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Quality of Life in Children after Cardiac Surgery for Congenital Heart Disease

Elnur Tahirović[1], Hidajeta Begić[2], Husref Tahirović[3] and James W. Varni[4]

[1] University of Sarajevo, Sarajevo University Clinical Center, Heart Center, Sarajevo, Bosnia and Herzegovina
[2] Tuzla University Clinical Centre, Department of Paediatrics, Tuzla, Bosnia and Herzegovina
[3] Tuzla University Clinical Centre, Department for Research and Education, Tuzla, Bosnia and Herzegovina
[4] Texas A&M University, College of Medicine, Department of Pediatrics and College of Architecture, Department of Landscape Architecture and Urban Planning, College Station, Texas, USA

ABSTRACT

The aim of this study was to assess the quality of life children after cardiac surgery for congenital heart disease (CHD) and to compare these results with healthy children. To assess the quality of life children after surgery for CHD we performed a cross-sectional study of 114 patients who were patients at the Department of Paediatrics in Tuzla, between the ages of 2 and 18 years, of both sexes, and with one of their parents. We used the »PedsQL™ 4.0 Generic Core Scales«, with both child self-report and parent proxy-reports. By self assessment, the PedsQL total scores for quality of life were statistically significantly different between children after cardiac surgery for ages 13 to 18 years and healthy children, while by parent report PedsQL total scores were statistically significantly different between children after cardiac surgery for ages 5 to 7 years and healthy children. By self assessment, children after cardiac surgery for ages from 5 to 7 and 13 to 18 years reported that they have a statistically significantly lower quality of life in the segment school functioning compared to the healthy children. By parental assessment, children after cardiac surgery for ages 2 to 4, 5 to 7 and 8 to 12 years have a statistically significantly lower quality of life in the segments of physical and psychosocial health, emotional, social and school functioning. The results of our study indicate that children after cardiac surgery for CHD by self and parent assessment have a lower quality of life than healthy children.

Key words: *quality of life, congenital heart disease, cardiac surgery, PedsQL™*

Introduction

Major achievements in non-invasive diagnostic, invasive and cardio-surgical treatment over the past twenty years have significantly altered the course and prognosis of congenital heart disease (CHD). Foetal echocardiograms and neonatal screening for CHD have resulted in that most CHDs are identified early in life, with interventions typically initiated in the neonatal or infant. This has resulted in a reduction in infant mortality from CHD pathology, and an increase in long-term survivability. Despite all the measures taken to treat these patients, they still may experience interrupted regular education, limitations to movement and activities, disturbed social relationships with their parents and the environment, problems in adjustment, including physical, psychosocial, cognitive and emotional difficulties.

The possible causes of these difficulties are chronic hypoxia in the pre-surgical period, intraoperative cerebral distress, possible residual changes as well as long-term hospitalization and over-protection by parents who limit social contact. All this can lead to the fact that the quality of life of patients with CHD is somewhat poorer than that of the healthy population.

In a search of the literature, we found that several research teams[1–5] in their studies found that the quality of life of patients with CHD after surgical correction of the anomaly was somewhat poorer in comparison with a group of healthy children. According to Moons et al.[6] in some patients CHD may be considered to be a chronic state which creates special problems when the symptoms

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of the illness affect the daily activities of the patient and when the barriers caused by the disease affect the quality of their life. However, other research[7,8,9,10] found that patients with CHD after surgical correction of the anomaly have a normal quality of life in relation to their peers, and that most of those children do not have any limitations in their daily life.

The aim of this research is to investigate whether the quality of life of children after cardiac surgery for CHD differs from that of healthy subjects as perceived by the children and their parents in Bosnia and Herzegovina.

Materials and Methods

Geographical location of the research site

The Tuzla Canton area is situated in the north–eastern part of Bosnia and Herzegovina and has an area of 782,649 km^2 with a population in 2007 of 496,380 with 106,092 children aged 0–18 years. In the same period the neonatal mortality rate was 16/1000 of live births[11].

Subjects

The study included 114 children after surgery for congenital heart disease, who were patients at the Paediatric Clinic in Tuzla, between ages 2 and 18 years, of both sexes, and one of their parents. Time after surgical intervention was at least one year. Exclusion criteria for the patients were clinical evidence of chronic disease, developmental disorders or some other disease which could influence HRQOL. The patients were divided according to ages into the following groups: from 2 to 4 years (n =18), from 5 to 7 years (n=25), from 8 to 12 years (n =32) and from 13 to 18 years (n=39). 53 boys and 61 girls were involved in the study.

The control group was formed by matching each patient with one or two healthy control subjects which together with his parents came to visit children who are due to different diseases treated at the Department of Pediatrics in Tuzla. The subjects in the control group were selected by random selection, but they had to meet the following criteria: they did not suffer from heart or other chronic diseases, they were resident in the Tuzla Canton and they were the same age and sex as the patients.

In filling out the questionnaire, the parents and children of studied and control group were informed about what the data requested was for and that by filling out the questionnaire they were giving their consent to taking part in the research.

Methods

A cross-sectional study was performed to evaluate the health-related quality of life of children after surgery for congenital heart defects. User agreement was signed with MAPI Research Institute, Lyon, France, prior to using the questionnaires. We used the PedsQL™ 4.0 Generic Core Scales[12] which are brief, very easy to use, resulting in minimal missing data, and include both parent proxy-reports and child self-reports. The PedsQL™ 4.0 Generic Core scales was adopted for the following age groups: from 2 to 4 years, from 5 to 7 years, from 8 to 12 years and from 13 to 18 years. The PedsQL scales are composed of parallel child self-report and parent proxy report formats. The 23-item PedsQL 4.0 Generic Core Scales encompass Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items) Scales. To create the Psychosocial Health Summary score, the mean is computed as the sum of the items divided by the number of items in the Emotional, Social, and School Functioning scales. The Physical Health Summary Score is same as the Physical Functioning Scale.

A 5-point Likert scale is used for the child self-report for ages 8 to 18 years and the parent proxy report (0, never a problem; 1, almost never a problem; 2, sometimes a problem; 3, often a problem; 4, almost always a problem). For additional ease of use for the young child self-report (ages 5–7 years), the Likert scale was reworded and simplified to a 3-point scale (0, not a problem; 2, sometimes a problem; 4, a big problem). Items are reverse-scored and linearly transformed to a scale from 0 to 100 points such that higher scores indicate better HRQOL[13]. The average time required to complete the PedsQL™ was ten to fifteen minutes.

Scale internal consistency reliability for the PedsQL™ 4.0 Generic Core Scales was determined by calculating Cronbach's coefficient alpha[13]. The value of Cronbach's for PedsQL 4.0 Generic Core Scales in the study ranged from 0.73 to 0.84 which is in an acceptable range for group comparisons (from 0.70 to 0.90).

Statistical analysis

Data are presented as absolute and relative numbers, means ± standard deviation. Comparisons between groups were made by using t-test. Level of significance was defined with $p<0.05$. In the analysis we used the statistical package Arcus QuickStat Biomedical version[14].

Results

The PedsQL 4.0 Generic Core Scales were completed by 114 children who had undergone cardio-surgical correction for CHD. All 114 children came for checkups to the Cardiology Department, Tuzla Children's Hospital. Of this number, 108 children were tested directly; four were tested by phone and two by e-mail. The data on school activities, due to non-attendance of kindergarten or school (due to age) are lacking in 25 children. Self-reported PedsQL™ scales were completed for 96 children older than 5, along with parent proxy-reported PedsQL™ scales for their children for all 114 subjects, of which 98 or 86% were filled in by the mother and 16 or 14% by the father. Of the total of 114 subjects, 53 or 46.5% were male and 61 or 53.5% were female. In the first age group (2–4 years) there were 18 subjects, in the second (5–7 years) 25, in the third (8–12 years) 32 and in the fourth (13–18 years) 39 subjects.

All 114 subjects with cardio-surgically corrected CHD were hemodynamically stable at the time of testing, without signs of heart failure, pulmonary hypertension or cyanosis. The average age at the time of testing was 10.1 years (±4.5) and the average period since the cardio-surgical correction was 3.8 years (±3.2).

This research is part of a comprehensive survey on the quality of life of children after heart surgery in Bosnia and Herzegovina so that the description of the patients and their clinical and demographic characteristics (Table 1 and Table 2) have already been published in our previous article (15).

Table 1 shows the hemodynamic and diagnostic structure of CHD in children whose quality of life was examined.

The quality of life in subjects in the control group was assessed in 127 healthy children using the PedsQL 4.0 Generic Core Scales. In the first age group (2–4 years) there were 19 subjects, in the second age group (5–7) 25, in the third (8–12) 44 and in the fourth (13–18) 39 subjects. Of the total of 127 subjects in the control group 63 or 49.6% were male and 64 or 50.4% were female. The demographic data of children after surgery for congenital heart defects and the control group are shown in Table 2.

The results of the quality of life test in children after surgery for the CHD and control groups are shown in Table 3.

As shown in Table 3, toddlers in the control group have a better quality of life in physical health and activities, psychosocial health, emotional and social functioning. In the opinion of the parents there was a statistically significant difference in the school functioning in children aged 5–7, 8–12, 13–18, as well as physical health and activities, psychosocial health, emotional functioning in children aged 5–7 and 8–12.

The group of children age of 8–12 years reported that there are not significant problems in all parts of HRQOL but the parents found their children to be significantly less competent in physical and psychosocial health, emotional, social and school functioning. Teens aged 13–18

TABLE 1
HEMODYNAMIC AND DIAGNOSTIC STRUCTURE OF CONGENITAL HEART DISEASE

Level of hemodynamics disorders		Type of congenital heart disease	N
Group 1	Anomalies with the left-right shunt		62
	Atrial shunt	Atrial septal defect	24
	Ventricular shunt	Atrioventricular septal defect	5
		Ventricular septal defect	23
	Arterial shunt	Patent ductus arteriosus	8
		Aorto-pulmonary artery shunt	2
Group 2	Obstructive anomalies		21
	Obstruction of the pulmonary circulation	Pulmonary stenosis	7
		Mitrale valve stenosis	1
	Obstruction of the systemic circulation	Aortic stenosis	4
		Coarctation of the aorta	9
Group 3	Complex anomalies		31
	Enlarged pulmonary circulation	Transposition of great arteries	9
		Total anomalous pulmonary venous connection	2
		Univentricular heart	1
	Reduction of the pulmonary circulation	Tetralogy of Fallot	14
		Pulmonary atresia	5

TABLE 2
DEMOGRAPHIC DATA OF CHILDREN AFTER SURGERY FOR CONGENITAL HEART DEFECTS AND CONTROL GROUP

Demographic data	Children after surgery for congenital heart defects			Control group		
	N	Male N (%)	Female N (%)	N	Male N (%)	Female N (%)
Age (year)						
2–4	18	9	9	19	14	5
5–7	25	12	13	25	10	15
8–12	32	17	15	44	23	21
13–18	39	15	24	39	16	23
Total	114	53 (46.5)	61 (53.5)	127	63 (49.6)	64 (50.4)

TABLE 3
THE RESULTS OF THE PEDIATRIC QUALITY OF LIFE INVENTORY™ IN CHILDREN AFTER SURGERY FOR THE CONGENITAL HEART DISEASE AND CONTROL GROUPS

PedsQL™ Scale	CACSCHD*		Control group		Different	t	P
	N	$\overline{X}$±SD	N	$\overline{X}$±SD			
Toddler (2–4 y)							
Proxy-report							
Total score	18	84.71±15.5	19	95.22±7.8	10.52	0.19	0.4243
Physical health	18	89.4±14.9	19	97.2±6.6	7.80	2.28	0.0288
Psychosocial health	18	83.0±12.1	19	94.7±7.2	11.72	3.42	0.0016
Emotional functioning	18	78.3±13.6	19	90.3±10.3	11.95	3.15	0.0033
Social functioning	18	87.3±19.2	19	98.1±4.8	10.88	2.46	0.0186
School functioning	–	–	19	97.9±4.2	–	–	–
Young child (5–7 y)							
Self report							
Total score	25	84.5±20.9	25	88.8±9.59	4.3	0.19	0.1832
Physical health	25	88.7±8.5	25	91.1±6.4	2.45	1.5	0.1402
Psychosocial health	25	88.1±9.4	25	88.5±8.3	0.49	0	1
Emotional functioning	25	85.5±12.2	25	84.2±11.8	–1.30	0.30	0.7601
Social functioning	25	92.0±10.8	25	90.0±10.3	–2	0.70	0.4829
School functioning	18	61.7±41.6	25	90.5±9.4	28.89	2.93	0.0060
Proxy-report							
Total score	25	82.72±20.0	25	92.69±8.31	9.97	2.32	0.0123
Physical health	25	89.6±11.4	25	94.5±6.6	4.87	1.99	0.0517
Psychosocial health	25	84.7±9.8	25	92.6±7.2	9.76	3.50	0.001
Emotional functioning	25	79.6±11.0	25	93.2±9.6	13.56	3.34	0.0016
Social functioning	25	91.0±10.4	25	94.4±8.8	3.40	1.17	0.2473
School functioning	17	62.0±39.5	18	93.9±7.8	31.88	3.31	0.0022
Child (8–12 y)							
Self-report							
Total score	32	88±20.9	44	90.4±10.1	2.4	0.57	0.2842
Physical health	32	91.3±13.2	44	92.4±8.8	1.14	0.53	0.5922
Psychosocial health	32	86.8±12.5	44	89.9±7.6	3.02	1.37	0.1747
Emotional functioning	32	83.1±15.3	44	85.0±12.3	1.88	0.64	0.5207
Social functioning	32	91.4±10.3	44	93.5±8.6	2.06	0.96	0.3362
School functioning	32	87.5±16.6	44	91.2±10.8	3.75	1.33	0.1847
Proxy-report							
Total score	32	87.03±15.3	44	91.86±9.55	4.83	1.44	0.0759
Physical health	32	90.3±13.2	44	96.1±6.4	5.80	2.69	0.0087
Psychosocial health	32	85.8±12.8	44	90.8±6.8	4.95	2.38	0.0195
Emotional functioning	32	81.0±18.1	44	83.8±11.0	2.76	0.59	0.5505
Social functioning	32	92.2±8.6	44	95.6±7.0	3.47	1.73	0.0866
School functioning	32	85.7±19.6	44	92.9±10.2	7.17	2.08	0.0408
Teen (13–18 y)							
Self-report							
Total score	39	89.4±12.4	39	83.9±14.6	–5.5	1.69	0.0472
Physical health	39	88.4±14.4	39	86.4±12.5	–1.99	0.67	0.5002
Psychosocial health	39	89.6±8.9	39	83.4±12.2	–6.19	2.59	0.0113
Emotional functioning	39	82.3±14.0	39	75.8±16.8	–6.54	2.12	0.0372
Social functioning	39	94.1±10.2	39	91.7±11.0	–2.44	1.32	0.1892
School functioning	39	92.3±10.8	39	82.6±15.7	–9.74	3.46	0.0009
Proxy-report							
Total score	39	88.5±13.8	39	85.9±15.8	–2.6	0.94	0.741
Physical health	39	88.0±12.6	39	87.8±14.0	–0.24	0.33	0.7358
Psychosocial health	39	89.2±11.7	39	85.4±13.7	–3.76	1.46	0.1465
Emotional functioning	39	81.1±14.0	39	77.0±20.4	–4.05	1.03	0.3094
Social functioning	39	92.9±12.2	39	92.8±11.6	–0.12	0	1
School functioning	39	91.5±16.0	39	86.7±14.4	–4.87	1.46	0.146

*Children after cardiac surgery for congenital heart disease

years reported problems in physical and psychosocial health, emotional and school functioning, while their parents reported that there are no significant statistical different in the HRQOL.

Discussion

An analysis of the quality of life assessed by a general health-related quality of life measure in all 114 children after cardio-surgical correction of CHD in relation to the control subjects showed a wide range of expected and unexpected results. The possible reason for these results is the clinical heterogeneity of the tested population, with the domination of children after surgery for CHD with a left to right shunt. The stable clinical status of children after surgery for CHD at the time of testing and the time passed since the cardio-surgical correction up to the assessment period, are significant factors, which to a great extent affect the subjective assessment of some segments of the quality of life, by their own assessment, as well as the parents' assessment.

In children after surgery for CHD aged from 2 to 4 years, according to the parents, the quality of life was statistically significantly lower in terms of physical health, psychosocial health and emotional and social functioning, in relation to the control subjects. Uzark et al.[16] in their research found that according to the parental assessment in children from 2 to 4 years with cardiovascular diseases, there was only a statistically significant difference in terms of emotional functioning in relation to healthy children of the same age. However in that study, in contrast to the results of our research, the values they received for some segments of the quality of life for this age group were higher than the values for the older age groups. These differences could be explained by the presumption that the parents of children of this age group were younger and without a certain amount of parental experience, so some of the expected problems encountered by children at this age were interpreted as results of their illness.

According to self-assessment in children after surgery for CHD aged 5 to 7, there was a statistically significantly poorer quality of life in terms of school activities in relation to the control subjects, whilst according to the parents the quality of life in children after surgery of CHD was weaker in terms of school activities, psychosocial and emotional health in relation to the control subjects. Other authors[17,18] in their studies have also stated that school activities are more impaired in children with CHD and that school activities and cognitive function are more impaired in children with complex heart anomalies. In our research only 20% of children in this age group had complex CHD. One of the important reasons for these results is the time that passed since the operation before testing, that is, the fact that most of our subjects underwent surgery precisely at pre-school age. Our study confirms the previous research[17,19] that school activities are also related to certain psycho-social weaknesses. These authors also state that more impaired cognitive development and school activities are also caused by the poorer social economic status of the family. This may have a very negative effect on children after surgery for CHD and cause those children to be depressive, withdrawn, dissatisfied and poorly motivated for their activities in various fields of life.

Comparing the results of the assessment of the quality of life in children after surgery for CHD aged from 8 to 12 according to their own assessment, with those of their healthy peers, it is noticeable that there is no statistically significant difference in any of the segments. However, according to the parents, the quality of life of the same subjects was statistically significantly lower in the segment of physical health and activity, psycho-social health and school activities than their healthy peers.

By comparing the results of the assessments of the quality of life by children after surgery for CHD aged 13 to 18 and their parents, we did not find that their quality of life was lower than that of the subjects in the control group. The segments of psycho-social and emotional health and school activities, in the opinion of children after surgery for CHD, were statistically significantly better than the healthy patients, whilst the results of the parents' assessment showed that there was no statistically significant difference in relation to the control group. Favarato et al.[7] in their study in patients aged 12 to 19, found that 91% of the patients assessed that their quality of life was good, based on the fact of the lack of symptoms of their illness or restriction in normal activities. In contrast to our results, Uzark et al.[16] in their research found that the quality of life in children with heart diseases aged 13–18 years, according to their own assessment, was different in the segments of physical health and activity, psycho-social health and in social and school activities, whilst according to the parents' assessment, the differences were in the segments of psycho-social and emotional health and school activities. Uzark et al. reported also that the disease severity measured by the PedsQL™ influence of HRQOL so that children with complex or severe cardiovascular disease, uncorrectable or palliated (includes single ventricle) have significant lower HRQOL reported by both parent and self-report in comparison with children with mild cardiovascular disease and healthy children[16].

Conclusion

The results of our assessment indicate that it is exceptionally important to monitor the quality of life of children after surgery for CHD both immediately after surgery and during their later growth and development. Examining the quality of life of the patients should be a continuous process so that any disturbances may be noticed in good time and resolved. For this reason it is vital for experts to be involved alongside the doctors, such as psychologists, social workers and the patients' teachers. This would enable this population to have a normal life just like their peers. It is also of extreme importance for children after surgery for CHD to be integrated into ev-

eryday life in their own homes and society as a whole, without feeling that they are different from other children, and in that way problems can be avoided which would reduce the quality of their lives.

Limitations of the Research

The present study has several potential limitations. First, study included a relatively small number of patients after cardiac surgery for congenital heart disease. Second, the current study only included mothers, which could have affected the results, thereby limiting the conclusions that may be drawn regarding the fathers. Finally, the study was cross-sectional, limiting conclusions regarding causality; a longitudinal design is required to understand the true causal nature of the relationship between specific problems of children after cardiac surgery for congenital heart disease and HRQOL.

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E. Tahirović

Heart Center Sarajevo, Clinical Center University of Sarajevo, Bolnička 25, 71000 Sarajevo, Bosna i Hercegovina
e-mail: elnur.tahirovic@gmail.com

KVALITETA ŽIVOTA DJECE S KONGENITALNIM SRČANIM OBOLJENJIMA NAKON OPERACIJE SRCA

S A Ž E T A K

Cilj ovog istraživanja bio je procijeniti kvalitetu života djece s kongenitalnim srčanim oboljenjima nakon operacije srca te usporediti dobivene rezultate sa rezultatima zdrave djece. U svrhu procjene kvalitete života provedena je transverzalna studija 114 pacijenata Odjela za pedijatriju u Tuzli, u dobi od 2 do 18 godina, oba spola i s jednim od roditelja. Koristili smo »PedsQL™ Generic Core« skalu, sa samoprocjenom djeteta te procjenom roditelja. Kod samoprocjene, rezultati skale za kvalitetu života su bili statistički značajno različiti između djece nakon operacije srca, u dobi od 13 do 18 godina, i zdrave djece. Za razliku od toga, kod procjene roditelja rezultati su bili statistički značajno različiti između djece nakon operacije srca, u dobi od 5 do 7 godina, i zdrave djece. Kod samoprocjene, djeca nakon operacije srca u dobi od 13 do 18 godina i od 5 do 7 godina su svoju kvalitetu života u području funkcioniranja u školi procijenila statistički značajno nižom u usporedbi sa zdravom djecom. Prema procjeni roditelja, djeca nakon operacije srca u dobi od 2 do 4 godine, od 5 do 7 godina i od 8 do 12 godina imaju statistički značajno nižu kvalitetu života, s obzirom na fizičko i psihosocijalno zdravlje te emocionalno i društveno funkcioniranje, kao i funkcioniranje u školi. Rezultati ove studije pokazuju da djeca sa kongenitalnim srčanim oboljenjima nakon operacije srca imaju nižu kvalitetu života od zdrave djece, kako prema samoprocjeni, tako i prema procjeni roditelja.