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Original Article

Quality of life in children with congenital heart disease after cardiac surgery

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Abstract

Background Major achievements in congenital heart disease (CHD) treatment over the past 20 years have altered the course and prognosis of CHD. Improvement of quality of life (QoL) is now a major goal of CHD treatment.

Objective To assess the QoL in children after cardiac surgery for CHD.

Methods A cross-sectional study was performed in children aged 2 to 18 years. The case group had 20 children with a history of corrective heart surgery in the 12 months prior to the study. The control group had 20 healthy children, age-matched to the case group. The QoL of both groups was assessed by Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales. The same post-operative children were also assessed with the PedsQL Cardiac Module. Data were analyzed using T-test with $P < 0.05$ as the level of significance.

Results This study recruited 40 subjects: 20 post-operative and 20 healthy children. PedsQL Generic Core Scales assessment showed significant differences between groups in the physical function parameter of QoL ($P<0.05$) in children aged 13-18 years, but there were no significant differences in the social, emotional, and school function parameters. In children aged 2-12 years, there were no significant differences in physical, social, emotional, or school parameters. The PedsQL Cardiac Module assessment revealed that 35% of post-operative children was at risk for physical appearance problems, 80% was at risk for anxiety problems, 40% was at risk for cognitive problems, and 80% was at risk for communication problems.

Conclusion Thirteen to 18-year-old children with non complex CHD have poorer physical function than healthy children. Post operative children are at risk for physical appearance, anxiety, cognitive, and communication problems. **[Paediatr Indones. 2017;57:285-90 ; doi: http://dx.doi.org/10.14238/pi57.6.2017.285-90]**.

Keywords: *quality of life; children; cardiac surgery; congenital heart disease*

Congenital heart disease (CHD) is still a devastating problem in many countries worldwide.[1,2] Despite the measures taken to treat these patients, they may experience educational, physical, social, cognitive, and emotional problems. Thus these children are at risk for having a poor quality of life (QoL).[3]

Cardiac surgery is one of the many modalities of CHD treatment. Major achievements in cardio-surgical treatment over the past 20 years have altered the course and prognosis of CHD. Both palliative and corrective surgery aims to improve QoL.[4-7] Several studies have shown that the QoL of children with CHD after surgical correction was poorer in comparison with healthy children.[3,8,9] A study in Poland assessed QoL

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in subjects 10 years after corrective cardiac surgery. The study showed that exercise capacity, physical activity, and QoL of young adults with a history of surgical treatment for CHD were worse than observed in healthy peers, and their health status did not fulfill the definition of complete recovery.[10] These results were different from other studies which showed that post-cardiac surgical children have similar QoL with healthy children.[11,12] To date, there have been few studies on QoL in children after cardiac surgery in Indonesia. Thus we aimed to assess QoL in children with CHD after cardiac surgery compared to age-matched, healthy peers in Haji Adam Malik General Hospital, Medan, North Sumatera, Indonesia.

Methods

A cross-sectional study was performed from April 2014 to April 2015 in the Pediatric Cardiology Outpatient Clinic, Haji Adam Malik General Hospital, Medan, North Sumatera, Indonesia. The case group comprised children with CHD, aged 2 to 18 years, with a history of corrective heart surgery in the 12 months prior to study. The control group comprised healthy children without physical, emotional, social, and educational problems, who were age-matched to the case group. The subjects were divided based on age: 2-4 years, 5-7 years, 8-12 years, and 13-18 years. Hemodynamically unstable children, children with developmental and mental problems, and children with other chronic diseases that can affect QoL were excluded. Data were collected on subjects' age, sex, CHD type, surgery type, and residual CHD after surgery. Quality of life was assessed using the *Pediatric Quality of Life Inventory* (PedsQL). *The Generic Core Scales Version 4.0 PedsQL* was used in post-operative and healthy children, while the PedsQL Cardiac Module was used to assess disease-specific QoL in post-operative children.[3]

Data are presented as absolute numbers, means, and standard deviations. Comparisons between groups were analyzed by T-test. Level of significance was defined as $P < 0.05$. For the analysis, we used the *SPPS version 18* statistical package software. This study was approved by the Ethics Committee of University of Sumatera Utara Medical School, Medan.

Results

Subjects' characteristics are described in **Table 1**. There were 20 post-operative children and 20 healthy children. CHD types were ventricular septal defect (VSD), atrial septal defect (ASD), patent ductus arteriosus (PDA), tetralogy of Fallot (ToF), and transposition of great arteries (TGA).

Table 1. Demographic data of subjects

Characteristics	Post-operative children (n=20)	Healthy children (n=20)
Age, n		
2-4 years	8	8
5-7 years	4	4
8-12 years	3	3
13-18 years	5	5
Sex, n		
Male	15	15
Female	5	5
CHD type		
VSD	10	
ASD	1	
PDA	5	
ToF	4	
TGA	-	
Mean post-op duration (SD),* years	1.6 (0.6)	

*time from surgery until QoL examination

The post-operative children's characteristics are shown in **Table 2**. The surgery types were VSD closure, ASD closure, PDA ligation, and total correction for ToF. Four children had residual shunt after surgery. Almost all surgeries were conducted with cardiopulmonary bypass (CPB), with the exception of PDA ligation.

The results of the QoL assessment in children with CHD after cardiac surgery and control group are shown in **Table 3**. There were no significant differences of QoL in post-operative and healthy children in the age groups of 2-4 years, 5-7 years, and 8-12 years. However, in the 13-18-year age group, both parent and child reported poorer physical function in post-operative children ($P < 0.05$).

Disease-specific QoL results from the PedsQL Cardiac Module are shown in **Tables 4** and **Table 5**. Response scale in PedsQL was 0 (never a problem), 1

Table 2. Post-operative children's characteristics

No	Age, years	Sex	Diagnosis	CPB	Surgery type	Post-op duration, months	Residual shunt
1	3.4	M	Large VSD	+	VSD closure	25	-
2	4	M	VSD + PDA	+	VSD closure + PDA ligation	12	+
3	3	M	ToF	+	Total correction	14	-
4	4	M	Moderat VSD	+	VSD closure	20	-
5	2.6	F	Large PDA	-	PDA ligation	22	-
6	4	F	Large PDA	-	PDA ligation	22	-
7	3	M	Large PDA	-	PDA ligation	14	-
8	3	M	Large VSD	+	VSD closure	22	-
9	6.5	M	Moderate VSD	+	VSD closure	22	-
10	6	M	Moderate VSD	+	VSD closure	12	-
11	7	M	ToF	+	Total correction	12	-
12	5.6	F	ToF	+	Total correction	32	-
13	11	F	Large PDA	-	PDA ligation	24	-
14	10	M	Large VSD	+	VSD closure	24	-
15	11	M	Large ASD	+	ASD closure	26	-
16	18	M	Large VSD	+	VSD closure	12	-
17	14	M	Large VSD	+	VSD closure	36	+
18	17	M	ToF	+	Total correction	20	-
19	14	F	Large PDA	-	PDA ligation	14	+
20	13	F	Large VSD	+	VSD closure	13	+

CPB=cardiopulmonary bypass
Post-op duration=time from surgery until QoL examination in months

(almost never a problem), 2 (sometimes a problem), 3 (often a problem), and 4 (almost always a problem). These scales was converted to 0-100; being 0=100, 1=75, 2=50, 3=25, 4=0. We concluded a child was at risk of having a problem if the scale response was < 75. Both parent and child report showed that some postoperative CHD children had risk for physical appearance, anxiety, cognitive, and communication problems.

Discussion

Children with CHD are at risk for poor QoL. Despite the measures taken to treat these patients, they may experience interrupted education, limited movement and activities, disturbed social relationships with their parents and/or the environment, as well as problems in adjustment, including physical, social, cognitive, and emotional difficulties.3 Major achievements in cardio-surgical treatment over the past 20 years have altered the course and prognosis of CHD. Both palliative and corrective surgery aims to improve QoL.[4,5]

Our study showed that post-operative children aged 13-18 years had poorer physical function than healthy children, while social, emotional, and school function showed no significant differences in this age group. It was probable that this difference was caused by residual shunt, late diagnosis and late surgery in 13-18 years old group (mean post operative duration was 19 months prior to study). There were no significant differences of QoL in the age groups of 2-4 years, 5-7 years, and 8-12 years. The physical function parameter of the PedsQL includes walking, running, doing exercise or sport activites, taking a bath, and doing chores at home. Social function is how the child gets along with other children. Emotional function includes feelings of fear, sadness, worry, anger, and trouble sleeping. School function is how the child studies, such as difficulty paying attention, keeping

Table 3. PedsQL assessment in both groups

PedsQL	Post-operative children		Healthy children		P value
	N	Mean (SD)	N	Mean (SD)	
2-4 years					
Parent report					
Physical	8	88.9(6.32)	8	93.5(4.40)	0.11
Emotional	8	83.7(5.82)	8	83.1(6.51)	0.84
Social	8	87.5(8.86)	8	87.5(4.62)	0.10
5-7 years					
Parent report					
Physical	4	85.4(7.35)	4	92.5(5.00)	0.16
Emotional	4	81.2(10.3)	4	81.2(10.3)	0.10
Social	4	88.7(13.1)	4	88.7(6.29)	0.10
School	4	78.7(4.78)	4	80.0(7.07)	0.78
Child report					
Physical	4	91.3(3.90)	4	93.7(4.78)	0.90
Emotional	4	89.6(3.59)	4	87.5(5.00)	0.73
Social	4	93.7(4.78)	4	91.2(2.50)	0.39
School	4	78.7(2.50)	4	75.0(7.07)	0.25
8-12 years					
Parent report					
Physical	3	93.7(5.42)	3	98.3(2.88)	0.26
Emotional	3	66.6(10.4)	3	69.8(10.4)	0.10
Social	3	85.0(13.2)	3	88.3(7.63)	0.72
School	3	85.0(5.00)	3	81.6(2.88)	0.10
Child report					
Physical	3	91.3(3.36)	3	93.3(5.77)	0.14
Emotional	3	88.3(2.88)	3	91.3(5.77)	0.49
Social	3	83.3(7.63)	3	86.6(2.88)	0.51
School	3	78.3(7.63)	3	85.0(5.00)	0.11
13-18 years					
Parent report					
Physical	5	89.3(5.22)	5	92.1(4.41)	0.03
Emotional	5	80.0(14.5)	5	78.0(11.51)	0.81
Social	5	76.0(14.3)	5	76.0(6.51)	0.10
School	5	80.0(9.35)	5	80.0(6.12)	0.10
Child report					
Physical	5	89.35(7.17)	5	95.0(3.53)	0.00
Emotional	5	86.00(8.21)	5	84.0(4.18)	0.69
Social	5	85.00(13.2)	5	89.0(7.41)	0.57
School	5	84.00(6.51)	5	86.0(8.21)	0.23

up with studies, and missing work or school because of illness.[13]

A study in Tuzla, which also used the PedsQL to assess QoL, showed that post-operative children aged 2-4 years, 5-7 years, and 8-12 years had poorer QoL than healthy children in the parameters of physical, emotional, social, and school function. But in children aged 13-18 years, there were no significant differences in QoL.[3] The difference may be due to the Tuzla study including all types of surgery (palliative and corrective) and complex CHD. In contrast, our study only assessed QoL after corrective heart surgery with no complex CHD.

Disease-specific QoL assessment using the PedsQL Cardiac Module showed that post-operative CHD children were at risk for physical appearance, anxiety, cognitive, and communication problems. Physical appearance tends to be a problem among children aged 8-12 years and 13-18 years and was associated with post-operative scars. Most children felt ashamed of their disease and post-operative scars. These children are also at risk for anxiety problems before going to the hospital, meeting the physician, or having a medical procedure. Some also found it difficult to communicate about their heart disease with other people.

Table 4. PedsQL cardiac module assessment based on parent report

No	Age, years	Heart	Therapy	Physical appearance	Anxiety	Cognitive	Communication
1	3.4	100	100	100	25	66	25
2	4	85.7	-	100	75	66.6	33.3
3	3	96	-	91.6	93.75	91.6	75
4	4	92.82	-	100	81.25	83.3	91.6
5	2.6	92.8	-	91.6	56.25	83	66
6	4	96	-	83	62.5	75	75
7	3	96.4	-	83	31.25	83	33
8	3	75	-	83	93.7	75	66.6
9	6.5	96.4	-	83.3	75	75	50
10	6	100	-	83	81.25	80	75
11	7	96.4	-	83	62.5	80	83
12	5.6	89.2	-	83.3	43.75	65	50
13	11	100	-	41.6	68.75	85	66.6
14	10	92.5	-	80	50	80	50
15	11	89.2	-	65	56.2	55	75
16	18	85.7	100	66	66.6	80	75
17	14	100	-	75	75	80	80
18	17	92.8	-	75	68.75	85	58.3
19	14	89	-	70	56.25	70	75
20	13	89.2	95	66.6	75	80	83
Mean (SD)		94.5 (8.6)	98.3 (2.9)	81.9 (11.7)	62.5 (20.9)	76.2 (8.1)	64.7 (18.5)

Table 5. PedsQL cardiac module assessment based on child report

No	Age, years	Heart	Therapy	Physical appearance	Anxiety	Cognitive	Communication
1	6.5	96.4	-	66	50	70	66.6
2	6	96.4	-	75	81.25	85	75
3	7	96.4	-	75	62.5	70	66.6
4	5.5	96.4	-	91.6	50	50	50
5	11	100	-	58.3	62.5	90	50
6	10	92.8	-	83.3	87.5	60	58.3
7	11	92.8	-	50	50	55	66.6
8	18	82.14	100	75	68	50	83
9	14	96.4	-	50	50	85	58.3
10	17	92.8	-	83.3	50	75	50
11	14	96.4	100	58	50	65	66
12	13	92.8		66.6	81.25	75	75
Mean (SD)		100 (28.9)	100 (38.9)	64.1 (34.1)	52.6 (27.5)	69.2 (13.6)	64.1 (34.6)

Some limitations of this study were the small sample size (only 20 postoperative children) and not assessing the time between diagnosis and surgery. In conclusion, post-cardiac surgery children aged 13-18 years have poorer physical function than healthy children. These children are at risk for physical appearance, cognitive, anxiety, and communication problems.

Conflict of Interest

None declared.

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