



Original Research

Quality of Life in Children with Acyanotic (Left to Right Shunt) Congenital Heart Disease in dr. Soetomo General Hospital, Surabaya, IndonesiaSalsabila Fabianca Alsaid^{1*}, Taufiq Hidayat², Heroe Soebroto¹¹Faculty of Medicine, Universitas Airlangga, Indonesia.²Dr. Soetomo General Hospital, Surabaya, Indonesia.

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ABSTRACT

Acyanotic congenital heart disease is a disease that affects the patient physically and psychologically result in the patient not being able to carry out his life normally. As a result, patients will feel lonely, rejected, and isolated from society which makes social integration more difficult. The picture of quality of life in acyanotic CHD patients can be used as a therapeutic evaluation material to improve quality of life. **Material and Methods:** This study used descriptive analytic method with total sampling. The variable studied was quality of life using Pedsql Inventory 3.0 Cardiac Module questionnaire to the patients aged 2-18 years who were treated at Dr. Soetomo General Hospital Surabaya in 2019—2020. **Results:** 74 Acyanotic CHD patients (left to right shunt) obtained an average quality of life of 73.89 ± 9.79 with low-value aspects, namely Heart Problems and Therapy I (72.92 ± 18.20), Cognitive (59.53 ± 18.40), and Communication (71.40 ± 24.21). There was a significant difference in the type of combination diagnosis compared with other types with a significance of 0.014 ($p < 0.05$). **Conclusion:** Aspects that have a negative impact on the patient's quality of life are Heart Problems and Therapy I, Cognitive, and Communication. The Combination type is a diagnosis with the lowest quality of life compared to other types.

Introduction

Every year, thousands of children are born with Congenital Heart Disease (CHD). Congenital heart disease (CHD) is an abnormality in the structure and function of the heart that is acquired before birth due to abnormal development while still in the womb. The incidence of CHD worldwide is estimated at 1.2 million cases out of 135 million live births each year with the majority of CHD being acyanotic type left-to-right shunts ^[1]. Acyanotic congenital heart disease is a disease that affects the life of the sufferer. The condition of patients who have growth delays, weak physical conditions, as

well as psychological and physical differences with healthy people, tends to be related to a lack of social acceptance, especially in the school and work environment later. The physical and psychological disturbances experienced by patients result in them not being able to carry out their duties as normal people. As a result, they have to avoid activities that threaten their safety so that patients will feel lonely, rejected, isolated from society which makes social integration more difficult ^[2].

The number of births with congenital heart disease and the serious impact it has on the patient's life make this data on the quality of life important data to study because it affects the livelihoods of the nation's next generation. The current management of CHD is not only aimed at increasing the patient's life expectancy, but is also expected to improve the patient's quality of life because chronic disease conditions tend to affect the quality of life for anyone who experiences it. Children with chronic diseases tend to experience problems in social, emotional, and behavior than healthy children of the same age. Thus, data on the quality of life in CHD patients are important as material to determine therapy to develop a management strategy for acyanotic CHD (left to right shunt) care in improving the patient's quality of life ^[3].

Material and Methods

This research uses descriptive analytic type with total sampling method, which is taking all data about acyanotic left to right shunt congenital heart disease patients aged 2-18 years in the outpatient unit of Departement of Pediatrics in Dr. Soetomo General Hospital for the period 2019–2020 who met the sample criteria. The willingness of the patient and the patient's parents to participate in this study as the research sample was obtained in writing on the informed consent form. Patients with neurodevelopmental disorders or with other comorbid medical conditions as well as having complex disorders such as pneumonia, Atrioventricular Septal Defect (AVSD), and Eisenmenger syndrome were excluded from this study, resulting in a sample that complies with this study of 74 patients. The data obtained are primary data from online interviews using the PedsQL 3.0 Cardiac Module questionnaire to the patient's parents (parent-report).

PedsQL 3.0 Cardiac Module is a multidimensional instrument that aims to measure the quality of life in patients aged 2-18 years based on the intensity of the problems faced by patients in living their lives. In this questionnaire (Appendix 5), it consists of reports from children and reports from parents which are adjusted to the age criteria of the patients being sampled. Age of patients were grouped into toddlers (2–4 years), young children (5–7 years), children (8–12 years), and adolescents (13–18 years) ^[4].

Adolescent patients (13–18 years) and children (8–12 years) will receive a questionnaire containing reports from children and parents reports. In patients under five (2-4 years), there is only a questionnaire in the form of parental reports. Each of the questionnaires consisted of 27 questions with aspects of heart problems and therapy I consisted of 7 questions, therapy II consisted of 5 questions, physical appearance consisted of 3 questions, anxiety consisted of 4 questions, cognitive problems consisted of 5 questions, and communication consists of 3 questions. However, in this study only parental reports were used ^[4].

The list of patient conditions listed in the questions in the questionnaire is filled in based on how often these things have been a problem for the patient in the last one month. Each of the questions in the questionnaire has 5 answer choices, namely 0 = never; 1 = almost never; 2 = sometimes; 3 = often; 4 = almost always, except for the child report questionnaire in pediatric patients which has 3 answer options, namely 0 = never; 2 = sometimes; 4 = almost always. Each question can only choose one answer ^[4].

The respondent's answer will be transformed into a scale of 0-100 with the composition of values as follows: 0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0. If more than 50% of the assessment points are

missing, then the rating scale should not be calculated into the results of the study. If 50% or more of the assessment points are filled in, then what is entered is the average of the rating scale. The results of the assessment are taken from the sum of all points from each aspect and then divided by the number of questions answered. A higher value indicates a lower problem in the patient [4].

General characteristics and distribution of patients based on gender, age category, type of diagnosis, duration of diagnosis, nutritional status, and comorbidities will be presented in the frequency distribution table. The patient's quality of life and determining the aspects that have a problem were analyzed using univariate analysis or descriptive analysis. Differences in quality of life based on the type of diagnosis were analyzed by bivariate analysis using the One Way Anova statistical test which aims to determine whether there is a difference between the two variables being tested. This is because the quality of life data based on the type of diagnosis meets the applicable requirements, which are from more than 2 independent groups, normally distributed, and have homogeneous variants. Furthermore, the data was further tested using Fisher LSD to find out which groups had differences with other groups. All data obtained were processed using the SPSS version 25.0 program.

Result

In a total of 74 study samples, there were more female patients than male patients. Most of the patients were in the toddler age category, which is 2-4 years. Based on data regarding the type of congenital heart disease diagnosis, the most common diagnoses in Acyanotic CHD patients were Atrial Septal Defect (ASD) and Ventricular Septal Defect (VSD) with a total of 28 patients each. The majority of patients know of congenital heart

disease at less than one year after birth. Most of the samples had poor nutritional status, and only a small proportion had other comorbidities (Table 1).

Table 1. General characteristics and distribution of patients

Characteristic	N	%
Gender		
Female	48	63.6
Male	26	36.4
Age		
Toddlers	27	36.4
Young children	16	20.8
Children	20	27.3
Adolescent	11	15.6
Type of diagnosis		
PDA	15	19.5
ASD	28	36.4
VSD	28	36.4
Combination	3	3.9
Duration of diagnosis		
< 1 years	37	49.4
1 - 5 years	20	27.3
> 5 years	17	23.4
Nutritional status		
Underweight	36	49.4
Normal	32	42.9
Above the normal range	6	7.8
Comorbidities		
Have	18	23.4
Don't have	56	76.6

All the questions asked were answered well by the sample/subject. Through online interviews with the patient's parents using the PedsQL 3.0 Cardiac Module questionnaire, the patient's average quality of life was 73.89 ± 9.79 . In the aspect that has a value below the average quality of life value, it is considered a problem aspect that has a bad impact on the patient's quality of life. Thus, broadly speaking, aspects of Cardiac problems and

Therapy I with an average of 72.92 ±18.20, Cognitive aspects with an average of 59.53 ±18.40, and Communication aspects with an average of 71.40 ±24.21 are aspects that have problems and adversely affect the patient's quality of life (Table 2).

Table 2. Quality of life based on all aspects

Aspects	Min.	Max.	Mea	SD
Heart problems and Treatment I	29.0	100.00	72.9	18.20
Treatment Perceived Physical	40.0	100.00	83.0	14.31
Treatment Anxiety	41.6	100.00	84.3	16.89
Cognitive Problems	7		5	
Communication	0.00	100.00	76.1	21.21
Total			0	
	25.0	100.00	59.5	18.40
	0		3	
	8.33	100.00	71.4	24.21
			0	
	54.6	91.67	73.8	9.79
	3		9	

In the aspect of heart and therapy I, the specific problems that have the highest adverse impact on the patient's quality of life are susceptibility to colds, fast heart rate, and needing more rest than their friends. On the cognitive aspect, the specific problems that have a negative impact on the patient's quality of life are deciding to do something when someone is disturbing them, difficulty with math assignments, difficulty in writing/making school assignments, difficulty focusing on something, and the one that has the highest impact is trying to remember what was read. In the aspect of communication, the specific problem that has the

highest adverse impact on the patient's quality of life is asking the doctors and nurses questions, then telling the doctors and nurses about how they feel, explaining their heart problems to others.

It is known that the significance value of the One Way Anova test is 0.014 (p<0.05). Thus, it can be concluded that there is a difference in the average quality of life of at least one of the four types of diagnosis. To find out the types of diagnoses that have different quality of life, further test is needed in the form of Fisher Least Significant Difference (LSD). In the type of diagnosis of PDA, ASD, and VSD there was no significant difference in the average quality of life. Meanwhile, in the combination diagnosis type, there were significant differences compared to other types, which were 0.002 (p<0.05) when compared with PDA and ASD, and 0.003 (p<0.05) when compared to VSD (Table 3).

Table 3. Differences in quality of life by type

Diagnosis	Mean ± SD	P
PDA	75.74 ± 10.65 ^a	0.014
ASD	74.50 ± 9.65 ^a	
VSD	74.14 ± 8.44 ^a	
Combination	56.48 ± 1.85 ^b	

^aP>0.05 compared to the PDA, ASD, and VSD groups;
^bP=0.002 compared to PDA and ASD, P=0.003 compared to VSD

Discussion

Congenital heart disease is a structural or functional abnormality that causes hemodynamic disorders in children so that it can affect the patient physically,

socially, emotionally, and behaviorally. This condition makes children naturally adapt to their conditions in living their daily lives. The views of children and parents as well as the form of adaptation of children regarding their health conditions reflect the quality of life in children. So that the management of patients with acyanotic congenital heart disease is not only focused on increasing life expectancy, but also on improving the patient's quality of life [5].

In children with chronic disease conditions, it was found that the influence on their growth and development was in the form of delays in physical development, communication, cognitive, adaptive, motor, and socialization compared to normal children. This impact depends on the child's view of the body, illness, therapy, and his view of death [6]. The views of children and families regarding their health conditions in daily life are reflected in the form of quality of life in children. A child's quality of life depends on his ability to adapt to his illness and to deal with various stresses caused by his condition [7].

Quality of Life in Patients

Quality of life can be measured in various ways, one of which is using a questionnaire. The Pediatric Quality of Life Inventory (PedsQL) 3.0 Cardiac Module is an instrument that can assess the effect of heart disease conditions in children on their daily lives. This Pedsql is a questionnaire that covers important aspects of quality of life in patients with heart disease, namely heart problems and therapy I, therapy II, physical appearance, cognitive, communication, and anxiety. The purpose of this study was to assess the patient's quality of life, determine the aspects of the problem that have the disorder, and look for differences in the quality of life of each type of left to right acyanotic congenital heart disease.

In the aspect of heart problems and therapy I, the specific problems that have a bad impact on the patient's quality of life are susceptibility to colds, fast heart rate, needing more rest than their friends. This is due to hemodynamic disorders such as enlargement of the pulmonary arteries due to pulmonary hypertension that occurs in children with congenital heart disease causing disruption of the pulmonary defense system, resulting in frequent patients experiencing respiratory infections [8]. Tolerance to activity is a good indicator of the compensatory status of the heart or the degree of cardiac abnormality. The patient's fast heart rate indicates a compensation for the lack of oxygen intake throughout the body due to a left-to-right shunt. Patients who feel tired easily and need more rest than their friends can be caused by two conditions, namely reduced exercise / activity tolerance which can describe hemodynamic disorders in patients and intentional activity restrictions arising from anxiety about the worsening of symptoms that occur. might happen [5].

On the cognitive aspect, specific problems that have a negative impact on the patient's quality of life are deciding to do something when something is distracting, difficulty with math assignments, difficulty in writing / making school assignments, and difficulty focusing on something, trying to remember what has been done. be read. Cognitive function cannot be limited to IQ index alone. Cognitive must be reviewed from all aspects, such as learning, memory, psychomotor speed, attention, concentration, reasoning, calculation, and executive function. The presence of a deficit in the patient's cognitive function can be caused by organic pathologies secondary to the brain as a result of a heart defect or the impact of surgery and can be exacerbated by the psychosocial conditions experienced by the patient. As discussed earlier,

children with chronic diseases have more stress than normal children. This will have an impact on psychosocial which will affect cognitive function in patients^[9].

In the aspect of communication, specific problems that have a negative impact on the patient's quality of life are telling doctors and nurses what they feel, asking doctors and nurses questions, explaining their heart problems to others. This can be because the child does not understand how to express his problem or complaint to others, or the patient has a fear of talking to doctors or medical staff. Personality type also has an impact on a person's ability to adapt to someone, especially if there are accompanying conditions and stressors obtained from the environment^[10].

Differences in Quality of Life by Type of Diagnosis

In this study, the patient's average quality of life was 73.89 ± 9.79 . In this study, the most Acyanotic type of congenital heart disease was found in patients with CHD, Ventricular Septal Defect (VSD) and Atrial Septal Defect (ASD) with 28 patients each. In a previous study conducted in India by Abqari, et al., (2016) it was found that the most acyanotic CHD found was VSD. However, in another study, namely by Katherine, et al., (2019), it was stated that ASD was the most common type and after that was VSD in Dr. Soetomo General Hospital Surabaya, Indonesia. Another study conducted by Hariyanto (2016) said that the most acyanotic CHD types were found in VSD and ASD in research at RSUP. Dr. M. Djamil Padang^[11].

However, in this study, there was no significant difference in the quality of life of patients according to each type of CHD, except in patients with combined type of CHD. In the quality of life of patients based on the type of diagnosis, there was a difference of 0.014, which means that the difference has a significant value of at least one of

the four types of CHD. The combination type had a significant difference with a significance of $P=0.002$ compared to PDA and ASD; $P=0.03$ compared to VSD with the type of combination as the lowest mean value of 56.48 ± 1.85 . This is because combined cardiac structural abnormalities can cause complex CHD^[12]. Overall, complex CHD has a compromised quality of life compared to CHD with simple defects^[13]. This is evidenced by a significant decrease in quality of life in patients with this level of complexity. moderate or severe in his research which concluded that the complexity of CHD affects the patient's quality of life.

The type of combination referred to in this study is a condition where the patient has more than one congenital heart defect. This shows that the heart has more holes which causes a lot of displacement of blood flow from left to right where oxygenated blood returns directly to the lungs without flowing throughout the body. Unbalanced blood flow causes hemodynamic disturbances in the form of high flow pressure to the lungs, which results in pulmonary hypertension or enlarged pulmonary arteries. In addition, the hemodynamic disturbance obtained is a reduction in cardiac output (CO) caused by a left to right shunt which causes a lack of oxygen distribution to body tissues^[14].

This hemodynamic disturbance causes impaired growth and decreased exercise tolerance in patients due to the body's inability to meet oxygen demands. In addition, increased blood flow to the lungs can also disrupt the defense system in the lungs which makes it easy for recurrent respiratory infections^[5]. The disturbances found due to hemodynamic disorders certainly affect the patient's physical and psychological and have an impact on aspects of the patient's quality of life.

In the combination type, there are certainly more holes than in the single type. This of course affects

the amount of blood that moves from left to right. Generally, the volume of displaced blood determines the severity of the symptoms^[14]. Thus, the combination type obtained a higher level of symptom severity than the single type. This has an impact on the patient's overall life which results in a significantly reduced quality of life compared to patients with a single type of congenital heart disease.

Conclusion

Aspects that have a negative impact on the patient's quality of life are Heart Problems and Therapy I, Cognitive, and Communication. The Combination type is the diagnosis with the lowest quality of life compared to other types due to the higher number of holes compared to the Single type. Lastly, out of 74 respondents, it was concluded that the average quality of life is 73.89 ± 9.79 regarding the patients around the age 2-18 years suffering from acyanotic type of congenital heart disease (left to right shunt) that were admitted at Dr. Soetomo General Hospital in the year 2019 – 2020.

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