

Quality of Life in Children and Adolescents with Congenital Heart Diseases in Zahedan, Iran

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Abstract

Background

Life expectancy has increased in congenital heart diseases (CHD) patients and the interest has risen considering the quality of life (QOL). The study aimed to compare patients and proxy-parents reports on CHD children's QOL.

Materials and Methods

This cross-sectional study performed on 165 CHD patients aged 2-18 years during 2016 using Pediatric Quality of Life 3.0 (PedsQL™ 3.0) inventory. PedsQL™ 3.0 has same dimensions with different question for various age groups. The internal consistency of the inventory scales and subscales was assessed by means of Cronbach's alpha. Scales with reliability ≥ 0.70 were recommended.

Results

The overall mean score of QOL was significantly higher in parents' perceived (51.78 ± 10.87) compared to children's perceived (48.61 ± 11.25) ($t = -2.615$, $P = 0.009$). The anxiety was significantly higher (56.23 ± 17.93 vs. 47.31 ± 17.96) in parents' perceived compared to children ($t = -2.281$, $P = 0.025$). The cognition has been perceived significantly better by children than parents' (51.22 ± 15.76 vs. 41.53 ± 13.15). Children with simple diseases had higher score of quality of life (53.09 ± 13.44) compared with those children with complex diseases (42.73 ± 18.23) ($t = 2.786$, $P = 0.007$) for 2-4 years age in parents' perceived. The mean scores in heart problem scale were 46.74 ± 13.64 and 61.14 ± 18.17 and for the communication scale were 28.49 ± 13.87 and 41.77 ± 20.23 for pre and post operated children respectively for the age group of 5-7 years in parents' perceived.

Conclusion

Resulted no impacts by two clinical (types of diseases and operation) factors on CHD patients' Health-related quality of life (HRQOL). Therefore should be considered more clinical factors to detect the gap in QOL in CHDs.

Keywords: Children, Congenital heart diseases, Iran, Perceived, Quality of Life.

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1- INTRODUCTION

Congenital heart diseases (CHDs) are the most frequent fetal malformations, with a prevalence of 8 in 1000 live births (1). Prevalence of CHD was increasing by time from 7.93 to 17.51 in 1000 live births in Iran (2). Also, the mortality rate of CHD patients has been began to fall and continuing to decrease because of advances in diagnostic, surgical and catheter interventional techniques (3). Life expectancy rises due to these causes in these patients so that has drawn out heightened interest in quality of life issues (4). Demographics studies predicted that there will be a noticeable large number of children with CHD that confirms the attention on these patients. Despite of growing population of these survivors and mentioned promotions and advances in medical and healthcare systems, many of these survivors continually faced with worries and challenges on communicational, cognitional, psychosocial, educational, and behavioral aspects that influence their quality of life (5, 6). The concept of quality of life (QOL) is based on the World Health Organization's definition of health that has been expressed as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or morbidity"(7), and concentrated on the subjective perception of the impact of disease on the various dimension of life. Health-related quality of life (HRQOL) would be considered as an impact or influence of a specific disease or medical therapy on a patient's daily activities and ability to perform in various life contexts (8, 9). Evaluation of HRQOL is important, because it allows for better communication among patients, parents, and health care providers; prioritization of problems in part on the basis of patient and/or parent preferences; monitoring of changes over time or in response to specific therapies; and screening for other significant medical

problems (10). In spite of high advantages, observed lacking of validated surveys and evaluated study of HRQOL in the pediatric population in the area of the study. A more-complete understanding of the impact of CHD on HRQOL in the pediatric population may improve patient-centered medical treatment and outcomes (11). Many of researchers expressed that congenital or acquired cardiovascular diseases exert negative impacts on the HRQOL of patients and their relatives (12-14). The assessment of HRQOL in children and adolescents with heart disease has been used as an important health outcome, to identify groups and subgroups that are at risk, track health habits and to better understand the impact of different diagnoses of heart disease on the quality of life of this population. A recent study of children after the Fontan procedure found that medical and patient's conditions as well as family income are the most important factors to predict these patients health status (15).

Previous studies on the psychological adaptation in children with CHD have identified several predictors that may also be important to change the HRQOL level. These predictors may are: diagnosis of a cyanotic CHD reduced physical capacity, presence and duration of deep hypothermic circulatory arrest and early parental distress (16). Measuring HRQOL in children with CHD is a relatively new technique and its various dimensions might be assessed using different methods and concepts. The Pediatric Quality of Life Inventory™ 3.0 Cardiac Module (PedsQL™ 3.0 Cardiac Module) is a specific instrument that can be easily and quickly applied to measure HRQOL in children and adolescents with heart disease. It is validated for use in clinical practice, where it facilitates the identification of risk, health status, and the results of treatment in pediatric populations with heart disease (12, 17).

Accordance with all the matters above introduced to understand the gap in perception due to self and proxy-parents reports of quality of life, we aimed to evaluate the quality of life in children and adolescents with CHD.

2- MATERIALS AND METHODS

A cross-sectional descriptive and analytical study was utilized to measure the quality of life in children with congenital heart diseases who were collected from Ali Asghar hospital belongs to the Zahedan University of Medical Sciences, Zahedan, Iran, for 8 months from February 2016. The measurements were based on self-child and proxy-parents' reports.

2-1. Participants' population

Our target population included of two groups; patients with CHD age ranged from 2 to 18 years and about equal number of their parents accompanying their children who were attendant as outpatient

2-2. Exclusion criteria

After consulting with the advanced clinical nurse practitioner and a cardiologist specialized, children with identified chromosomal anomalies and other genetic syndromes and children with major chronic diseases were excluded.

2-3. Ethical issues

The study was approved by the local research ethics committee of the Zahedan University of medical Sciences, Zahedan, Iran accordance with the ethical standards of the Helsinki Declaration and founded by children and adolescent health research center of ZaUMS. An independent researcher obtained informed consent from qualifying patients and provided instructions on completing the questionnaires. The patients and their parents who agreed to participate in the study signed consent form and entered to

the study. One hundred and sixty-five patients met inclusion criteria.

After taking participants' consents and providing enough explanation by the project's staffs, the child and proxy-parents' reports questionnaires were distributed. Children were assessed by means of a standardized interview containing a HRQOL assessment instruments. All interviews were conducted at the hospital. Parents were assessed at the same time with the questionnaires. The following medical variables were asked from the patients' parents: type of CHD (classified as cyanotic or non-cyanotic according to the commonly used definitions in pediatric cardiology), heart surgeries.

2-4. HRQOL assessment tool

The difficulty of defining and conceptualizing QOL has been become a constant challenge amongst many researchers, especially in constructing a valid and reliable instrument with scales in all concepts and considering the perception is under development on the different individuals.

In general, the QOL assessment tools in childhood have little congruence in relation to the content covered, with different conceptions about normal childhood development in different age groups and the importance of family function and social context as factors that are necessary for their well-being. The broad spectrum of contents and the variety of scales and items investigated in the QOL instruments in childhood, reflect the differences in their process of preparation, theoretical line used, target population and application (18). Solans performed a systematic review on instruments of QOL for children and adolescents and found the existence of 30 generic and 64 specific-disease instruments that published within 5 years from 2001. Samples of generic instruments for pediatric population were: "Pediatric Quality of Life Inventory

(PedsQL)", "Autoquestionnaire de Qualité de Vie Enfant Imagé (AUQUEI)", "Child Health Questionnaire (CHQ)" and "Kid screen" (18). The PedsQL 3.0 instrument used for the CHD group in this study was provided and developed by Varni that is using to assess HRQOL and has well-documented reliability and validity in the pediatric patients and healthy populations(19). To assess quality of life, patients and their parents completed the PedsQL 3.0 with various items in various age groups. The PedsQL 3.0 scales were composed of parallel child self-report and parent proxy-report formats.

The Parents' report for Toddlers (age 2-4) of the PedsQL 3.0 Cardiac Module has been composed of 23 items comprising 6 dimensions (number of items) that are: 1- Heart problems and Treatment (7), 2- Treatment II (3), 3- Perceived Physical Appearance (3), 4- Treatment Anxiety (4), 5- Cognitive Problems (3) and 6- Communication (3). Child an parent reports for young children (ages 5-7) of the PedsQL 3.0 Cardiac Module has been composed of 25 items comprising 6 dimensions (number of items) that are: 1- Heart problems and Treatment (7), 2- Treatment II (3), 3- Perceived Physical Appearance (3), 4- Treatment Anxiety (4), 5- Cognitive Problems (5) and 6- Communication (3).

Also, child an parent reports for children (ages 8-12) and teens (ages 13-18) of the PedsQL 3.0 Cardiac Module has been composed of 27 items comprising 6 dimensions (number of items) that are: 1- Heart problems and Treatment (7), 2- Treatment II (5), 3- Perceived Physical Appearance (3), 4- Treatment Anxiety (4), 5- Cognitive Problems (5) and 6- Communication (3). Five answer options were listed in the versions for children 8 to 18 years old and their parents (0 = it is never a problem; 1 = it is almost never a problem; 2 = it is sometimes a problem; 3 = it is often a problem; and 4 = it is almost

always a problem). The answers in the version for children 5 to 7 years old was simplified to three options (0 = not at all; 2 = sometimes; and 4 = a lot) on a visual analog scale that exhibited a happy, neutral, and sad face, respectively. The items were reverse scored and linearly transformed to a 0–100 scale (0 = 100; 1 = 75; 2 = 50; 3 = 25; and 4 = 0) so that higher scores indicated a better HRQOL. The mean score was computed as the sum of all the items over the number of items answered in taking into account the missing data.

The following stages proceed by the authors on the original version of the PedsQL 3.0 Cardiac Module. First, the original English version of the PedsQL 3.0 Cardiac Module was independently translated into Persian by two faculty members in the field of health followed by a joint discussion to combine the two independent versions into a single. Then this issued version backward to original language by two Persian-English bilingual persons .This process conducted according to the international guideline for questioner translation (forward-backward translation).

A pilot study performed on 20 patients with heart disease and their parents at an outpatient setting from, five children in each age range (2-4, 5 -7, 8-12, and 13- 18 years old), and their parents were interviewed, for a total of 40 individuals, to assess their responses to the questions and identify possible mistakes and difficulties resulting from the translation. After that, the efforts of the investigators were devoted to achieving linguistic and conceptual equivalence. The cross-cultural adaptation of the questionnaire was performed during this stage to achieve semantic equivalence (equivalence between words), idiomatic equivalence (equivalent expressions or items needing substitution). The internal consistency of

the PedsQL™ 3.0 Cardiac Module Scale and Subscales was assessed by means of Cronbach's alpha. Scales with reliability ≥ 0.70 are recommended to compare groups of patients. The **Table.1** showed Cronbach's alpha for all dimensions and respondents in specific age group and overall. Application of the questionnaire carried on an average of 10 minutes for both children and parents.

2-5. Statistical study

Statistical analyses were performed using the SPSS 19 (SPSS, Chicago, IL, USA). First, the clinical variables were subjected to descriptive analysis. The numerical variables were expressed as the means and standard deviations (SD), and the categorical variables were expressed as absolute and relative frequencies. The distribution of all the variables was tested. Differences for parametric variables were established using Student's t-tests. For that purpose 0.05 error regarding 95% confidence interval (CI) were considered.

Table-1: Cronbach's alpha for all dimensions and respondents in specific age groups

Age group	Responsive	Dimension	Cronbach's Alpha for each dimension	Total Cronbach's Alpha
2_4 years	Parents	Heart Problems and Treatment	0.763	0.89
		Treatment II	0.752	
		Perceived Physical Appearance	0.857	
		Treatment Anxiety	0.81	
		Cognitive Problems	0.73	
		Communication	0.825	
5_7 years	Parents	Heart Problems and Treatment	0.758	0.89
		Treatment II	0.837	
		Perceived Physical Appearance	0.75	
		Treatment Anxiety	0.752	
		Cognitive Problems	0.721	
		Communication	0.754	
	Patients	Heart Problems and Treatment	0.774	0.89
		Treatment II	0.835	
		Perceived Physical Appearance	0.779	
		Treatment Anxiety	0.773	
		Cognitive Problems	0.783	
		Communication	0.910	
8_12 years	Parents	Heart Problems and Treatment	0.903	0.87
		Treatment II	0.916	
		Perceived Physical Appearance	0.808	
		Treatment Anxiety	0.964	
		Cognitive Problems	0.786	
		Communication	0.832	
	Patients	Heart Problems and Treatment	0.905	0.84
		Treatment II	0.821	
		Perceived Physical Appearance	0.779	

		Treatment Anxiety	0.947	
		Cognitive Problems	0.881	
		Communication	0.945	
13_18 years	Parents	Heart Problems and Treatment	0.951	0.92
		Treatment II	0.823	
		Perceived Physical Appearance	0.835	
		Treatment Anxiety	0.774	
		Cognitive Problems	0.779	
		Communication	0.773	
	Patients	Heart Problems and Treatment	0.951	0.93
		Treatment II	0.778	
		Perceived Physical Appearance	0.835	
		Treatment Anxiety	0.777	
		Cognitive Problems	0.799	
		Communication	0.773	

3- RESULTS

Descriptive results of patients are observed in **Table.2** and **Table.3**. Sex distribution of patients was not equally, with more boys taking part in the study. The sample of participants consisted of 94(57%) boys and 71(43%) girls that they distributed in four age groups of 2-4 years, 5-7 years, 8-12years and 13-18 years with 46%, 30%, 16% and 8%, respectively. Hundred five (65%) participants had simple diseases and of them 59(55.1%) had undergone surgery when this measure were 87(52.7%) for overall patients. **Table.4** showed means and standard deviation (SD) of the PedsQL scores and its dimensions for different age groups regarding self- child and the proxy-parent's reports. The overall mean score of PedsQL was significantly higher in parents' perceived (51.78±10.87) compared to children's perceived (48.61±11.25) ($t= -2.615$, $P=0.009$). Same pattern occurred for age groups of 5-7 and 13-18 years. Children in the age group of 8-12 years perceived higher score of PedsQL compared to parents, but not significantly. The dimensions of PedsQL; treatment, physical activities and communication showed that they have

similar scores in both children and parents' perceived for all age groups. Dimension of heart problem showed a significant difference in favor of parents for the overall age groups compared with children perceived ($P<0.001$). The results showed that for this specific dimension did not observe any dissimilarity for each specific age group in the study. The anxiety dimension was significantly higher (56.23 ±17.93 vs. 47.31± 17.96) in parents' perceived compared to children ($t= -2.281$, $P=0.025$). Children and parents had different perceived in regard of cognition scale. This dimension has been perceived significantly better by children than parents' (51.22±15.76 vs. 41.53± 13.15).

Table.5 showed comparison of health related quality of life and its dimensions between children with simple and complex heart diseases in various age groups for children and parents' perceived separately. For the first age group 2-4 years, the parents filled out the inventory and the results showed that the first dimension affected by type of diseases such that in parents' perceived, the heart problem dimension, children with simple diseases (53.09±13.44) had higher score of quality

of life compared with those children with complex diseases (42.73 ± 18.23) ($t=2.786$, $P=0.007$). The results for the age group of 5-7 did not show any significant differences between the type of diseases for all dimensions and HRQOL in both children and parents' perceived. Same trend could be observed for the age group of 13-18. Communication as a dimension for the quality of life, showed a significant difference in mean between the two types of diseases in the case of children perceived. **Table.6** showed comparison of health related quality of life and its dimensions between pre and post operated children in various age groups regarding children and parents' perceived. For the age group of 2-4 the children could not fill out the inventory. Therefore for this specific age group we consider the results for the parents' perceived. The t- test analysis revealed any differences between pre and post operated children in the

parents' perceived in the mean of scores for HRQOL and its dimensions. Similar pattern could be observed for the age groups of 8-12 and 13-18 for both children and parents' perceived. But the age group of 5-7 showed the valuable results for the dimensions of heart problem and communication. The results could be seen in the table that tells us a significant differences between pre and post operated children so that for the heart problem the mean scores were 46.74 ± 13.64 and 61.14 ± 18.17 and for the communication dimension means score were 28.49 ± 13.87 and 41.77 ± 20.23 for pre and post operated children respectively. Similar to type of disease that not influenced the patients HRQOL in self and proxy- parents' reports, surgical operation had same effect. If any different observed due to these factors, the differences was in low age groups because of not adaptation in early years of their life.

Table-2: Sex distribution frequency of participants in different age groups

Gender	Statistics	Age groups (year)				Total
		2-4	5-7	8-12	13-18	
Female	Number	33	21	10	7	71
	%	44.0%	42.0%	37.0%	53.8%	43.0%
Male	Number	42	29	17	6	94
	%	56.0%	58.0%	63.0%	46.2%	57.0%
Total	Number	75	50	27	13	165
	%	100.0%	100.0%	100.0%	100.0%	100.0%

Table-3: Type of diseases frequency distribution in pre and post operated children

Type of disease	Statistics	Operation		Total
		Pre	Post	
Simple	n	48	59	107
	%	44.9%	55.1%	100.0%
Complex	n	30	28	58
	%	51.7%	48.3%	100.0%
Total	n	78	87	165
	%	47.3%	52.7%	100.0%

Table-4: Comparison of health related quality of life and its dimensions between children and parents' perceived for different age groups

Dimensions	Age groups (year)	Participant	Mean	SD	t-test	P-value	
Heart Problem	2_4	Children					
		Parents	49.27	16.09			
	5_7	Children	52.54	14.56	-1.056	0.294	
		Parents	56.29	17.52			
	8_12	Children	53.01	18.01	0.416	0.679	
		Parents	50.96	21.12			
	13_18	Children	55.82	19.08	-1.636	0.121	
		Parents	66.16	14.29			
	Total	Children	46.13	18.57	3.404	<0.001	
		Parents	53.01	17.85			
	Treatment	2_4 y	Children				
			Parents	67.28	17.63		
5_7 y		Children	61.69	19.79	-1.715	0.090	
		Parents	68.45	16.67			
8_12 y		Children	61.81	12.79	1.152	0.254	
		Parents	57.88	13.19			
13_18 y		Children	80.00	16.04	0.153	0.880	
		Parents	79.23	9.09			
Total		Children	63.51	20.23	-1.760	0.079	
		Parents	67.14	16.84			
Physical activities		2_4	Children				
			Parents	54.59	12.64		
	5_7	Children	52.39	13.38	0.135	0.893	
		Parents	52.00	13.19			
	8_12	Children	49.51	12.59	-0.052	0.960	
		Parents	49.69	14.61			
	13_18	Children	57.61	14.26	-0.661	0.515	
		Parents	61.31	15.35			
	Total	Children	51.53	12.08	-1.430	0.154	
		Parents	53.55	13.55			
	Anxiety	2_4	Children				
			Parents	46.98	19.74		
5_7		Children	47.31	17.96	-2.281	0.025	
		Parents	56.23	17.93			
8_12		Children	62.44	15.68	1.217	0.228	
		Parents	57.54	16.03			
13_18		Children	69.58	19.89	-0.758	0.455	
		Parents	75.05	18.00			
Total		Children	48.73	22.02	-2.136	0.033	
		Parents	53.67	19.95			

Communication	2_4	Children					
		Parents	38.82	12.98			
	5_7	Children	35.22	14.71	-0.476	0.647	
		Parents	36.96	19.19			
	8_12	Children	49.47	18.79	0.924	0.359	
		Parents	45.14	17.89			
	13_18	Children	60.00	21.18	-0.190	0.851	
		Parents	61.54	21.66			
	Total	Children	39.18	19.32	-0.933	0.352	
		Parents	41.09	17.70			
	Cognition	2_4	Children				
			Parents	48.17	16.79		
5_7		Children	29.88	7.89	0.378	0.706	
		Parents	29.21	8.25			
8_12		Children	51.22	15.76	2.588	0.012	
		Parents	41.53	13.15			
13_18		Children	58.33	16.61	-0.198	0.845	
		Parents	59.71	20.27			
Total		Children	42.61	16.19	0.131	0.896	
		Parents	42.36	17.25			
HRQOL		2_4	Children				
			Parents	50.96	10.32		
	5_7	Children	46.51	8.90	-1.679	0.097	
		Parents	49.86	9.36			
	8_12	Children	54.27	7.59	1.734	0.088	
		Parents	50.52	8.98			
	13_18	Children	63.56	10.91	-0.846	0.405	
		Parents	67.17	11.66			
	Total	Children	48.61	11.25	-2.615	0.009	
		Parents	51.87	10.87			

SD: Standard deviation; HRQOL: Health-related quality of life.

Table-5: Comparison of health related quality of life and its dimensions between children with simple and complex heart diseases in various age groups for children and parents' perceived

Participants											
Parents							Children				
Dimensions Of QOL	Types Of diseases	N	Mean	SD	t-test	P-value	N	Mean	SD	t-test	P-value
2_4 years age groups											
Heart Problem	Simple	45	53.09	13.44	2.786	0.007					
	Complex	28	42.73	18.23							
Treatment	Simple	45	69.51	14.83	1.285	0.203					
	Complex	30	64.17	21.23							
Physical Appearance	Simple	45	56.08	12.13	1.507	0.136					
	Complex	30	51.68	12.79							
Anxiety	Simple	45	49.11	18.49	1.163	0.248					

	Complex	30	43.68	21.68							
Communication	Simple	45	40.20	13.26	1.483	0.142					
	Complex	30	35.82	11.39							
Cognitive problems	Simple	45	49.67	16.33	0.963	0.339					
	Complex	30	45.83	17.74							
HRQOL peds 3.0	Simple	45	52.94	10.10	2.590	0.012					
	Complex	30	46.84	9.86							
5_7 years age groups											
Heart Problem	Simple	30	52.36	19.48	-1.627	0.110	22	54.86	17.08	1.180	0.246
	Complex	20	60.63	14.29			15	49.14	9.30		
Treatment	Simple	30	67.52	10.70	-0.446	0.658	22	60.21	21.43	-	0.588
	Complex	20	69.66	22.92			15	63.87	17.60		
Physical Appearance	Simple	30	53.50	13.50	1.141	0.259	22	52.23	16.44	-	0.928
	Complex	20	49.19	12.50			15	52.64	7.39		
Anxiety	Simple	30	55.85	18.45	-0.001	0.999	22	46.11	18.59	-	0.628
	Complex	20	55.86	17.62			15	49.08	17.47		
Communication	Simple	30	37.11	18.07	0.175	0.862	22	35.78	17.63	0.276	0.785
	Complex	20	36.14	20.95			15	34.40	9.41		
Cognitive problems	Simple	30	28.49	7.12	-0.564	0.575	22	29.59	8.06	-	0.787
	Complex	20	29.84	9.88			15	30.31	7.88		
HRQOL peds 3.0	Simple	30	49.14	8.56	-0.391	0.697	22	46.46	8.52	-	0.971
	Complex	20	50.22	10.93			15	46.57	9.73		
8_12 years age groups											
Heart Problem	Simple	17	50.05	19.19	-0.729	0.473	29	54.50	15.90	1.669	0.104
	Complex	10	56.07	23.21			6	41.56	23.56		
Treatment	Simple	16	59.81	8.71	1.088	0.288	27	62.22	13.32	0.614	0.544
	Complex	9	53.89	18.67			6	58.61	11.47		
Physical Appearance	Simple	17	51.96	12.59	0.436	0.667	29	48.92	11.67	-	0.917
	Complex	10	49.26	19.68			6	49.51	16.94		
Anxiety	Simple	17	59.72	15.52	0.742	0.465	29	62.57	16.16	-	0.627
	Complex	10	55.07	16.12			6	65.97	10.89		
Communication	Simple	17	49.57	20.25	1.099	0.282	29	45.98	18.04	-	0.013
	Complex	10	41.78	12.35			6	66.67	14.91		
Cognitive problems	Simple	17	44.41	12.06	0.930	0.361	29	51.38	14.19	-	0.537
	Complex	10	39.75	13.45			6	55.63	19.82		
HRQOL peds 3.0	Simple	16	52.41	7.72	0.673	0.508	27	53.85	8.32	-	0.486
	Complex	9	49.96	10.36			6	56.32	3.82		
13_18 years age groups											
Heart Problem	Simple	9	69.57	11.13	1.329	0.211	12	55.65	17.23	-	0.949
	Complex	4	58.50	19.33			3	56.48	30.23		
Treatment	Simple	9	79.44	9.82	0.122	0.905	12	79.17	16.63	-	0.703
	Complex	4	78.75	8.54			3	83.33	16.07		
Physical Appearance	Simple	9	63.73	17.66	0.840	0.419	12	55.06	9.03	-	0.175
	Complex	4	55.88	7.37			3	67.81	27.93		
Anxiety	Simple	9	74.38	16.61	-0.193	0.850	12	67.19	20.14	-	0.370
	Complex	4	76.56	23.59			3	79.17	19.09		

Communication	Simple	9	60.19	18.06	-0.325	0.751	12	59.03	20.24	-	0.736
	Complex	4	64.58	31.46			3	63.89	29.27		
Cognitive problems	Simple	9	60.00	19.47	0.074	0.943	12	57.08	13.16	-	0.579
	Complex	4	59.06	25.15			3	63.33	30.55		
HRQOL peds 3.0	Simple	9	67.88	12.22	0.320	0.755	12	62.20	7.31	-	0.353
	Complex	4	65.56	11.85			3	69.00	22.00		

Table-6: Comparison of health related quality of life and its dimensions between pre and post operated children in various age groups for children and parents' perceived

Participants											
Parents							Children				
Dimensions Of QOL	Operation	N	Mean	SD	t-test	P-value	N	Mean	SD	t-test	P-value
2_4 years age groups											
Heart Problem	pre	33	48.05	14.43	-	0.613					
	post	40	49.99	17.57	0.508						
Treatment	pre	35	67.21	18.03	-	0.941					
	post	40	67.52	17.70	0.074						
Physical Appearance	pre	35	53.77	9.10	-	0.723					
	post	40	54.80	14.96	0.355						
Anxiety	pre	35	45.36	19.73	-	0.522					
	post	40	48.33	20.13	0.643						
Communication	pre	35	39.43	13.28	-	0.534					
	post	40	37.59	12.18	0.624						
Cognitive problems	pre	35	45.55	14.86	-	0.217					
	post	40	50.40	18.39	1.245						
HRQOL peds 3.0	pre	35	49.43	9.96	-	0.408					
	post	40	51.44	10.78	0.833						
5_7 years age groups											
Heart Problem	pre	19	46.74	13.64	-	0.005	25	54.60	14.71	1.252	0.219
	post	31	61.14	18.17	2.973		12	48.25	13.84		
Treatment	pre	19	63.67	17.75	-	0.116	25	60.85	21.24	-	0.713
	post	31	71.26	15.28	1.602		12	63.46	17.09		
Physical Appearance	pre	19	51.35	9.63	-	0.859	25	53.98	12.56	1.044	0.303
	post	31	52.04	15.06	0.179		12	49.08	14.97		
Anxiety	pre	19	57.81	15.99	-	0.552	25	45.15	17.77	-	0.298
	post	31	54.65	19.19	0.600		12	51.81	18.28		
Communication	pre	19	28.49	13.87	-	0.015	25	34.67	13.37	-	0.748
	post	31	41.77	20.23	2.516		12	36.37	17.76		
Cognitive problems	pre	19	29.49	6.90	-	0.760	25	30.76	9.36	0.982	0.333
	post	31	28.75	9.10	0.307		12	28.04	2.60		
HRQOL peds 3.0	pre	19	46.26	8.44	-	0.052	25	46.67	8.47	0.159	0.875
	post	31	51.60	9.64	1.991		12	46.17	10.12		
8_12 years age groups											
Heart Problem	pre	7	40.52	20.65	-	0.078	15	55.11	15.16	0.814	0.421

	post	20	56.40	19.33	1.840		20	50.16	19.54		
Treatment	pre	6	62.50	4.18	1.034	0.312	14	61.07	15.48	-	0.854
	post	19	56.16	14.64			19	61.93	11.09		
Physical Appearance	pre	7	56.02	5.04	1.019	0.318	15	49.51	10.12	0.199	0.843
	post	20	49.19	17.28			20	48.65	14.16		
Anxiety	pre	7	48.31	17.67	-	2.018	15	62.36	17.44	-	0.795
	post	20	61.39	13.71			20	63.75	13.92		
Communication	pre	7	48.81	15.54	0.359	0.723	15	45.00	16.31	-	0.229
	post	20	45.94	18.95			20	52.92	20.64		
Cognitive problems	pre	7	42.50	10.68	-	0.045	15	50.25	10.81	-	0.535
	post	20	42.75	13.39			20	53.50	17.72		
HRQOL peds 3.0	pre	6	48.76	8.00	-	0.899	14	53.19	8.16	-	0.487
	post	19	52.40	8.84			19	55.12	7.48		
13_18 years age groups											
Heart Problem	pre	2	53.93	15.05	-	1.362	7	65.37	21.52	2.000	0.067
	post	11	68.38	13.68			8	47.45	12.63		
Treatment	pre	2	82.50	10.61	0.536	0.603	7	82.86	16.55	0.631	0.539
	post	11	78.64	9.24			8	77.50	16.26		
Physical Appearance	pre	2	53.43	0.00	-	0.776	7	63.37	19.98	1.532	0.149
	post	11	62.74	16.37			8	52.57	1.59		
Anxiety	pre	2	87.50	8.84	1.069	0.308	7	67.86	21.17	-	0.766
	post	11	72.79	18.56			8	71.09	20.03		
Communication	pre	2	70.83	5.89	0.643	0.533	7	59.52	20.09	-	0.939
	post	11	59.85	23.22			8	60.42	23.46		
Cognitive problems	pre	2	45.63	7.95	-	1.075	7	58.75	15.63	0.088	0.932
	post	11	62.27	20.97			8	57.97	18.50		
HRQOL	pre	2	65.64	3.44	-	0.194	7	66.29	13.54	0.901	0.384
	post	11	67.45	12.70			8	61.17	8.18		

4- DISCUSSION

The results of the present study showed that the overall mean score of PedsQL was significantly higher in the proxy-parents report compared to self-report such that in the cognition dimension, this difference was in the favor of self-report in age group of 8-12 years, in anxiety, the difference was in favor of parents' perceived in the age group of 5-7 years. For the age group of 2-4 years, children with simple diseases had higher quality of life in the heart problems. Communication score was lower for children with sample diseases in self-perceived. In comparison of quality of life scores between pre and post-surgical operation in CHD patients, heart problems

and communication had lower scores in pre operation in proxy-parent reports for the age group of 5-7 years. Karsdorp demonstrated that young people had lower quality of life compared to their elder counterparts in the behavior problems (20). Along with Karsdorp study, Ternestedt showed a large impact on elder patients' quality of life (16). Our results confirmed by these studies' findings (16, 20). Teixeira concluded a non-significant difference of QOL between age groups (21) in which was dissimilar with our results. Landolt revealed that the child's age was correlated with self-reported of quality of life positively and was correlated with proxy-parent report negatively in overall or some

of QOL dimensions (22). The results of the present study showed that the quality of life in overall and in some of the dimensions was higher in the elder age groups of adolescents or children in which was similar with Ternestedt (16) and dissimilar with Teixeira (21). Different methodologies have limited our study to be compared with other studies results directly. Some important studies have been involved in chronic disease groups in children with end-stage renal disease, epilepsy and cystic fibrosis (23), so that has been reported that children with diabetes experience had less reduction in QOL compared to other chronic diseases.

Brosig confirmed higher quality of life reported by parents of children with CHD than parents of children with other chronic diseases (24). In our study we received to the conclusion that overall QOL and the dimension of heart problem had different scores between proxy-parent and self-reports in favor of parents. It means that parents had better perception and understanding about the problems of heart. In the case anxiety scale different perception was observed for age group of 5-7 years in favor of parents. In the cognition scale, the significant variation observed in favor of children aged 8-12 years. And finally for the total HRQOL score, this significant higher of the score was in favor of parents. In conclusion would be reported that parents had better perceived of their children about the quality of life. Spijkerboer found that children with CHD had more negative views compared their parents in overall quality of life and some of its dimensions (25). Lawoko reported some parental problems with children who suffered from CHD in different areas of the QOL in compared with own children perceived (26). Similarly, Buechel (27) and Landolt (22) revealed that proxy-parents reports showed a poorer HRQOL in their children than the child's reports. Eiser conducted a

study in assessing quality of life in cancer survivors to compare the self- children and proxy-mothers perception. Despite the lengthy treatment, survivors of all form cancers did not consider their lives to be significantly at risk compared with a healthy population. Eiser had also Quoted a poorer quality of life in total and the dimensions from parents side compared to survivors from Grootendorst and Ennett's studies (28). Arafa resulted that parents had better perception on HRQOL than own children (29). The most HRQOL dimensions were impaired in self- report. These dimensions were autonomy, motor, social, and emotional functioning. But in proxy- parents reports the dimension of cognitive functioning were low (22). Several studies showed that children with CHD have different level in quality of life and some of its dimensions regarding the severity of illness. In our study not observed significant differences between quality of life and the dimensions scores based on the severity of diseases (complex and simple) except the communication dimension that was in favor of patients with complex diseases. Uzark (12) reported that the proxy- parents perceived on overall quality of life level was not significantly different in young CHD children with severity diseases, but children with more severe cardiovascular disease had worse physical and psychosocial quality of life that was comparable with our results. Similarly, Ternestedt compared several patient subgroups and showed that not only the severity of illness, but also the presence of cyanosis had not an impact on HRQOL (16). Knowles showed that children with serious CHDs experience lower QOL than unaffected (30) similar with Uzark (12), Ternestedt (16) in confirming our results, but Knowles (30) result was dissimilar. Uzark reported that parents perceived of quality of life was not significantly different in young children with cardiovascular disease, but children with

more severe cardiovascular disease have worse physical and psychosocial quality of life. One in 5 children with cardiovascular disease perceives impaired psychosocial functioning, including children with mild disease severity. Arafa Revealed that severity of illness and type of heart defect were associated significantly with poorer HRQOL (29). Contrary to the results by Krol (31) that showed HRQOL in children with congenital heart disease was not influenced by severity of disease. Similar to Krol (31), DeMaso (32) found non-significant relationship between the severity of congenital heart defect and quality of life. Teixeira reported that no significant differences in QOL scores were related to the severity of the illness and patients with better social support had better QOL in general and across all dimensions. Females had greater social support than the male participants and consequently better quality of life. In some of dimension, Teixeira also reported that patients who were satisfied with their physical abilities had better QOL in overall, physical and psychological dimensions (21). The effect of surgery on HRQOL scores has been studied by many researchers. In these terms we concluded that surgery in overall had not significant impact on the CHD patients' QOL and the dimensions for all age groups based on the both proxy-parents and self-reports. But in two specific scales we observed significant impacts. First, heart problem scores showed a higher value for post-operation due to proxy-parent perceived for 5-7 years age group; and communication was the second exception that followed same trends. Ternstedt reported similar findings with our results (16). Some studies identified that QOL after cardiac surgery was measured worse for children with cardiac defects using child self-report in comparison with 'healthy' group reports (33-35), when we found better QOL.

Children with more 'severe' CHDs rated QOL lower, although 'severe' was variously defined as cyanosis (33). Or type of intervention (12). Recent studies showed that children with CHD undergone cardiopulmonary bypass surgery may be faced with decreasing in the quality of life at follow-up (15, 22, 25, 36). To compare our results with mentioned researches' results in majority would be found same results in limited studies in contrary. The main implications that can be drawn from our findings are that children with CHD are particularly affected in terms of physical functioning in infancy and cognitive functioning in higher age.

4-1. Study limitation

The PedsQL as a generic measure of HRQOL may lack sensitivity for specific problems of children with CHD. However, the PedsQL has successfully been used in children with a variety of different CHD diseases and has been shown that it would be a valid and reliable measure allowing comparison between different groups of CHD patients accordance.

5- CONCLUSION

It should be noted that the PedsQL is a subjective measurement toll for QOL for chronic diseases accordance with self and parents-proxy reports; therefore, different caregivers and different tools to measure the quality of life may rate the child's quality of life differently with many reported, but overall from the present study concluded that the gap between self and proxy-parents reports diminished by age. The results of the present study showed any impacts by two clinical (types of diseases and operation) factors on CHD patients' HRQOL regarding self and proxy-parents reports.

6- CONFLICT OF INTERESTS

The authors would like to declare for not any conflict of interests.

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