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Turkish validity and reliability study of Pediatric Quality of Life Inventory (PedsQL) 3.0 cardiac module for 8–18 years old children and parents

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ABSTRACT

Background: This study aimed to evaluate the Turkish validity and reliability of the 8–12- and 13–18-years child and parent forms of the Pediatric Quality of Life Inventory (PedSQL) 3.0 Cardiac Module.
Methods: This methodological study was conducted in children (8–18 years old) with cardiac disease and their parents. The PedsQL 4.0 were also used to collect data for the parallel form method. Pearson correlation coefficients between the scale and its sub-dimensions were evaluated for construct validity. For construct validity, mean scores of children with cardiac disease and healthy children and their parents were compared. Cronbach's alpha coefficient was calculated to evaluate the internal consistency of the items.
Results: In this study, 136 children aged 8–12 years and 135 adolescents aged 13–18 years with cardiac diagnosis and their parents participated. The Cronbach alpha coefficients were found to be above 0.80 for all sub-dimensions and the total scale. Correlations between PedsQL 3.0 Cardiac module and PedsQL 4.0 scores were moderate to highly significant. A significant difference was found between the mean scores of the children with cardiac disease and healthy child and parent forms ($p < .001$).
Conclusion: PedsQL 3.0 Cardiac Module's 8–12- and 13–18-year child and parent forms are valid and reliable for the Turkish language.
Application to practice: It is important to evaluate the PedsQL cardiac module, which is a very comprehensive scale, with accurate measurements to increase the general health level and life satisfaction of these patient groups.

Introduction

Congenital heart diseases (CHD) are seen quite frequently and if not treated in the neonatal period, they can lead to structural cardiac malformations with mortality/morbidity (Mandalenakis et al., 2020; Maya et al., 2020; O'Neal Maynord et al., 2021). Approximately half of newborns with CHD are diagnosed in the first week of life (Tsao et al., 2022; Virani et al., 2021). According to the study of Vemuri et al. (2022), about 15–20% of children with heart disease have complex heart conditions. Even if these children survive, they continue their lives with a low quality of life. Most of these children die in the first year of life. Parents of their surviving children reported that the children suffered significantly throughout their lives (Vemuri et al., 2022). The incidence of CHD is 2.4–13.7 per 1000 live births (American Heart Association, 2019). It is reported by the Turkish Statistical Institute that the number of babies born with CHD is between 12,000–13,000 every year (TUIK, 2020). In recent years, it has been reported that the death rate of children with heart disease has decreased significantly because of new surgical techniques and advances in intensive care, cardiopulmonary bypass, heart transplantation, and interventional catheterization. The number of children with CHD is increasing, and 85–90% of these children reach adulthood (Grimaldi Capitello et al., 2021). These developments in pediatric cardiology have led to the study of morbidity and health-related quality of life in children with heart disease.

Congenital heart disease is often associated with physical symptoms and can impair the patient's psychological, and social well-being and functioning (Amodeo et al., 2022; Simeone et al., 2022; Xiang et al., 2019). Therefore, specific tools are being developed for the assessment

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of the health-related quality of life to increase a general understanding of the disease. Quality of life can be measured in healthy individuals as well as in disease-specific ones (Varni et al., 2003). Quality-of-life tools are developed for children with cardiac problems covering children aged 2–18 years (Varni et al., 2001). The Pediatric Quality of Life Inventory 3.0 module was developed specifically for asthma, cancer, and cardiac disease (Uzark et al., 2003; Varni et al., 2003). Recently, more attention has been given to assessing patients' quality of life with CHD. The cardiac module of the Pediatric Quality of Life Inventory has been translated into several languages and adapted into Hungarian, Spanish, Portuguese, Swedish, Arabic, and Hindi (Berkes et al., 2010; Do Nascimento Moraes et al., 2013; González-Gil et al., 2012; Grimaldi Capitello et al., 2021; Marino et al., 2011, 2010; Musallam et al., 2018; Sand et al., 2013). Some forms can be used in all children 2 to 18 years with a cardiac diagnosis or undergoing cardiac surgery. In this study, we aimed to adapt the PedsQL 3.0 cardiac module to the Turkish language by examining the 8–12- and 13–18-year forms for children and parents.

Objective

In this study, we aimed to investigate the psychometric properties of PedsQL 3.0 cardiac module 8–12- and 13–18-years child and parent forms in Turkish.

Methods

Participants

It was a methodological, descriptive, and cross-sectional study. The pediatric cardiac patients followed in the pediatric cardiology clinic of a training and research hospital and the healthy children who applied to the cardiology outpatient clinics constituted the population of the study. Written informed consent was obtained from each parent. Patients aged 8–18 years with a cardiac diagnosis who were followed up in the cardiology clinic as an inpatient or outpatient were included in the study. In this study, 8–12- and 13–18-years child and parent forms of the scale were used. The scale consists of 27 questions. To reach healthy data at the end of the research, the rule of approximately 5 times the number of items, which was suggested in the validity and reliability studies, was applied (Çapık et al., 2018). For this reason, 136 children with cardiac problems between the ages of 8–12 and 136 healthy children, and 135 adolescents with cardiac problems between the ages of 13–18 and 136 healthy adolescents were included in the study for the construct validity.

Since the research was conducted in a single center, the sample was limited to 5 times the total number of items. This sample number could be reached due to the limited population of patients aged 8–18 years with CHD. It was achievable because many patients with CHD also have cognitive or genetic problems. For construct validity, it is recommended to take samples separately for explanatory and confirmatory factor analyses (Çapık et al., 2018). Only explanatory factor analyses were performed in this study.

The eligibility criteria for the cardiac patient's sample were: (a)Child between the ages of 8–18, (b)Having heart disease (congenital or acquired), (c)Child/adolescent and parent's willingness to participate in the study voluntarily, (d)Obtaining consent form from child and parent. The exclusion criteria were: (a) Having a genetic or cognitive disease other than a congenital disease (Down syndrome, etc.), (b) Having a cognitive problem / mental retardation that prevents him/her from expressing himself/herself, (c) The lack of willingness of the child and family to participate in the study, (d) Child/adolescent or parent's illiteracy, (e) At least 3 months after cardiac surgery.

Inclusion criteria for the healthy sample were: (a) Child between the ages of 8–18, (b) Absence of any known heart disease, (c) Child/adolescent and parent's willingness to participate in the study voluntarily, (d) Obtaining consent form from child and parent, (e) Absence of a congenital or other known genetic or cognitive disease. Exclusion criteria were: (a) Having a cognitive problem / mental retardation that prevents him/her from expressing himself/herself (b) Having a genetic or cognitive disease (c) The lack of willingness of the child and family to participate in the study (d) Child/adolescent or parent's illiteracy.

Outcomes

Data collection tools

The data of the study were collected by face-to-face interview method through the following forms.

Sociodemographic data collection form. This form included variables such as age, gender, diagnosis, cardiac surgery, and angiography status for the child with cardiac problems. For the healthy child, it included the age, gender, and reasons for applying to the cardiology outpatient clinic.

Pediatric quality of life inventory (PedsQL) 3.0 cardiac module. It is designed to provide greater measurement precision for limited populations. Disease-specific modules have been planned and developed, available for asthma, rheumatology, diabetes, cancer, and heart conditions. It includes forms covering the child/young/young adult group between the ages of 2–25 and their parents. The 8–12- and 13–18-years children and parent forms include these subdimensions; heart problems and its treatment (7 items), treatment II (5 items), perceived physical appearance (3 items), treatment anxiety (4 items), cognitive problems (5 items), and problems with communication (3 items). It is a total of 27 items of multi-dimensional inventory with six subdimensions. The inventory is prepared according to the five-point Likert system; the scale scoring is "0: never a problem; 1: almost no problem; 2: sometimes there is the problem; 3: there is often trouble; 4: there is almost always a problem". Higher scores show lower health. A 5-point Likert scale, increasing from 0 (never) to 4 (almost always), was used. Items are scored in reverse and converted to a 0–100 scale linearly as follows: $0 = 100$, $1 = 75$, $2 = 50$, $3 = 25$, $4 = 0$. If >50% of the items in the scale are missing or unanswered, the scale scores should not be calculated. The mean score is equal to the number of items answered over the sum of the items. When the items of the 8–12- and 13–18-years child forms were compared, it was seen that the only difference was in the 5th item in the Treatment II sub-dimension (I am worried about the side effects of my medications (13–18 years) / I am worried about how my drugs will affect my body (8–12 years)). 8–12 and 13–18 age parent forms are seen to be the same (Uzark et al., 2003).

Pediatric quality of life inventory (PedsQL) 4.0 generic score. The form, which is a modular approach to health-related quality of life, was developed by Varni et al. (2001). The inventory includes two parallel forms: The child and parent forms. In the PedsQL 4.0 Quality of Life Inventory validity and reliability study, the reliability coefficient (α) for the total score was found 0.90 for the family form and 0.88 for the child form. In the study of Varni et al. (2001), physical functions for the family were 0.88, for the child 0.80; psychosocial functions were found to be 0.86 for the family and 0.83 for the child. It has been shown in many studies to have high internal consistency, validity, reliability, and sensitivity (Sönmez & Başbakkal, 2007; Varni et al., 2001, Varni et al., 2003; Varni & Limbers, 2009). The Turkish validity and reliability of the 8–18-year-old child and parent form were performed by Memik et al. (2007). PedsQL 4.0 inventory consists of 23 items: physical functionality (8 items), emotional functionality (5 items), social functionality (5 items), and school functionality (5 items). It is a self-report scale developed with focus groups and cognitive interviews. Child reports include ages 5–7, 8–12, and 13–18 (Memik et al., 2007). Parent reports include ages 2–4, 5–7, 8–12, and 13–18 and assess parents' perceptions of their children's health-related quality of life. The forms are written in a different language according to their developmental period. The directions

ask how problematic each item has been in the last 1 month on the 5-point response scale. It is used for 5–18-years-old children and 2–18-years-old children's parent forms. It scores "0: never a problem; 1: almost no problem; 2: sometimes there is the problem; 3: there is often trouble; 4: there is almost always a problem". Items are scored inversely converted into a scale from 0 to 100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) so that lower scores indicate higher health-related quality of life. The total score of the scale is obtained by summing the scores from the scale points and dividing by the number of filled items (Memik et al., 2007; Memik et al., 2008; Sönmez & Başbakkal, 2007; Varni et al., 2001).

Procedure

The study was performed between February 2022 and May 2022 in a third-level children's hospital. A nurse researcher (RN, Ph.D. student) interviewed the participants who agreed to attend a single session. First, an interview was conducted with the parents that lasted 10 min, during which they were informed in detail about the study, signed the informed consent document, and completed questionnaires in paper format. Second, the children were interviewed separately from their parents so that parents did not influence their response to questionnaires (also in paper format) this interview lasted 5–10 min.

Data analysis

Descriptive statistics were calculated for the clinical and demographic characteristics of all patients participating in this study. Numbers, percentages, and averages are indicated. Percentages are given for categorical or multiple variables. Cronbach's alpha coefficient was used to evaluate the internal consistency reliability of the scale. Pearson correlation analysis was used to assess construct validity. The mean score of cardiac patients and healthy children and their parents were evaluated using the independent sample *t*-test. The SPSS version 23.0 software package was used for all statistics.

Validity and reliability stages of the scale

1) ***Getting expert opinion/ Language validity****;* The scale was translated into Turkish by the researchers and a person who is fluent in English. A single translation was obtained after the two translations were evaluated by the researcher and his advisor. Expert opinion was obtained from 10 experts (Pediatric Cardiology, and Child Health and Diseases Nursing associate professors and professors) regarding the items in both English and Turkish versions. Each item was asked to be scored between 1 and 4 points (1 point; not appropriate, 2 points; somewhat appropriate (revision required), 3 points; highly appropriate (but minor modification needed), and 4 points; highly appropriate). After the expert opinions were taken, the content validity index (CVI) was used to determine the consistency among the experts, and the agreement was found to be 0.97 (0.96–1.00). Necessary corrections were made on the scale in line with the opinions received, the back translation of the Turkish form was made by a professional translator in the field of health who knows both languages, then the back translation and the original scale were compared by the translator, and it was found that the forms were compatible with each other.
2) ***Cronbach Alpha (α) Coefficient****:* The Cronbach Alpha Coefficient is checked to determine whether the scale items are consistent with each other and measure the same conceptual structure. The Cronbach Alpha Coefficient is expected to be at least 0.70. The Croncbach α Coefficient was calculated for the total scale sub-dimensions of the PedsQL 3.0 Cardiac Module. The item-total score, split-half, and Hotelling T2 were also used for reliability analysis.
3) ***Construct Validity:*** The relationship between the scores on the PedsQL 3.0 Cardiac Module and the scores on the PedsQL 4.0 was evaluated by examining the Pearson correlation coefficients. The construct validity of the Turkish version of the PedsQL 3.0 Cardiac Module was evaluated using explanatory factor analyses (EFA).
4) ***Construct Validity/Known Groups Comparison****:* The same scale is applied to two groups (children with heart disease and healthy children), who are thought to have different scores in terms of the conceptual structure we aim to measure, and the results are compared. Since the groups to which the scale was applied are different, it is expected that there will be a difference between the scores obtained from the scale. For this purpose, the scales were also applied to healthy children and their parents. The 136 cardiac patients aged 8–12 and their parents were compared with the 136 healthy children and their parents. Similarly, 135 cardiac patients aged 13–18 and their parents were compared with 135 healthy children and their parents.

Ethical considerations

The permission of the author who developed the scale was obtained via e-mail for the study. Verbal and written informed consent of the participants and their parents was obtained. This study was approved by the hospital's clinical ethics committee (approval number: 2022/09–12, 13/05/2022).

Results

Demographic variables of patient and healthy group

Demographic variables about the patient and healthy group presented in Table 1. The mean age of the patients in the 8–12 age group was 10.38 ± 1.45, and 52.2% of them were girls. It is seen that arrhythmia (25.7%), VSD (11.8%), heart failure (11.8%), and mitral insufficiency (11.8%) are common. Cardiac surgery was performed in 30.1% of the patients and angiography was performed in 46.3% of the patients. For known group comparison, the mean age of the healthy children included in the study was 10.30 ± 1.47 years, 53.7% of the girls and 42.6% of them applied to the cardiology outpatient clinic for sports examination (Table 1).

The mean age of patients in the 13–18 age group was 15.03 ± 1.52, and 53.3% of them were girls. It is seen that arrhythmia (27.4%), heart failure (12.6%), and mitral insufficiency (11.1%) are common. Cardiac surgery was performed in 28.1% of the patients and angiography was performed in 43.7% of them. For known group comparison, the mean age of the healthy adolescents included in the study was 15.04 ± 1.68 years, 53.3% of the girls and 43% of them applied to the cardiology outpatient clinic for sports examination (Table 1).

Analysis of PedsQL 3.0 cardiac module 8–12 years old child and parent scores

In the sub-dimension of heart problems and treatment of children aged 8–12 and their parents, it is seen that they often experience shortness of breath during sports activities and exercise and have a cold easily. They reported that they sometimes forgot to take heart medication, did not look good in terms of their perceived physical appearance, were afraid of seeing the doctor, going to the doctor, and receiving treatment in terms of treatment anxiety. They reported that in the cognitive problems sub-dimension they sometimes had difficulties in solving mathematical problems, doing homework, and remembering what they read. In the communication sub-dimension, they sometimes had difficulties in telling how they felt and asking questions to the doctor/nurse, and often had difficulties in explaining their heart problems to other people.

Analysis of PedsQL 3.0 cardiac module 13–18 years child and parent scores

In the sub-dimension of heart problems and treatment, children aged 13–18 and their parents reported that they sometimes experience shortness of breath during sports activities and exercise, have colds

Table 1
Demographics of children.

Variables	8–12 years (n = 136)		13–18 years (n = 135)	
Patient Group	N (%)	M ± SS (Min-Max)	N (%)	M ± SS (Min-Max)
Age		10.38 ± 1.45 (8–12)		15.03 ± 1.52 (13–18)
Gender				
Girl	71 (52.2)		72(53.3)	
Boy	65 (47.8)		63(46.7)	
Diagnosis				
Aortic insufficiency	8 (5.9)		7 (5.2)	
Arrhythmia	35 (25.7)		37 (27.4)	
ASD shut down	1 (0.7)		2 (1.5)	
Dilated cardiomyopathy	11 (8.1)		14 (10.4)	
Heart failure	16 (11.8)		17 (12.6)	
Coronary artery disease	14 (10.3)		12 (8.9)	
Myocarditis	3 (2.2)		3 (2.2)	
Mitral insufficiency	16 (11.8)		15 (11.1)	
Pulmonary stenosis	10 (7.4)		10 (7.4)	
Tricuspid atresia	6 (4.4)		7 (5.2)	
VSD	16 (11.8)		11 (8.1)	
Cardiac Surgery Performing Status				
Yes	41 (30.1)		38 (28.1)	
No	95 (69.9)		97 (71.9)	
Angiography Performing Status				
Yes	63 (46.3)		59 (43.7)	
No	73 (53.7)		76 (56.3)	
Healthy Group				
Age		10.30 ± 1.47 (8–12)		15.04 ± 1.68 (13–18)
Gender				
Girl	73 (53.7)		72(53.3)	
Boy	63 (46.3)		63(46.7)	
Reason for Applying to Cardiology Outpatient Clinic				
Sports Examination	58 (42.6)		58 (43.0)	
Other	78 (57.4)		77 (57.0)	

easily, and their lips turn blue when they run. It was determined that they sometimes responded to most items in the dimensions of treatment, perceived physical appearance, treatment anxiety, cognitive problems, and communication.

Analysis of confidence coefficients of PedsQL 3.0 cardiac module 8–12 / 13–18 years child and parent form

The Cronbach's alpha coefficient of the 8–12-years child form was 0.91, and it ranged from 0.86 to 0.94 for its sub-dimensions (Table 2). The item-total score correlations of all items were found to be between $r = 0.33$ and 0.72 ($p < .001$). As a result of the split-half analysis, Cronbach alpha value was found as 0.826 for the first half and 0.829 for the second half, the Spearman-Brown coefficient was 0.961, the Guttman split-half coefficient was 0.960, and the correlation coefficient between the two halves was 0.924, and the Hotelling's T2 value was found as 445.934, $F = 13.975$, and $p = .000$. Item-subscale correlations were $r = 0.52$ to 0.84 in the heart problems and treatment sub-dimension, $r = 0.80$ to 0.85 in the treatment sub-dimension, $r = 0.72$ to 0.85 in the perceived physical appearance sub-dimension, $r = 0.76$ to 0.91 in the treatment anxiety sub-dimension, $r = 0.59$ to 0.89 in the cognitive problems sub-dimension, and $r = 0.69$ to 0.78 in the communication sub-dimension of the 8–12-years child form ($p < .001$).

The Cronbach's alpha coefficient of the 8–12-years parent form was 0.90, and its sub-dimensions ranged from 0.85 to 0.96 (Table 2). The item-total score correlations of all items were found to be between $r = 0.31$ and 0.74 ($p < .001$). As a result of the split-half analysis,

Table 2
PedsQL 3.0 cardiac module mean scores and Cronbach's coefficients.

	8–12-years- child		13–18-years- child	
Patient Group	M ± SS	Cronbach Coefficients	M ± SS	Cronbach Coefficients
Heart Problems and Treatment	33.03 ± 17.93	0.90	54.55 ± 19.83	0.91
Treatment II	46.13 ± 27.16	0.94	76.40 ± 25.60	0.83
Perceived Physical Appearance	38.35 ± 25.28	0.90	67.53 ± 31.26	0.85
Treatment Anxiety	40.71 ± 23.34	0.93	59.02 ± 27.34	0.95
Cognitive Problems	45.62 ± 23.72	0.91	59.85 ± 22.24	0.89
Communication	47.91 ± 27.07	0.86	64.44 ± 23.98	0.91
Total	41.17 ± 14.94	0.91	62.78 ± 15.01	0.94
Parent Group	8–12-years- parent		13–18-years- parent	
Heart Problems and Treatment	50.47 ± 19.36	0.89	63.65 ± 15.60	0.93
Treatment II	52.83 ± 20.26	0.86	80.85 ± 21.48	0.80
Perceived Physical Appearance	50.79 ± 23.28	0.85	68.45 ± 30.32	0.88
Treatment Anxiety	40.11 ± 26.24	0.96	54.62 ± 35.78	0.99
Cognitive Problems	54.15 ± 21.68	0.91	55.74 ± 22.72	0.90
Communication	42.76 ± 30.34	0.94	54.87 ± 35.74	0.97
Total	49.23 ± 14.24	0.90	63.59 ± 16.57	0.95

Cronbach alpha value was found as 0.812 for the first half and 0.821 for the second half, the Spearman-Brown coefficient was 0.938, the Guttman split-half coefficient was 0.938, and the correlation coefficient between the two halves was 0.883, and the Hotelling's T2 value was found as 442.858, F = 13.879, and $p = .000$. Item-subscale correlations were $r = 0.47$ to 0.79 in the heart problems and treatment sub-dimension, $r = 0.59$ to 0.77 in the treatment sub-dimension, $r = 0.55$ to 0.82 in the perceived physical appearance sub-dimension, $r = 0.85$ to 0.92 in the treatment anxiety sub-dimension, $r = 0.62$ to 0.87 in the cognitive problems sub-dimension, and $r = 0.84$ to 0.92 in the communication sub-dimension of the 8–12-years parent form ($p < .001$).

The Cronbach alpha coefficient of the 13–18-years child form was 0.94, and it ranged from 0.83 to 0.95 for its sub-dimensions (Table 2). The item-total score correlations of all items were found to be between $r = 0.36$ and 0.82 ($p < .001$). As a result of the split-half analysis, Cronbach alpha value was found as 0.904 for the first half and 0.884 for the second half, the Spearman-Brown coefficient was 0.862, the Guttman split-half coefficient was 0.845, and the correlation coefficient between the two halves was 0.758, and the Hotelling's T2 value was found as 491.704, F = 15.383, and $p = .000$. Item-subscale correlations were $r = 0.60$ to 0.83 in the heart problems and treatment sub-dimension, $r = 0.73$ to 0.89 in the treatment sub-dimension, $r = 0.81$ to 0.92 in the perceived physical appearance sub-dimension, $r = 0.80$ to 0.91 in the treatment anxiety sub-dimension, $r = 0.66$ to 0.85 in the cognitive problems sub-dimension, and $r = 0.57$ to 0.81 in the communication sub-dimension of the 13–18-years child form ($p < .001$).

The Cronbach alpha coefficient of the 13–18-year parent form was 0.95, and its sub-dimensions ranged from 0.80 to 0.99 (Table 2). The item-total score correlations of all items were found to be between $r = 0.32$ and 0.70 ($p < .001$). As a result of the split-half analysis, Cronbach alpha value was found as 0.863 for the first half and 0.865 for the second half, the Spearman-Brown coefficient was 0.656, the Guttman split-half coefficient was 0.654, and the correlation coefficient between the two halves was 0.488, and the Hotelling's T2 value was found as 713.913, F = 22.335, and $p = .000$. Item-subscale correlations were $r = 0.69$ to 0.80 in the heart problems and treatment sub-dimension, $r = 0.49$ to 0.76 in the treatment sub-dimension, $r = 0.64$ to 0.88 in the perceived physical appearance sub-dimension, $r = 0.85$ to 0.96 in the treatment anxiety sub-dimension, $r = 0.50$ to 0.83 in the cognitive problems sub-dimension, and $r = 0.83$ to 0.88 in the communication sub-dimension of the 13–18-years parent form ($p < .001$).

Analysis of the relationship between the PedsQL 3.0 cardiac module and the PedsQL 4.0 child and parent reports

There was a high correlation ($r = 0.931$, $p < .001$) between the PedsQL 3.0 Cardiac Module and the PedsQL 4.0 total score 8–12-years child form. Except for the relationship between the treatment II sub-dimension and social functioning/ problems, a moderate and mostly high correlation was found between all other sub-dimensions.

There was a high correlation ($r = 0.825$, $p < .001$) between the PedsQL 3.0 Cardiac Module and the PedsQL 4.0 total score 8–12-years parent form. Except for the relationship between treatment II, perceived physical appearance, treatment anxiety sub-dimension, and physical functioning/ health and activity sub-dimension, a moderate and high relationship was found between all other sub-dimensions.

There was a high correlation ($r = 0.849$, $p < .001$) between the PedsQL 3.0 Cardiac Module total score and the PedsQL 4.0 total score for the 13–18-years child form. There was no correlation between treatment II, communication, and the school sub-dimension. A moderate and high correlation was found between all other sub-dimensions.

There was a high correlation ($r = 0.760$, $p < .001$) between the PedsQL 3.0 Cardiac Module total score and the PedsQL 4.0 total score for the 13–18-year parent form. There was no correlation between communication, physical functioning/ health and activity, and school sub-dimension. A moderate and high level of correlation was found between all other PedsQL 3.0 Cardiac Modules and the PedsQL 4.0 subdimensions (Table 3).

EFA results of PedsQL 3.0 cardiac module 8–12 / 13–18 years child and parent reports

According to the results of the EFA of 8–12-years child form, the Kaiser Meyer-Olkin (KMO) coefficient was 0.771, Bartlett's test ($\chi 2$) value was 3819.88, and $p = .000$, to determine the factor structure of the 27-item scale, principal component analysis, one of the explanatory factor analysis methods, was performed and after factor analysis, it was seen that it contained a 6-factor structure with an eigenvalue above 1.00, which explained 74.3% of the total variance. Of the total explained variance ratio, 31% belonged to the heart problems and treatment sub-dimension (factor loads $r = 0.62$ to 0.91), 14.4% to the treatment sub-dimension (factor loads $r = 0.73$ to 0.91), 11.6% to perceived physical appearance sub-dimension (factor loads $r = 0.65$ to 0.88), 8% to the treatment anxiety sub-dimension (factor loads $r = 0.73$ to 0.92), 5.2% to the cognitive problems sub-dimension (factor loads $r = 0.68$ to 0.91), and 3.9% to the communication sub-dimension (factor loads $r = 0.76$ to 0.79).

According to the results of the EFA of 8–12-years parent form the Kaiser Meyer-Olkin (KMO) coefficient was 0.787, Bartlett's test ($\chi 2$) value was 3394.62, and $p = .000$, to determine the factor structure of the 27-item scale, principal component analysis, one of the explanatory factor analysis methods, was performed and after factor analysis, it was seen that it contained a 6-factor structure with an eigenvalue above 1.00, which explained 70.3% of the total variance. Of the total explained variance ratio, 29% belonged to the heart problems and treatment sub-dimension (factor loads $r = 0.46$ to 0.97), 15.1% to the treatment sub-dimension (factor loads $r = 0.61$ to 0.86), 8.6% to perceived physical appearance sub-dimension (factor loads $r = 0.44$ to 0.94), 7.8% to the treatment anxiety sub-dimension (factor loads $r = 0.88$ to 0.93), 5.2% to the cognitive problems sub-dimension (factor loads $r = 0.58$ to 0.96), and 4.4% to the communication sub-dimension (factor loads $r = 0.87$ to 0.94).

According to the results of the EFA of 13–18-years child from the Kaiser Meyer-Olkin (KMO) coefficient was 0.744, Bartlett's test ($\chi 2$) value was 4452.46, and $p = .000$, to determine the factor structure of the 27-item scale, principal component analysis, one of the explanatory factor analysis methods, was performed and after factor analysis, it was seen that it contained a 6-factor structure with an eigenvalue above 1.00, which explained 81% of the total variance. Of the total explained variance ratio, 39.7% belonged to the heart problems and treatment sub-dimension (factor loads $r = 0.47$ to 0.81), 19% to the treatment sub-dimension (factor loads $r = 0.65$ to 0.93), 8% to perceived physical appearance sub-dimension (factor loads $r = 0.63$ to 0.86), 5.9% to the treatment anxiety sub-dimension (factor loads $r = 0.74$ to 0.91), 4.8% to the cognitive problems sub-dimension (factor loads $r = 0.61$ to 0.90), and 3.4% to the communication sub-dimension (factor loads $r = 0.35$ to 0.97).

According to the results of the EFA of 13–18-years parent from the Kaiser Meyer-Olkin (KMO) coefficient was 0.716, Bartlett's test ($\chi 2$) value was 3767.39, and $p = .000$, to determine the factor structure of the 27-item scale, principal component analysis, one of the explanatory factor analysis methods, was performed and after factor analysis, it was seen that it contained a 6-factor structure with an eigenvalue above 1.00, which explained 77% of the total variance. Of the total explained variance ratio, 28.4% belonged to the heart problems and treatment sub-dimension (factor loads $r = 0.66$ to 0.87), 16.8% to the treatment sub-dimension (factor loads $r = 0.44$ to 0.83), 11.3% to perceived physical appearance sub-dimension (factor loads $r = 0.85$ to 0.88), 8.6% to the treatment anxiety sub-dimension (factor loads $r = 0.78$ to 0.97), 6.5% to the cognitive problems sub-dimension (factor loads $r = 0.69$ to 0.83), and 4.8% to the communication sub-dimension (factor loads $r = 0.63$ to 0.70).

Table 3
Correlation coefficients between PedsQL 3.0 cardiac module and PedsQL 4.0 child and parent reports.

	Physical functioning/ Health and activity	Emotional functioning	Social functioning/ Problems with others	School	Total
8–12-years- child form					
Heart Problems and Treatment	0.659**	0.466**	0.374**	0.615**	0.610**
Treatment II	0.250**	0.283**	0.159	0.233**	0.273**
Perceived Physical Appearance	0.768**	0.887**	0.858**	0.607**	0.901**
Treatment Anxiety	0.737**	0.822**	0.660*	0.491**	0.797**
Cognitive Problems	0.512**	0.616**	0.596**	0.658**	0.675**
Communication	0.576**	0.759**	0.780**	0.423**	0.732**
Total	0.828**	0.778**	0.793**	0.724**	0.931**
8–12-years- parent form					
Heart Problems and Treatment	0.452**	0.673**	0.639**	0.605**	0.744**
Treatment II	0.163	0.426**	0.457**	0.359*	0.409**
Perceived Physical Appearance	0.123	0.821**	0.672**	0.588**	0.614**
Treatment Anxiety	0.050	0.766**	0.647**	0.506**	0.531**
Cognitive Problems	0.604**	0.343**	0.572**	0.272**	0.625**
Communication	0.712**	0.430**	0.793**	0.336*	0.774**
Total	0.469**	0.776**	0.836**	0.597**	0.825**
13–18-years- child form					
Heart Problems and Treatment	0.603**	0.231**	0.196*	0.644**	0.509**
Treatment II	0.464**	0.392**	0.376**	0.158	0.441**
Perceived Physical Appearance	0.765**	0.744**	0.760**	0.366**	0.830**
Treatment Anxiety	0.573**	0.607**	0.350**	0.286**	0.568**
Cognitive Problems	0.553**	0.438**	0.379**	0.606**	0.603**
Communication	0.432**	0.623**	0.382**	0.158	0.501**
Total	0.844**	0.714**	0.564**	0.613**	0.849**
13–18-years- parent form					
Heart Problems and Treatment	0.340**	0.466**	0.486**	0.309**	0.497**
Treatment II	. 215*	. 299**	. 331**	0.187*	0.319**
Perceived Physical Appearance	0.450**	0.816**	0.813**	0.399**	0.758**
Treatment Anxiety	0.277**	0.673**	0.613**	0.383**	0.581**
Cognitive Problems	0.446**	0.356**	0.552**	0.085*	0.472**
Communication	0.028	0.398**	0.332**	0.279	0.289**
Total	0.429**	0.692**	0.731**	0.367**	0.680**

Comparison of PedsQL 3.0 cardiac module 8–12 / 13–18 years child and parent reports with healthy group

Higher scores indicate higher health-related quality of life. For the known group comparison, it is expected that there will be a difference between the scores obtained from the scale. It is seen that there is a difference between the patient and healthy groups in terms of the total scale and sub-dimensions of the 8–12-years child and parent forms. The difference in scores between the patient and the healthy group was quite high, and a statistically significant difference was found between the groups ($p < .001$). It is seen that there is a difference between the patient and healthy groups in terms of the total scale and sub-dimensions of the 13–18-years child and parent forms. A statistically significant difference was found between the groups in terms of all sub-dimensions except for the cognitive problems sub-dimension in the patient group ($p < .001$) (Table 4).

Discussion

Evaluation of quality of life scales in a way to include the subjective experiences of patients and the determination of their relationship with the disease is an important guide in providing adequate education and counseling services to patients (Lee et al., 2020). In patients diagnosed with cardiovascular disease, both the general health level and the satisfaction gained from life can be measured individually, and it can be determined which dimension of the quality of life is particularly affected at the individual level, depending on the returns of the disease. Researchers are interested in understanding children's and adolescents' subjective perceptions, which will help them learn about their quality of life. This has led to an increase in assessment tools that help assess the quality of life among children of different age groups and different health conditions. One of these measures is the Pediatric Quality of Life Inventory 3.0 Cardiac Module. This module has been used in Europe and has been translated into several languages (Varni et al., 2001; Varni & Limbers, 2009).

The translation-back translation method was applied in the language validity of the PedsQL 3.0 Cardiac Module Child and Parent forms. Content validity is the most frequently used method for language validity of measurement tools (Crestani et al., 2017). In the Greek validity and reliability study, the translation-back translation method was applied, and it was determined that there was an agreement between the experts (Drakouli et al., 2016). In this study, the CVI was used to determine the consistency among the experts regarding the items, and the CVI was found to be 0.97 (0.96–1.00). It has been observed that there is excellent agreement between the experts. In the study of Do Nascimento Moraes et al., 2013, after the language validity of the PedsQL 3.0 scale was ensured, children aged 5–18 years, diagnosed with chronic rheumatic heart disease, diagnosed with rheumatic fever, and without any physical or mental comorbidities were included. In the scale, the Spearman correlation coefficient was calculated to evaluate the correlation of each item with its related subscale. The scores of different patient groups were compared according to disease severity for discriminant validity. The test-retest method was used for convergent validity. It has been seen that the scales are valid and reliable in Portuguese (Do Nascimento Moraes et al., 2013). In our study, the scores obtained from the PedsQL 3.0 Cardiac Module and the PedsQL 4.0 and its sub-dimensions were calculated and the correlation between them was examined. A moderate-high level of correlation was found between the PedsQL 3.0 Cardiac Module child and parent report and the PedsQL 4.0 child and parent report total scale scores. However, no relationship was found between the PedsQL 4.0 school dimension and some sub-dimensions of the cardiac module. In the validity and reliability study of the Italian version, PedsQL 3.0 Cardiac Module and PedsQL 4.0 scores were found to have moderate-high correlation (emotional and school sub-dimensions excluded) (Grimaldi Capitello et al., 2021).

Explanatory and confirmatory factor analysis can be used in psychometric scale studies. PedsQL 3.0 Cardiac Module consists of 6 sub-dimensions, each dimension can be evaluated separately by scoring. In adaptation studies of PedsQL 3.0 Cardiac Module in other language,

Table 4
Comparison of the Mean Scores of the Patient and Healthy Groups.

	Patient Group	Healthy Group	Test	
	M ± SS	M ± SS	t	p
8–12-years- child form				
Heart Problems and Treatment	33.03 ± 17.93	78.67 ± 15.64	12.429	0.000
Treatment II	46.13 ± 27.16	96.87 ± 7.62	8.518	0.000
Perceived Physical Appearance	38.35 ± 25.28	79.04 ± 27.55	4.712	0.000
Treatment Anxiety	40.71 ± 23.34	88.09 ± 17.00	12.274	0.000
Cognitive Problems	45.62 ± 23.72	74.55 ± 15.84	7.154	0.000
Communication	47.91 ± 27.07	82.96 ± 23.34	8.466	0.000
Total	41.17 ± 14.94	83.19 ± 12.35	12.923	0.000
8–12-years- parent form				
Heart Problems and Treatment	50.47 ± 19.36	86.31 ± 13.18	14.283	0.000
Treatment II	52.83 ± 20.26	96.91 ± 7.84	8.448	0.000
Perceived Physical Appearance	50.79 ± 23.28	84.43 ± 27.62	4.786	0.000
Treatment Anxiety	40.11 ± 26.24	86.16 ± 20.23	9.928	0.000
Cognitive Problems	54.15 ± 21.68	69.92 ± 15.32	3.239	0.001
Communication	42.76 ± 30.34	69.42 ± 24.63	5.605	0.000
Total	49.23 ± 14.24	83.13 ± 12.73	10.778	0.000
13–18-years- child form				
Heart Problems and Treatment	54.55 ± 19.83	71.42 ± 18.10	4.408	0.000
Treatment II	76.40 ± 25.60	95.92 ± 8.70	10.707	0.000
Perceived Physical Appearance	67.53 ± 31.26	78.08 ± 25.26	2.750	0.006
Treatment Anxiety	59.02 ± 27.34	80.64 ± 24.85	6.497	0.000
Cognitive Problems	59.85 ± 22.24	60.62 ± 20.05	−1.136	0.257
Communication	64.44 ± 23.98	80.00 ± 24.62	4.836	0.000
Total	62.78 ± 15.01	77.02 ± 13.12	7.289	0.000
13–18-years- parent form				
Heart Problems and Treatment	63.65 ± 15.60	89.86 ± 9.82	8.978	0.000
Treatment II	80.85 ± 21.48	96.00 ± 10.20	10.358	0.000
Perceived Physical Appearance	68.45 ± 30.32	85.43 ± 21.61	3.828	0.000
Treatment Anxiety	54.62 ± 35.78	82.54 ± 22.15	6.544	0.000
Cognitive Problems	56.37 ± 23.04	63.33 ± 19.51	−1.017	0.310
Communication	54.87 ± 35.74	80.00 ± 24.62	2.843	0.000
Total	63.71 ± 16.64	83.35 ± 11.98	7.794	0.000

factor analysis was not performed (Do Nascimento Moraes et al., 2013). Although CFA was not performed due to our sample limitations, EFA results confirmed the 6-factor structure of PedsQL 3.0 Cardiac Module. The validity and reliability study conducted by Musallam et al. (2018) included 227 people, aged 8–12 and 13–18, followed by the pediatric cardiology service, and their families. For discriminant validity testing, the known group method was used and included a separate group of 154 healthy children. Spearman's test was used to compare child reports and parent reports. Construct validity was determined using the known group method and a comparison was made between the medians. It was determined that there was a difference between the patient group and the healthy group. The Cronbach's alpha coefficient was found to be 0.91 (Musallam et al., 2018). In this study, similar validity and reliability methods were applied, and Cronbach's alpha reliability coefficients for the PedsQL 3.0 Cardiac Module 8–12- and 13–18-years total scale and sub-dimensions ranged from 0.80 to 0.99. The reliability coefficient is quite high, and it has been determined that the scales are reliable for Turkish society. In this study, we found that the PedsQL 3.0 Cardiac Module 8–12 and 13–18 age total scale and subdimensions scores differed significantly in children with cardiac disease and healthy children. The quality of life decreases in children with CHD who have undergone cardiac surgery. In Raj et al.'s (2019) study involving children and adolescents, significant decreases were found in the overall quality of life in the group with CHD when compared to the healthy control group without CHD (Raj et al., 2019). In a study conducted by Tahiroviç et al. (2018) to evaluate the quality of life of children aged 2–18 years ($n = 114$) after surgery for CHD, a statistically significant difference was found between 13 and 18-year-old children after cardiac surgery and healthy children. According to child and parent evaluation, it has been shown that children with heart surgery for CHD had a lower quality of life than healthy children (Tahiroviç et al., 2018). In the study of Amedro et al. (2015) with 282 children aged 8–18 years with CHD, a limited relationship was found between the severity of heart diseases and their quality of life (Amedro et al., 2015). Erami et al. (2022) evaluated the validity and reliability of the PedsQL 3.0 cardiac module for the Iranian population, a low to moderate relationship was found between the adolescent and their parents' perceptions in all dimensions except communication. Adolescent and parent forms of the PedsQL 3.0 cardiac module were found to be acceptable for use in Iranian society (Erami et al., 2022).

Studies are carried out using the PedsQL 3.0 cardiac module in many languages, and the variables that affect their quality of life are evaluated (Ali et al., 2021; Amodeo et al., 2022; Nurhidayah et al., 2022; Simeone et al., 2022; Xiang et al., 2019). Based on the results of these studies, it is important to evaluate the PedsQL cardiac module, which is a very comprehensive scale, with accurate measurements to increase the general health level and life satisfaction of these patient groups.

Practice implications

This study concluded that the 8–12- and 13–18-years child and parent forms of the PedsQL 3.0 cardiac module are valid and reliable for the Turkish language. Healthcare professionals working with children with heart disease will have access to the highest-evidence short tool for assessing the quality of life of children and families.

Limitations of the study

This study had some limitations. In this study, the test-retest method, which is one of the convergent validity methods, was not applied. Patients who came to regular outpatient follow-ups and their

parents could be re-evaluated. The number of samples was limited as it was recommended to make separate samples for EFA and CFA, we performed only EFA. Quality of life scores could be compared by classifying according to disease severity.

Conclusions

PedsQL 3.0 Cardiac Module's 8–12- and 13–18-year child and parent forms are valid and reliable for the Turkish language. Its use in future research may be useful for clinical management of children with cardiac disease.

Authors statement

Tuba Büşra Altın: Idea/Concept, Design, Supervision, Data Collection and/or Processing, Critical Review, Literature Review, Article Writing, Analysis/ Comment.

Gülçin Özalp Gerçeker: Idea/Concept, Design, Supervision, Data Collection and/or Processing, Critical Review, Literature Review, Article Writing, Analysis/ Comment.

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Ethics committee approval

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

Ali, F., Ladak, L. A., Usmani, A. A., Raza, H. A., Siddiqui, M. T., & Hasan, B. (2021). Health-related quality of life in postcardiac interventional catheterization patients with congenital heart disease: A mixed-methods study protocol from Pakistan. *BMJ Open*, *11*(12), 52989. https://doi.org/10.1136/bmjopen-2021-052989.

Amedro, P., Dorka, R., Moniotte, S., Guillaumont, S., Fraisse, A., Kreitmann, B., ... Picot, M. C. (2015). Quality of life of children with congenital heart diseases: A multicenter controlled cross-sectional study. *Pediatric Cardiology*, *36*(8), 1588–1601. https://doi.org/10.1007/s00246-015-1201-x.

American Heart Association (2019). *Feeding tips for your baby with CHD.* American Heart Association Congenital Heart Defects. https://www.heart.org/en/health-topics/congenital-heart-defects/care-and-treatment-for-congenital-heart-defects/feeding-tips-for-your-baby-with-chd.

Amodeo, G., Ragni, B., Calcagni, G., Piga, S., Giannico, S., Yammine, M. L., ... Grimaldi Capitello, T. (2022). Health-related quality of life in Italian children and adolescents with congenital heart diseases. *BMC Cardiovascular Disorders*, *22*(1), 1–15. https://doi.org/10.1186/s12872-022-02611-y.

Berkes, A., Pataki, I., Kiss, M., Kemény, C., Kardos, L., Varni, J. W., & Mogyorósy, G. (2010). Measuring health-related quality of life in Hungarian children with heart disease: Psychometric properties of the Hungarian version of the pediatric quality of life inventoryTM 4.0 generic Core scales and the cardiac module. *Health and Quality of Life Outcomes*, *8*(14), 1–12. https://doi.org/10.1186/1477-7525-8-14.

Çapık, C., Gözüm, S., & Aksayan, S. (2018). Intercultural scale adaptation stages, language and culture adaptation: Updated guideline. *Florence Nightingale Hemşirelik Dergisi*, *26*(3), 199–210. https://doi.org/10.26650/fnjn397481.

Crestani, A. H., de Moraes, A. B., & de Souza, A. P. R. (2017). Content validation: Clarity/relevance, reliability, and internal consistency of enunciative signs of language acquisition. *CoDAS*, *29*(4), e20160180. https://doi.org/10.1590/2317-1782/201720160180.

Do Nascimento Moraes, A., Ramos Ascensão Terreri, M. T., Esteves Hilário, M. O., & Len, C. A. (2013). Health related quality of life of children with rheumatic heart diseases: Reliability of the Brazilian version of the pediatric quality of life inventoryTM cardiac module scale. *Health and Quality of Life Outcomes*, *11*(1), 1–10. https://doi.org/10.1186/1477-7525-11-198.

Drakouli, M., Petsios, K., & Matziou, V. (2016). OC19 – Measuring feasibility, reliability and validity of the Greek version of PedsQL cardiac module. *Nursing Children and Young People*, *28*(4), 68–69. https://doi.org/10.7748/ncyp.28.4.68.s50.

Erami, H., Hassanabadi, H., Nouri, R., Moradi, A., & Vahidshahi, K. (2022). Psychometric properties of the pediatric quality of life InventoryTM version 3.0 cardiac module in Iranian adolescent with congenital heart disease. *Journal of Psychology*, *25*, 490–508.

González-Gil, T., Mendoza-Soto, A., Alonso-Lloret, F., Castro-Murga, R., Pose-Becerra, C., & Martín-Arribas, M. C. (2012). The Spanish version of the health-related quality of life questionnaire for children and adolescents with heart disease (PedsQLTM). *Revista Española de Cardiología*, *65*(3), 249–257. https://doi.org/10.1016/j.rec.2011.10.012.

Grimaldi Capitello, T., Bevilacqua, F., Vallone, R., Dall'Oglio, A. M., Santato, F., Giannico, S., ... Rossi, A. (2021). Validity and reliability of the Italian version of the cardiac quality of life questionnaire for pediatric patients with heart disease (PedsQLTM). *BMC Cardiovascular Disorders*, *21*(1), 398. https://doi.org/10.1186/s12872-021-02157-5.

Lee, J. S., Cinanni, N., Di Cristofaro, N., Lee, S., Dillenburg, R., Adamo, K. B., ... Longmuir, P. W. (2020). Parents of very young children with congenital heart defects report good quality of life for their children and families regardless of defect severity. *Pediatric Cardiology*, *41*(1), 46–53. https://doi.org/10.1007/s00246-019-02220-1.

Mandalenakis, Z., Giang, K. W., Eriksson, P., Liden, H., Synnergren, M., Wåhlander, H., ... Dellborg, M. (2020). Survival in children with congenital heart disease: Have we reached a peak at 97%? *Journal of the American Heart Association*, *9*(22), 17704. https://doi.org/10.1161/JAHA.120.017704.

Marino, B. S., Drotar, D., Cassedy, A., Davis, R., Tomlinson, R. S., Mellion, K., ... Ittenbach, R. (2011). External validity of the pediatric cardiac quality of life inventory. *Quality of Life Research*, *20*(2), 205–214. https://doi.org/10.1007/s11136-010-9731-4.

Marino, B. S., Tomlinson, R. S., Wernovsky, G., Drotar, D., Newburger, J. W., Mahony, L., ... Shea, J. A. (2010). Validation of the pediatric cardiac quality of life inventory. *Pediatrics*, *126*(3), 498–508. https://doi.org/10.1542/peds.2009-2973.

Maya, S., Gunawijaya, E., Yantie, N. P. V. K., & Windiani, I. G. A. T. (2020). Growth, development, and quality of life in children with congenital heart disease. *Open Access Macedonian Journal of Medical Sciences*, *8*(B), 613–618. https://doi.org/10.3889/oamjms.2020.4047.

Memik, N.Ç., Ağaoğlu, B., Coşkun, A., & Işık, K. (2008). The validity and reliability of pediatric quality of life inventory in 8–12-Year-Old Turkish children. *Çocuk ve Gençlik Ruh Sağlığı Dergisi*, *15*(2), 87–98.

Memik, N.Ç., Ağaoğlu, B., Coşkun, A., Üneri, Ö., & Karakaya, I. (2007). The validity and reliability of the Turkish pediatric quality of life inventory for children 13-18 years old. *Türk Psikiyatri Dergisi*, *18*(4), 353–363.

Musallam, R., Obeidat, H. M., Saleh, M., & Khalaf, I. (2018). Cross-cultural validation of the pediatric quality of life inventory 3.0 cardiac module Arabic language. *International Journal of Applied and Natural Sciences (IJANS)*, *7*(3), 1–10.

Nurhidayah, I., Sari, T. I., & Nuraeni, A. (2022). Dimensions of quality of life among children with congenital heart disease: A survey. *Malaysian Journal of Medicine and Health Sciences*, *18*(S2), 59–63.

O'Neal Maynord, P., Johnson, M., Xu, M., Slaughter, J. C., & Killen, S. A. S. (2021). A multi-interventional nutrition program for newborns with congenital heart disease. *Journal of Pediatrics*, *228*(1), 66–73.e2. https://doi.org/10.1016/j.jpeds.2020.08.039.

Raj, M., Sudhakar, A., Roy, R., Champaneri, B., Sudevan, R., Kabali, C., & Kumar, R. K. (2019). Health-related quality of life (HRQOL) in children and adolescents with congenital heart disease: A cross-sectional survey from South India. *BMJ Paediatrics Open*, *3*(1), e000377. https://doi.org/10.1136/bmjpo-2018-000377.

Sand, P., Kljajić, M., & Sunnegĝrrdh, J. (2013). The reliability of the pediatric quality of life inventory 3.0 cardiac moduleTM for Swedish children with congenital heart defects. *Nordic Psychology*, *65*(3), 210–223. https://doi.org/10.1080/19012276.2013.824204.

Simeone, S., Rea, T., Platone, N., Guillari, A., Lanzuise, A., Assanta, N., Da Valle, P., Baratta, S., & Pucciarelli, G. (2022). Quality of life of families with children presenting congenital heart disease:longitudinal study protocol. *Healthcare*, *10*(7), 1273. https://doi.org/10.3390/healthcare10071273.

Sönmez, S., & Başbakkal, Z. (2007). A validation and reliabilition study for the pediatric quality of life inventory (PedsQL 4.0) on Turkish children. *Turkiye Klinikleri J Pediatr*, *16*, 229–237.

Tahiroviç, E., Begiç, H., Tahiroviç, H., & Varni, J. W. (2018). Quality of life in children after cardiac surgery for congenital heart disease. *Paediatrica Indonesiana*, *57*(6), 285. https://doi.org/10.14238/pi57.6.2017.285-90.

Tsao, C. W., Aday, A. W., Almarzooq, Z. I., Alonso, A., Beaton, A. Z., Bittencourt, M. S., ... Martin, S. S. (2022). Heart disease and stroke statistics—2022 update: A report from the American Heart Association. *Circulation*, *145*(8), e153–e639. https://doi.org/10.1161/cir.0000000000001052.

Turkish Statistical Institute (TUIK) (2020). *İstatistiklerle Çocuk*, 2020. https://www.tuik.gov.tr.

Uzark, K., Jones, K., T.M., B, & J.W., V (2003). The pediatric quality of life inventoryTM in children with heart disease. *Progress in Pediatric Cardiology*, *18*(2), 141–148 https://doi.org/10.1016/S1058-9813(03)00087-0.

Varni, J. W., Burwinkle, T. M., Seid, M., & Skarr, D. (2003). The PedsQLTM* 4.0 as a pediatric population health measure: Feasibility, reliability, and validity. *Ambulatory Pediatrics*, *3*(6), 329–341. https://doi.org/10.1367/1539-4409(2003)003<0329:TPAAPP>2.0.CO;2.

Varni, J. W., & Limbers, C. A. (2009). The PedsQLTM 4.0 generic core scales young adult version: Feasibility, reliability and validity in a university student population. *Journal of Health Psychology*, *14*(4), 611–622. https://doi.org/10.1177/1359105309103580.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQLTM 4.0: Reliability and validity of the pediatric quality of life inventoryTM version 4.0 generic Core scales in healthy and patient populations. *Medical Care*, *39*(8), 800–812. https://doi.org/10.1097/00005650-200108000-00006.

Vemuri, S., Butler, A. E., Brown, K., Wray, J., & Bluebond-Langner, M. (2022). Palliative care for children with complex cardiac conditions: Survey results. *Archives of Disease in Childhood*, *107*(3), 282–287. https://doi.org/10.1136/archdischild-2020-320866.

Virani, S. S., Alonso, A., Aparicio, H. J., Benjamin, E. J., Bittencourt, M. S., Callaway, C. W., et al. (2021). Heart disease and stroke statistics - 2021 update - professional heart daily. *Circulation*, *143*(8), e254–e743. https://doi.org/10.1161/CIR.0000000000000950.

Xiang, L., Su, Z., Liu, Y., Huang, Y., Zhang, X., Li, S., & Zhang, H. (2019). Impact of family socioeconomic status on health-related quality of life in children with critical congenital heart disease. *Journal of the American Heart Association*, *8*(1), e010616. https://doi.org/10.1161/JAHA.118.010616.