

ORIGINAL ARTICLE

Dimensions of Quality of Life among Children with Congenital Heart Disease: A Survey

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ABSTRACT

Introduction: Children with congenital heart disease (CHD) have a poor quality of life (QoL) than others. However, there are different outcome regarding the QoL description in each dimension. Therefore, this study is aimed to identify the QoL and its dimension in children with CHD in West Java, Indonesia. **Methods:** This was a descriptive quantitative study where forty-four respondents were selected using convenience sampling method. QoL and its dimensions were measured using the Pediatric Quality of Life (PedsQL™) cardiac module version 3.0 questionnaire. Furthermore, data were analyzed using descriptive analysis. **Results:** This study shows that the communication was the major problem in all age groups. While the second most common problems based on age of the respondent were: treatment anxiety (2-4 years old); followed by cardiac problems and its treatment (aged 5–7 years and 8–12 years); and then perceived physical appearance (age 13–14 years). **Conclusion:** Communication ability is the most crucial problem among children with CHD due to a lack of courage to express their feelings. Nurses are expected to encourage patients to express their feelings by establishing effective communication and improving comfort level to develop a healthy mutual relationship.

Keywords: Children, Congenital heart disease, Dimensions, Quality of life

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INTRODUCTION

Congenital heart disease (CHD) is the most common form of abnormality that occurs in children. Some study noted that nearly one-third of congenital abnormalities are heart defects (1,2). In addition, the prevalence of CHD worldwide has increases every year, and Asia has the highest, with an average of 9.3 per 1000 live births (1).

The impact of CHD is diverse for each child depending on the type of defect and its severity. Another study stated that children with congenital heart disease would experience fatigue, dyspnea, chest pain during activities, and eating disorders due to respiratory distress that will lead to growth problems (3). These limitations impact children's daily activities in general. In addition, children may experience repeated hospitalizations. This situation causes traumatic effect among the children both physically and psychologically. For example, repeated hospitalization causes reduction in children's

playtime, therefore significantly influences children's growth and development (4).

Congenital heart disease and its side effects influence a child's quality of life both directly and indirectly. The present study showed that the quality of life among children with CHD was lower than in healthy children (5,6). Sertzelik et al., (2018) found that two-thirds of children in his study had poor quality of life (6). In Indonesia, a similar study was conducted by Ariani et al., (2012) . However, the study involved a small sample of only 11 respondents. The study showed that the significant problem of Indonesian children with CHD is communication and cognitive problems. Nevertheless, these results require further investigation involving a more significant number of samples (5). Therefore, the present study aimed to investigate the QoL and its dimension (heart problems and medication, treatment, perceived physical appearance, anxiety treatment, cognitive problems, and communication) among children with CHD in West Java, Indonesia.

MATERIALS AND METHODS

Study Design and Samples

The study design was quantitative descriptive one,

which was conducted at a government referral hospital in West Java Province, Indonesia. The population was children with CHD aged 2-14 years in the pediatric cardiac outpatient unit. Forty-four respondents were recruited by convenience sampling method with the inclusion criteria: children could communicate well and did not have severe cognitive impairment.

Instrument

The quality of life and its dimensions were measured using the Pediatric Quality of Life (PedsQL™) questionnaire, version 3.0 of the heart module from Varni et al., (2014) (7). Permission to use the instrument was obtained from MAPI Research Institute, Lyon, France. Measurement results are indicated as the mean scores. This instrument has been widely used to study the quality of life in children with congenital heart disease. It is consisting of short questions, easy to use. The results obtained have a low risk of missing data and consists of reports of children and parents (8). The higher the score the better the quality of life indicated (7). Furthermore, the instrument has been adopted into Indonesian language and obtained the validity of the item-total correlation coefficient by 0.31-1.00 and reliability with the Cronbach Alpha value 0.71-0.87.

Data Collection

Data collection was carried out for three months. This research obtained ethical clearance from the Dr. Hasan Sadikin Hospital Health Research Ethical Committee, Indonesia, with the number: LB.04.04/A05/EC/147/V/2015. All respondents, including children and parents, were informed and signed the consent form when they agreed to participate. Respondents aged 8-14 years filled the questionnaire themselves, while parents filled up the questionnaire for children under eight years old.

Data Analysis

Demographic data were analyzed by calculating the frequency distribution of each demographic characteristic, while quality of life was calculated by the mean value of each dimension. The mean quality of life dimension for each participant were then ranked to determine which dimension has the highest followed by lowest mean score. Higher mean score indicates a higher quality of life.

RESULTS

The result of the study was represented in three tables. Table I shows that more than half of the respondents were females, age ranging between 8-12 years, were diagnosed with acyanotic CHD, which has been diagnosed for 1-5 years. They did not have comorbidities and underwent therapy for 1-5 years. Almost all respondents have not taken cardiac correction.

Table II shows that among the parents, the primary

Table I: Respondent Characteristics (Children)

Characteristics	F	%
Age		
2-4 years	12	27.3
5-7 years	10	22.7
8-12 years	14	31.8
13-14 years	8	18.2
Gender		
Male	16	36.4
Female	28	63.6
Type		
Cyanotic	4	9.1
Acyanotic	40	90.9
Length of diagnosis		
< 1 year	8	18.2
1-5 years	22	50.0
> 5 years	14	31.8
Length of treatment		
< 1 year	11	25.0
1-5 years	19	43.2
> 5 years	14	31.8
Cardiac Correction		
Yes	4	9.1
No	40	90.9
Comorbidities		
Yes	7	15.9
No	37	84.1

F: Frequency; %: Percentage

Table II: Respondents Characteristics (Parents)

Parents Characteristics	F	%
Age		
<45 years	24	54.5
45-59 years	19	43.2
>59 years	1	2.3
Gender		
Male	7	15.9
Female	37	84.1
Marital Status		
Married	40	90.9
Single Parents	4	9.1
Education		
Primary School	13	29.5
Junior High	13	29.5
Senior High	15	34.1
Diploma	1	2.3
Bachelor Degree	2	4.5
Work		
Yes	15	34.1
No	29	65.9

F: Frequency; %: Percentage

caregiver were mothers who were <45 years old and unemployed.

Furthermore, Table III shows that communication is the most prevalent problem experienced by the respondents. This problem is common in all age groups, with the lowest scores found at age 5–7 years (41.7±4.1). Based on their dimensions, there are three main problems of a child's quality of life vary according to the age. Respondents with an age range of 2-4 years have three main problems, which are: communication problems, treatment anxiety, heart problems and the treatment. Respondents in the age range of 3-5 years have the same three main problems. Then in the age range 8-12 years the problems are communication, heart problems and treatment, and cognitive problems. Meanwhile, adolescent respondents aged 13-14 years perceived three main problems: communication, physical appearance, and cognitive problems.

DISCUSSION

Quality of life problems often occurs in children with CHD (5,9,10). They often experience an interruption in education, activity limitation, restricted movement, disturbed social relationships, and adjustment problems. Raj et al (2014) discovered that children and adolescents with CHD reported a significant reduction in overall quality of life (11). These conditions align with Sertcelik's et al., (2018) study, which presented that children with CHD with surgical history have a lower quality of life score (6).

The current study revealed that the communication dimension is a significant problem of the child with CHD, faced by all age group. Similar findings were also stated in previous research conducted by other studies (5,12). The second problem perceived by the respondents, showed different factors depending on the stage of the child's age. Children aged 2-4 years perceived the second significant problem related with treatment anxiety, whereas children aged 5-7 years perceived heart problems and its treatment. Furthermore, older children (8-14 years) perceived physical appearance as a major problem.

Dimensions of Communication Problems

The results indicate that communication is the most significant problem experienced by respondents. Some children had difficulty expressing their feelings to doctors and nurses. Some children also had problems answering to doctors' and nurses' questions and had difficulty explaining their health problems to others. Parents tend to be overprotective of their children by limiting their activities and socialization. This condition causes the child's communication to be imperfect. Therefore, this situation impacts the child's lack of initiative, reduces their ability to take care of themselves, and culminates in low self-esteem (13,14,15).

Some children often hesitate to express their emotions fearing neglect and isolation (16). It implies that the nurses need to improve the therapeutic communication between the children to encourage them to be more confident in expressing their feelings. Building trust

Table III: Respondent Quality of Life's Score

Dimensions	N	Min	Max	Mean	SD
2-4 Years old					
Communication	12	0	100	43.75	34.5
Treatment anxiety	12	0	100	50.17	37.6
Heart problems and treatment	12	18	79	56.25	17.61
Cognitive Problems	12	25	83	63.75	20.46
Perceived Physical Appearance	12	42	100	77.5	23.32
Treatment II	9	17	100	77.89	26.98
2-4 Years old					
Communication	10	0	67	41.7	22.69
Heart problems and treatment	10	14	79	51.5	21.55
Cognitive Problems	10	10	80	53	21.11
Treatment anxiety	10	0	100	58.9	30.58
Treatment II	8	33	100	76.88	23.5
Perceived Physical Appearance	10	67	100	91.6	11.79
8 – 12 years old					
Communication	14	25	100	59.43	29.4
Heart problems and treatment	14	18	93	60.86	23.87
Cognitive Problems	14	15	90	65	19.61
Treatment II	8	30	100	70	21.55
Treatment anxiety	14	56	100	80.43	19.23
Perceived Physical Appearance	14	33	100	81.57	21.74
13 – 14 years old					
Communication	8	0	100	55.25	34.64
Perceived Physical Appearance	8	25	83	61.5	20.74
Cognitive Problems	8	35	85	62.5	17.32
Heart problems and treatment	8	46	75	65.13	9.23
Treatment II	7	65	100	85.71	12.05
Treatment anxiety	8	69	100	88.38	13.49

N: Total Response; Min: Minimal Score; Max: Maximal Score; Mean: Average score; SD: Standard Deviation

and a caring relationship with clients and their families through therapeutic communication is essential in nursing services for patients with chronic illnesses (16). Furthermore, nurses also need to assess child-parent communication patterns and suggest the family about the importance of exploring children's feelings. Parents also need to listen to and understand their child's feelings.

Dimensions of Treatment-Related Anxiety

In younger children, treatment anxiety is the next most common problem. Children are most anxious while they are waiting their turn to see a doctor and when they undergo doctor checkup. The repeated hospitalization period is traumatic for the child and cause anxiety. When children undergo medical treatment, they become more irritable and often cry (4). Thus, the presence of parents is very essential. In a study, it was found that 87.5% of children with congenital heart disease have treatment-related anxiety problems (11). While Dennis et al (2019) found that children with congenital heart disease had lower school functioning abilities, higher heart problems, and treatment-related anxiety (17). Before medical treatment, children need to be prepared psychologically by health workers and parents. The child may need toys, food, or drink that will reduce their anxiety. Here nurses have an essential role in reducing the anxiety felt by children. Children need to have the correct information. In addition, parents must also be trained to persuade children, for example, by giving them toys or stickers or praise them to boost up the morale or do other things that make the children happy. Nurses also need to facilitate peer family support groups that encourage one another to share their experiences.

Dimensions of Heart Problems and Treatment

Heart problems and its treatment are the most common problem among older children. The most complaining problem was heart palpitations that require more rest on the part of the children than other. The frequently complain included: fatigue, dyspnea, and chest pain during activity. To overcome heart problems and treatments, it is necessary to improve children's health with an appropriate diet, preventing anemias, and vaccinations are imperative (18). Providing small portions and frequent meals is an option to meet the nutritional needs of children with heart disease.

Dimension of Perceived Physical Appearance

Negative perceptions of physical appearance are a common problem among adolescent respondents. These problems perceived by the respondents were being ashamed of their body condition and feeling that they were not beautiful/handsome. In this study, nearly 10% of respondents had undergone cardiac correction and said they did not like other people seeing their surgical scars. As stated by Nousi and Christou (2010), children with congenital heart disease and who had undergone surgery, usually experience changes in body image due

to large incisions in the chest (18). Children in this stage have entered the early adolescence stage in their growth, they begin to care about their physical condition, and there is a desire to be attractive to others. Congenital heart disease causes delays in physical growth in some children, whose weight and height are lower than normal children (18). In this case, nurses can assist children in understanding their inner beauty. Children should be directed to their other positive characteristics beside their physical appearance (18, 19).

Dimensions of Cognitive Problems

Cognitive problem was the third most imperative complain in pre-school children and teenagers. Children have difficulty solving number of problems in this case, like writing school assignments, making reports, and remembering what they have read. Cognitive problems in children with congenital heart disease are affected by a decrease in cognitive function. Several studies stated that cognitive decline experienced by children with congenital heart disease is closely related to cyanosis or disease severity (20). Cognitive problems are also influenced by the long and repeated periods of treatment or medication that must be undertaken. This causes children to be absent from school too often and impaired learning process. This problem can be anticipated by bringing school textbooks to the hospital and copying lesson notes from their classmates. Positive aspects in this case must be that the children needs explored to increase their potential (21). Parents need to teach children to think positively regarding the problems they face. Parents should also be more concerned regarding the problems their children face and help them to overcome their problems.

Treatment II Dimensions

The difficulty of taking heart medication became the most significant problem in treatment dimension II, after the concern about the side effects of the drugs. Problems that they complained about were refusing and forgetting to take medications, drugs that they take causes pain, and the drugs that are available in pill and capsule form were more challenging to take. Almost all respondents said that it was easier to take medicine in powder or syrup form. Parents and nurses need to assess children's drug-taking habits and consult with doctors regarding difficulties in taking medicine.

CONCLUSION

The significant problem with the quality of life of children with CHD is communication, followed by different problems depending on the age range. The older children perceived physical appearance as the second-worst problem. So, to improve their quality of life, nurses need to enhance communication by facilitating therapeutic communication. Then children will be able to express their feelings without hesitation. Parents and nurses also need to encourage the child

to articulate their feelings and worries. Moreover, the utilization of toys or rewards can also help the children to feel more comfortable during the treatment process.

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