastalıkları çocukların ve ailelerin hayatlarını etkileyen en yaygın kronik çocukluk çağı hastalıklarından birisidir. Çocukların hayat kalitesinin değerlendirilmesi 1980'lerde kullanılmaya başlanmış olup son zamanlarda tedavi seçeneklerinin karşılaştırılmasında ve etkinliklerinin değerlendirilmesinde ve klinik uygulamada yaygın olarak kullanılmaktadır. Çalışmamızda Dr. Behçet Uz Çocuk Sağlığı ve Hastalıkları Eğitim ve Araştırma Hastanesi Çocuk Kardiyoloji Biriminde konjenital kalp hastalığı tanılı ve girişim uygulanmış olan 8-16 yaşları arasındaki 52 hastaya yaş grubuna özgü ve sağlıklı ilgili yaşam kalitesi ölçüğü olan Konjenital Kalp Hastalıkları Yaşam Kalitesi (ConQoL) anketi uygulanmıştır. 8-11 yaş grubu 27 hasta ve 26 sağlıklı kontrolden oluşuyordu. 12-16 yaş grubunda 25 hasta ve 26 sağlıklı kontrol vardı. 8-11 yaş grubunda koşuşturabilme, spor ve egzersiz yapılmasına izin verilmesi ve arkadaşlara ayak uydurabilme sorularında kontrol grubuna göre anlamlı bir fark olduğu saptanmıştır. 12-16 yaş grubunda spor ve egzersiz yapılmasına izin verilmesi, arkadaşlara ayak uydurabilme ve kulübe gitme veya okul dışında aktivitelere katılma sorularında kontrol grubuna göre anlamlı bir fark olduğu saptanmıştır. Konjenital kalp hastalıklı çocuklarda yaşam kalitesi özellikle fiziksel aktivite kısıtlanmasından etkilenmektedir.

**Anahtar Kelimeler:** Çocuk, ConQoL, Konjenital Kalp Hastalığı, Yaşam Kalitesi

### Abstract

Congenital heart disease (CHD) is one of the most common chronic pediatric conditions, exerting a substantial impact on the lives of children and families. The assessment of children's quality of life gained prominence in the 1980s and is now widely used in clinical practice for comparing treatment options and evaluating their efficacy. We applied the Congenital Heart Disease Quality of Life (ConQoL) questionnaire, age-appropriate and disease-specific, to 52 children aged 8-16 years with CHD who underwent intervention at the Pediatric Cardiology Unit of Dr. Behçet Uz Children's Diseases and Surgery Training and Research Hospital. A control group of 52 healthy individuals without CHD was also included. The 8-11 age group consisted of 27 patients and 26 healthy controls. There were 25 patients and 26 healthy controls in the 12-16 age group. There were significant differences in specific areas such as being able to run about, being allowed to do sports and exercise, and being able to do keep up with friends in 8-11-year-old patient group compared to the control group. The ConQoL Index Score was statistically significantly different between 12-16-year-old patient and control groups, about being allowed to do sports and exercise, being able to do keep up with friends, and being able to take part in clubs / do activities outside of school. Our findings underscore the impact of CHD on the quality of life in children with CHD, particularly manifesting in reduced physical activity.

**Keywords:** Child, ConQoL, Congenital Heart Disease, Quality of Life

### Introduction

Congenital heart diseases (CHD) are among the most common major congenital anomalies (1). Despite advances in interventional and surgical techniques, CHD is still an important cause of morbidity and mortality in the pediatric age group. Approximately one-third of children with CHD are critically ill in the first year of life, during which these children either die or require an urgent surgical intervention (2).

In general, "quality" refers to a degree of well-being. Quality of life (QoL) is a broader concept that includes personal well-being beyond personal health status. It comprises various components such as life satisfaction, subjective well-being, happiness,

functional competence, and social well-being, considering culture, value judgments, an individual's position and aspirations, and reflecting personal responses to diseases as well as the physical, mental, and social effects of daily life that affect the level of personal satisfaction achievable in living conditions (3,4). Therefore, the QoL assessment extends beyond the parameters of health-related measures (5-7). Health-related quality of life (HRQoL) is the patient's subjective perception of their satisfaction with their health, with their subjective perceptions directly tied to the individual's psychosocial well-being. Health-related QoL components were first incorporated into the definition of health in the Constitution of the World Health Organization (WHO) in 1948 (8). In recent years, the HRQoL approach has been widely used in adult and child psychiatry as an approach that examines the psychosocial consequences of physical health problems.

### Health-related Quality-of-life Scales and Their Use

The scales designed to assess QoL quantify an individual's physical, mental, and social well-being

ORCID No  
Havva Yazıcı 0000-0002-2564-7420  
Timur Meşe 0000-0002-4433-3929

Başvuru Tarihi / Received: 09.01.2024  
Kabul Tarihi / Accepted : 02.08.2024

Adres / Correspondence : Havva Yazıcı  
Ege University Faculty of Medicine, Department of Inborn Errors of Metabolism, Izmir, Turkey  
e-posta / e-mail : havvaya@gmail.com

based on the assumption that the individual engages in dynamic interactions with their environment. These QoL scales standardize the concept of QoL, rendering the collected data comparable (5). QoL assessment instruments are divided into two categories: generic and disease-specific scales. While generic QoL scales are superior to disease-specific QoL scales in social norm development studies, a significant drawback is their limited sensitivity to subtle changes. In treatment-specific evaluations, it is recommended to use disease-specific QoL scales instead of generic QoL scales. Conversely, disease-specific QoL scales, frequently chosen for their high sensitivity in obtaining information have a notable disadvantage – they do not address the individual as a whole (9-11).

#### *Quality of Life in Children and Adolescents and Scales Used*

The initial investigations into HRQoL in children commenced in the 1980s. Despite their relatively basic nature, these early assessments in children were deemed significant as they played a pioneering role in the development of both generic and disease-specific QoL scales (11).

The evaluation of QoL in children varies from those in adults. According to the literature, only 13% of approximately 20,000 studies related to HRQoL across all fields are focused on children. Awareness of these differences concerning the developmental periods of children is crucial for researchers involved in developing and utilizing QoL scales. In children, the evaluations consider activities such as eating, going to the toilet on their own, bathing, performing small daily tasks, and playing. When evaluating social functioning in adults, areas such as the school environment or friendships are not highly significant, however, in the evaluation of social functioning in children, meeting with friends, playing games with them, and the level of adaptation to school hold considerable importance.

When conducting QoL assessments in children, determining whether objective or subjective evaluations should take precedence is a topic of debate. Despite differing opinions on whether parents or children themselves should perform QoL assessments, the prevailing idea in recent years is that children should assess their QoL by themselves as much as possible (10-12). In situations where a child or an adolescent is too ill or too young to respond to the scale questions or do not want to answer the questions, it is recommended to use parent forms for QoL assessment.

Despite CHD's widespread impact, there is a limited number of studies on the QoL of children with CHD in the world. This study aims to investigate the QoL in children who underwent open-heart surgery or cardiac catheterization for CHD via Congenital Heart Disease Quality-of-Life Questionnaire (ConQoL) Scale.

## **Material and Method**

### *ConQoL Scale*

The ConQoL is a disease-specific QoL measurement tool developed specifically for children and adolescents. It was designed to explore the subjective perception of QoL in children or young people or pinpoint areas where assistance can be provided in clinic settings. Unlike similar scales, ConQoL adopts a child-centered approach, deriving from interviews with children and adolescents rather than relying solely on opinions of experts or parents. The questionnaire asks questions about the impact of events rather than just the frequency of events or symptoms because this approach recognizes that an event may occur frequently, but may not necessarily be perceived by the child as affecting their HRQoL.

ConQoL has two age-specific versions: one for children aged 8-11 years and another for those aged 12-16 years. The version for 8-11 age group consists of 29 questions, with 13 related to symptoms, 6 to activities, and 10 to relationships. The version for 12-16 age group consists of 35 questions, with 13 relating to symptoms, 7 to activities, 10 to relationships and 5 to controlling and coping with the illness. Recognizing that symptoms reported by children may not always align with their perceived importance, ConQoL incorporates a separate scoring for symptoms. ConQoL generates 3 scores:

1. A QoL score derived from questions describing the frequency of symptoms experienced by the child in the past week related to activities, relationships and controlling and coping with the illness
2. A descriptive profile detailing the symptoms experienced by the child in the last week
3. A weighed symptom index score summarizing how these symptoms make life difficult for respondents

### *Participants*

This case-control study included a cohort of 52 patients with CHD and 52 healthy volunteers between April 2011 and June 2011. The study was conducted at Pediatric Cardiology Unit of Dr. Behçet Uz Children's Diseases and Surgery Training and Research Hospital. The age-appropriate ConQoL scale items were administered to participants. They were allowed to answer the survey questions in a calm environment with no external intervention within an average of 15 minutes.

Convenience sampling was used in the study. Eligible cases who met all of the following inclusion criteria participated in the study:

1. Diagnosis of CHD
2. Males and females, from 8 to 16 years of age
3. Had undergone open-heart surgery or interventional treatment at least 2 months before
4. Did not have any neurological problems preventing communication

5. They were allowed to answer the questions without parental influence

We categorized the patients into two subgroups according to the age-specific version of ConQol questionnaire: 8-11 years old and 12-16 years old groups. The primary aim was to compare ConQol index score and ConQol symptom score between case and control groups. The Standard Effect Size was determined as 0.8 with a 5% Margin of Error (95% confidence interval), 80% Power. With the power analysis performed with G-power, we aimed to include at least 25 patients in both groups.

#### Ethical Approval

The research related to human use complied with all the relevant national regulations and institutional policies, in accordance the tenets of the Helsinki Declaration. The study was approved by the Clinical Trials Ethics Committee of İzmir Dr. Behçet Uz Children's Diseases and Surgery Training and Research Hospital (Number: 2012/11). All patients or their legal guardians provided written informed consent.

#### Statistical Analysis

The Microsoft Excel program that automatically calculates the quality-of-life item (ConQol Index

Score) and symptom item (ConQol Symptom Score) was used for scoring. The program calculates the score, with 100 points being the best QoL and 0 points being the worst. The program cannot calculate the score if there are more than 3 unanswered questions.

Median and first quartile (Q1) and third quartile (Q3) value frequency were used for descriptive statistics. The distribution of variables was checked with the Kolmogorov-Smirnov test. The Mann-Whitney U test was used to compare quantitative data. SPSS 28.0 was used for statistical analyses. The statistical significance level was accepted as  $p < 0.05$  for all tests.

#### Results

The age-appropriate ConQol questionnaire was administered to 52 patients aged between 8 and 16 years who had undergone surgery or interventional procedures to treat CHD and 52 healthy volunteers aged between 8 and 16 years.

Table 1 and 2 demonstrate that no significant difference was found in ConQol Index Score and Symptom Score between the case patient and control groups in the 8-11 age group ( $p=0.155$  and  $p=0.581$ ) and 12-16 age group ( $p=0.055$  and  $p=0.169$ ).

**Table 1.** ConQol Index Score / Symptom Score in 8-11 years old case and control groups.

	Control Group (n=26)		Case Group (n=27)		P
	Q1-Q3	Median	Q1-Q3	Median	
<b>Symptom Score</b>	73.3-93.4	82.2	59.4-93.4	83.1	0.581 <sup>m</sup>
<b>ConQol Index Score</b>	61.5-82.4	70.7	50.2-75.6	69.1	0.155 <sup>m</sup>

<sup>m</sup>Mann-Whitney U test

**Table 2.** ConQol Index Score / Symptom Score in 12-16 years old case and control groups.

	Control Group (n=26)		Case Group (n=25)		P
	Q1-Q3	Median	Q1-Q3	Median	
<b>Symptom Score</b>	64.8-93.3	78.2	59.4-93.4	83.1	0.169 <sup>m</sup>
<b>ConQol Index Score</b>	64.6-86.3	71.8	55.3-72.6	64.8	0.055 <sup>m</sup>

<sup>m</sup>Mann-Whitney U test

The responses by 8-11 age group regarding the activities, as shown in Table 3, indicate that there was a significant difference in being able to run about ( $p=0.048$ ), being allowed to do sports and exercise ( $p=0.031$ ) and being able to keep up with friends ( $p=0.018$ ) between the case and control groups. No significant difference was found in the responses by the 8-11 age group in questions related to the relationships between the patient and control groups. Likewise, there was no significant difference between the patient and control groups in their responses to questions related to symptoms (Table 3).

As shown in Table 4, there was a significant difference in the responses to questions related to symptoms between the 12-16-year-old case and control groups in terms of slowed-down thoughts ( $p=0.030$ ). There was also another significant difference in the responses to questions related to activities between the 12-16 years old case and

control groups in terms of being allowed to do sports and exercise ( $p=0.001$ ), being able to keep up with friends ( $p=0.023$ ), and being able to take part in clubs/do activities outside of school ( $p=0.009$ ). In contrast, responses by the 12-16 age group to questions on relationships showed no significant differences between the case and control groups. Similarly, there was no significant difference between the patient and control groups of 12-16-year-olds in their responses to questions on control over health or body (Table 4).

#### Discussion

In the 8-11 age group, the age-appropriate ConQol questionnaire was administered to 27 patients and 26 controls and no statistically significant difference was observed between the patient and control groups in terms of ConQol Index Score and Symptom Score. In the 12-16 age group,

the relevant ConQoL QoL questionnaire was given to a group of 25 patients and a group of 26 controls, and no significant difference were found between the patient and control groups in the Symptom Score and ConQoL Index Score.

A study conducted at the Children's Hospital of Wisconsin assessed the QoL in 21 children aged 8 to 18 years with repaired tetralogy of Fallot (TOF), administering the Pediatric Quality of Life Inventory (PedsQL) to compare with normative data for children considered healthy, chronically ill, and with CHD. The same questionnaire was also administered to the parents of these children. The self-reported HRQoL in the clinically well group of patients with repaired TOF was similar to that in healthy children, although parental scores were lower. The QoL in the patient group was superior to that of the group with chronic diseases. The PedsQL questionnaire assesses physical health, social functioning, emotional functioning, and school functioning. Among these dimensions, only emotional functioning exhibited no significant difference between the patient group and the control group with chronic diseases. In parental scores, the scores were significantly lower in parents of children with repaired TOF compared to the scores of parents of

healthy children in all dimensions except emotional functioning (13).

In a study conducted in Poland, the QoL of 67 children aged between 8 and 18 years with mitral valve prolapse was assessed by administering KIDSCREEN-27, a HRQoL questionnaire, to the patient and healthy control groups, and no significant differences were observed in children with mitral valve prolapse compared to healthy children. KIDSCREEN measures five dimensions including physical well-being, psychological well-being, parents and autonomy, peers and social support, and school environment. Of these dimensions, only physical well-being exhibited statistically significant difference in the patient group (14).

A study conducted by Uzark et al. (15) evaluated the QoL in 347 children with cardiovascular disease, primarily consisting of those with CHD, between the ages of 5 and 18 years using PedsQL, and found that the QoL was lower in the patient group. A significant difference was found in the patient group compared to the control group in physical and psychosocial functioning among the dimensions of PedsQL outlined above.

**Table 3.** Comparison of responses by 8-11 years old case and control groups

Age 8-11	Control Group (n=26)		Case Group (n=27)		p
	Q1-Q3	Median	Q1-Q3	Median	
Standardized Symptom Score	73.3-93.4	82.2	59.4-93.4	83.1	0.581 <sup>m</sup>
Standardized ConQoL Score	61.5-82.4	70.7	50.2-75.6	69.1	0.155 <sup>m</sup>
<b>Symptoms</b>					
Short of breath	0.0-2.0	0.0	0.0-5.0	1.0	0.196 <sup>m</sup>
Too tired	1.0-4.0	2.0	0.0-5.0	3.0	0.330 <sup>m</sup>
Aches and pains	0.0-4.0	2.0	0.0-5.0	2.0	0.883 <sup>m</sup>
Dizzy or faint	0.0-1.0	0.0	0.0-3.0	0.0	0.425 <sup>m</sup>
Unable to keep up with schoolwork or homework	0.0-5.0	0.5	0.0-5.0	0.0	0.809 <sup>m</sup>
Difficulty concentrating	0.0-3.0	0.5	0.0-2.5	0.0	0.656 <sup>m</sup>
Forgetful	0.0-4.0	2.0	0.0-5.0	1.0	0.906 <sup>m</sup>
Slowed-down thoughts	0.0-2.0	0.0	0.0-5.0	1.0	0.210 <sup>m</sup>
Sad or fed up	0.0-2.0	1.0	0.0-5.0	2.5	0.190 <sup>m</sup>
Worried or nervous	0.0-4.0	1.5	0.0-8.0	3.0	0.098 <sup>m</sup>
Feeling different to others	0.0-3.0	1.0	0.0-5.0	3.0	0.328 <sup>m</sup>
Feel like treated differently to others	0.0-3.3	1.0	0.0-4.0	2.0	0.655 <sup>m</sup>
Uncomfortable with looks	0.0-2.0	0.0	0.0-2.0	0.0	0.876 <sup>m</sup>
<b>Activities</b>					
Able to run about	0.0-3.0	0.0	0.0-10.0	3.0	<b>0.048<sup>m</sup></b>
Allowed to do sports and exercise	0.0-2.3	0.0	0.0-10.0	4.0	<b>0.031<sup>m</sup></b>
Able to spend time with friends	0.0-3.3	1.0	0.0-3.0	0.0	0.450 <sup>m</sup>
Able to keep up with friends	0.0-2.0	0.0	0.0-7.0	3.0	<b>0.018<sup>m</sup></b>
Allowed to do things friends do	0.0-5.0	2.0	0.0-8.5	4.0	0.256 <sup>m</sup>
Able to go to clubs/do activities outside of school	0.0-3.5	0.0	0.0-3.0	0.0	0.947 <sup>m</sup>
<b>Relationships</b>					
My relationships with my friends were harmonious	0.0-2.0	0.0	0.0-4.5	1.0	0.160 <sup>m</sup>
My friends pay attention to me	0.0-3.5	0.0	0.0-2.3	0.0	0.856 <sup>m</sup>
Finding it difficult to make friends	0.0-10.0	3.0	0.0-10.0	1.5	0.722 <sup>m</sup>
They get unnecessarily worried about me too often.	0.0-10.0	2.5	0.0-10.0	4.0	0.851 <sup>m</sup>
They make fun of me, they tease me	1.0-10.0	7.5	2.0-10.0	8.0	0.751 <sup>m</sup>
I feel lonely	4.0-10.0	9.0	2.0-10.0	7.0	0.651 <sup>m</sup>
I'm allowed to do the things I can do	0.0-5.0	3.0	0.0-5.0	1.0	0.831 <sup>m</sup>
I think people understand what I can do	0.0-5.3	0.5	0.0-6.0	3.0	0.350 <sup>m</sup>
I think people expect me to do too much	0.0-8.3	3.0	0.8-10.0	6.0	0.155 <sup>m</sup>
I can do more than people think	0.0-5.0	1.0	0.0-5.0	3.0	0.391 <sup>m</sup>

<sup>m</sup>Mann-Whitney U test

**Table 4.** Comparison of responses by 12-16 years old case and control groups

Age 12-16	Control Group (n=26)		Case Group (n=25)		p
	Q1-Q3	Median	Q1-Q3	Median	
Standardized Symptom Score	64.8-93.3	78.2	52.9-82.4	73.4	0.169 <sup>m</sup>
Standardized ConQoL Score	64.6-86.3	71.8	55.3-72.6	64.8	0.055 <sup>m</sup>
<b>Symptoms</b>					
Short of breath	0.0-5.0	1.0	0.0-4.5	3.0	0.604 <sup>m</sup>
Too tired	1.0-6.0	3.0	1.0-6.5	4.0	0.481 <sup>m</sup>
Aches and pains	1.0-6.0	3.0	2.0-5.0	3.0	0.887 <sup>m</sup>
Dizzy or faint	0.0-4.3	0.5	0.0-4.5	1.0	0.788 <sup>m</sup>
Unable to keep up with schoolwork or homework	0.0-3.0	0.5	0.0-4.8	1.5	0.217 <sup>m</sup>
Difficulty concentrating	0.0-5.0	2.0	0.0-7.0	4.0	0.227 <sup>m</sup>
Forgetful	0.0-6.3	3.0	0.0-4.5	2.0	0.802 <sup>m</sup>
Slowed-down thoughts	0.0-2.3	0.0	0.5-5.0	3.0	<b>0.030<sup>m</sup></b>
Sad or fed up	0.0-5.5	2.0	1.5-6.0	3.0	0.172 <sup>m</sup>
Worried or nervous	0.0-5.5	2.0	1.3-6.8	3.0	0.280 <sup>m</sup>
Feeling different to others	0.0-5.0	0.0	0.0-7.5	4.0	0.060 <sup>m</sup>
Feel like treated differently to others	0.0-4.3	0.0	0.0-6.5	3.0	0.137 <sup>m</sup>
Uncomfortable with looks	0.0-3.3	0.0	0.0-4.0	2.0	0.117 <sup>m</sup>
<b>Activities</b>					
Able to run about	0.0-5.0	1.5	0.0-6.5	3.0	0.506 <sup>m</sup>
Allowed to do sports and exercise	0.0-4.0	0.5	1.0-10.0	6.0	<b>0.001<sup>m</sup></b>
Able to spend time with friends	0.0-5.0	1.0	0.0-5.0	3.0	0.383 <sup>m</sup>
Able to keep up with friends	0.0-5.0	1.0	1.0-8.5	5.0	<b>0.023<sup>m</sup></b>
Able to go sightseeing or shopping with my friends	0.0-6.3	1.5	0.5-8.0	3.0	0.306 <sup>m</sup>
Allowed to do things friends do	0.0-5.5	2.0	1.0-7.0	3.0	0.463 <sup>m</sup>
Able to go to clubs/do activities outside of school	0.0-2.0	0.0	0.3-8.8	4.0	<b>0.009<sup>m</sup></b>
<b>Relationships</b>					
My relationships with my friends were harmonious	0.0-7.0	0.0	0.0-5.0	1.0	0.670 <sup>m</sup>
My friends pay attention to me	0.0-5.5	1.0	1.0-6.5	2.0	0.297 <sup>m</sup>
Finding it difficult to make friends	5.0-10.0	10.0	3.0-10.0	9.0	0.314 <sup>m</sup>
They get unnecessarily worried about me too often.	1.8-10.0	6.0	1.0-6.0	5.0	0.148 <sup>m</sup>
They make fun of me, they tease me	6.5-10.0	10.0	4.0-10.0	10.0	0.500 <sup>m</sup>
I feel lonely	4.0-10.0	8.5	4.0-10.0	9.0	0.889 <sup>m</sup>
I'm allowed to do the things I can do	0.0-5.0	1.5	0.0-6.0	2.0	0.477 <sup>m</sup>
I think people expect me to do too much	2.0-9.3	5.0	3.0-9.5	6.0	0.906 <sup>m</sup>
I can do more than people think	0.0-6.0	1.5	0.0-6.0	3.0	0.822 <sup>m</sup>
I think people understand what I can do	0.0-5.3	3.0	0.0-5.0	3.0	0.795 <sup>m</sup>
<b>Control of Disease</b>					
I feel like my body doesn't belong to me	9.8-10.0	10.0	6.5-10.0	10.0	0.332 <sup>m</sup>
I feel like my health is out of my control	4.0-10.0	9.0	6.0-10.0	9.0	0.790 <sup>m</sup>
I'm tired of talking to people about my health	4.0-10.0	10.0	4.0-9.5	8.0	0.134 <sup>m</sup>
I think about my heart	0.0-9.5	3.0	1.0-9.0	4.0	0.561 <sup>m</sup>
My life is good	0.0-5.0	2.0	0.0-5.5	1.0	0.628 <sup>m</sup>

<sup>m</sup>Mann-Whitney U test

In the three aforementioned studies (13-15), the age ranges were broader than in our study; therefore, the difference in the ConQoL Index Score evaluating the QoL between two age groups in our study was not observed in these studies. While the QoL results in two of the three studies (13,14) mentioned above overlap with the QoL results of our 8-11 age group, the results of one study align with the QoL results of our 12-16 age group (15). As children age, their comprehension of the disease and their knowledge about it tend to increase. Therefore, in our study, while the QoL of the 8-11 age group did not appear to be significantly affected, it seems that the QoL of the 12-16 age group was affected.

Regarding questions related to activities, there was a statistically significant difference in the 8-11 age group for being able to run about, allowed to do sports and exercise, and able to keep up with friends. In the 12-16 age group, a statistically significant

difference was found in being allowed to do sports and exercise, able to keep up with friends, and allowed to participate in clubs/do activities outside of school. Previous similar studies (16-18) have demonstrated that restrictions in physical activities due to physical conditions or lack of parental permission can significantly impact the QoL in children. Scientific evidence indicates that physical activities should not be restricted even in moderate heart diseases (19).

In another study from Turkey, the effect of psychosocial factors and disease-related variables on QoL of children with CHD was evaluated by Sertçelik et al. (20). They included a total of 80 children, 40 of whom had cyanotic CHD and 40 had acyanotic CHD and their mothers. They evaluated them using the Parental Attitude Research Instrument and the KINDer Lebensqualitätsfragebogen – (KINDL) Quality-of-

Life Questionnaire for Children. They reported that symptoms of CHD affected the psychosocial quality-of-life subscales rather than the physical subscales. However, as observed in our study and other studies, families often adopt an overprotective attitude, leading to a negative impact on QoL in children (19-22).

There was no significant difference in questions related to the relationship between the two groups. However, in studies focusing on more specific patient groups, such as those with cyanosis, cardiac surgery, and manifestation of symptoms in physical appearance, significant differences were observed in questions related to relationships (16,21-23). We did not differentiate patients based on cyanosis status or the type of intervention (cardiac catheterization or open-heart surgery).

No significant difference was found between the patient and control groups in the questions related to control of health/body in the 12-16 age group. In studies conducted in the United Kingdom during the development of ConQol, clinicians gave low scores in the weighted score of the questions related to control of health/body, while children with and without CHD self-reported higher scores in the weight of impact on QoL (24). Other studies assessing the QoL in children with CHD have not focused on assessing health/body control (25-27).

This study had some limitations. Firstly, the study was conducted in a single center, and secondly, had a small study group. In parallel with these limitations, a comparison could not be made between subgroups that had undergone correction with surgical intervention or angiographic intervention, since a sufficient sample size could not be reached.

## Conclusion

Physical activity restrictions significantly impact children with CHD, for which overprotective attitudes of families play an important role. It is crucial to educate parents that there should be no limitations on physical activity for these children unless there is a medical necessity during follow-up.

## Conflict of interest statement

The authors state no conflict of interest.

**Ethics Committee Approval:** The research related to human use has been complied with all the relevant national regulations, institutional policies and in accordance the tenets of the Helsinki Declaration and has been approved by the local İzmir Dr. Behçet Uz Children's Diseases and Surgery Training and Research Hospital Ethics Committee (Number: 2012/11).

**Funding:** None declared.

## References

1. Ferenz C, Rubin JD, McCarter RJ. Congenital heart disease: prevalence at live birth. The Baltimore-Washington Infant Study. *Am J Epidemiol.* 1985;121(1):31-6.
2. Fyler DC, Rothman KJ, Parisi-Buckley L. The determinants of five year survival infants with congenital heart disease. *Cardiovasc Clin.* 1981;11(2):393-405.
3. Eiser C, Morse R. The measurement of quality of life in children: past and future perspectives. *J Dev Behav Pediatr.* 2001;22(4):248-56.
4. Sönmez S, Başbakkal Z. Türk çocuklarının pediatrik yaşam kalitesi 4.0 envanterinin (PedsQL 4.0) geçerlilik ve güvenilirlik çalışması. *Türk Klin J Pediatr.* 2007;16:229-37.
5. Orley J, Kuyken W. Quality of life assessment: international perspectives. proceedings of the joint-meeting organized by the World Health Organization and the foundation IPSEN in Paris, July 2 – 3, 1993, page 41-57.
6. Bowling A. Measuring health, a review of quality of life measurement. Open University Press. 1993:1-23.
7. The WHOQOL Group. What quality of life? World Health Organization quality of life assessment. *World Health Forum.* 1996;17(4):354-6.
8. Testa MA, Simonson DC. Assessment of quality-of-life outcomes. *N Engl J Med.* 1996;334(13):835-40.
9. Eser E. Yaşam kalitesinin sınıflandırılması ve sağlıkla ilgili yaşam kalitesinin ölçümü. 1. sağlıkta yaşam kalitesi sempozyumu program ve özet kitabı. 2004, sayfa 4-6.
10. Harding L. Children's quality of life assessment: a review of generic and health related quality of life measures completed by children and adolescents. *Clin Psychol Psychother.* 2001;8(2):79-96.
11. Eiser C, Mohay H, Morse R. The measurement of quality of life in young children. *Child Care Health Dev.* 2000;26(5):401-14.
12. Wallander JL, Schmitt M, Koot HM. Quality of life measurement in children and adolescents: issues, instruments and applications. *J Clin Psychol.* 2001;57(4):571-85.
13. Kwon EN, Mussatto K, Simpson PM, et al. Children and adolescents with repaired tetralogy of fallot report quality of life similar to healthy peers. *Congenit Heart Dis.* 2011;6(1):18-27.
14. Janiec I, Werner B, Sieminska J, et al. Quality of life of children with mitral valve prolapse. *Qual Life Res.* 2011;20(4):537-41.
15. 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):e1060-7.
16. Wray J, Sensky T. Congenital heart disease and cardiac surgery in childhood: effects on cognitive function and academic ability. *Heart.* 2001;85(6):687-91.
17. Visconti KJ, Saudino KJ, Rappaport LA, et al. Influence of parental stress and social support on the behavioral adjustment of children with transposition of the great arteries. *J Dev Behav Pediatr.* 2002;23(5):314-21.
18. Nelson W. Παιδιατρική. Επιμέλεια Μετάφρασης Χρούσος Γ. 15η έκδοση. Εκδ. Πασχαλίδη, Αθήνα, 2004.
19. Nousi D, Christou A. Factors affecting the quality of life in children with congenital heart disease. *Health Sci J.* 2010;4(2):94-100.
20. Sertçelik T, Alkan F, Sapmaz ŞY, et al. Life quality of children with congenital heart diseases. *Turk Pediatri Ars.* 2018;53(2):78-86.
21. Wright M, Nolan T. Impact of cyanotic heart disease on school performance. *Arch Dis Child.* 1994;71(1):64-70.
22. Kendall L, Sloper P, Lewin RJ, et al. The views of young people with congenital cardiac disease on designing the services for their treatment. *Cardiol Young.* 2003;13(1):11-9.
23. Nakou S. Measurement of quality of life in the health care field. applications in child birth. *Arch Helle Med.* 2001;18(3):254-66.
24. Macran S, Birks Y, Parsons J, et al. The development of a new measure of quality of life for children with congenital cardiac disease. *Cardiol Young.* 2006;16(2):165-72.

25. Wotherspoon JM, Eagleson KJ, Gilmore L, et al. Neurodevelopmental and health-related quality-of-life outcomes in adolescence after surgery for congenital heart disease in infancy. *Dev Med Child Neurol.* 2020;62(2):214–20.
26. Gaynor JW, Stopp C, Wypij D, et al. Neurodevelopmental outcomes after cardiac surgery in infancy. *Pediatrics.* 2015;135(5):816–25.
27. Noeder MM, Logan BA, Struempfler KL, et al. Developmental screening in children with CHD: ages and stages questionnaires. *Cardiol Young.* 2017;27(8):1447–54.