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Quality of life in children with chronic disease in Malang city assessed using pediatric quality of life inventory™



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ABSTRACT

Introduction: A chronic disease is known to be a condition that affects daily function and daily activity which tends to cause someone to be hospitalized. A chronic disease in children triggers several changes in physical, social, emotional, and educational aspects and it can affect the quality of life and development of the child. The purpose of this study is to determine the quality of life of children with chronic disease in Malang city using PedsQL™.

Method: This study is an analytic observational study using a cross-sectional design. Data collection was using purposive (non-probability) sampling with a total sample of 82 respondents. Data collection was carried out using a generic PedsQL™ questionnaire version 4.0 with a google form. Data analysis was performed using Univariate analysis (Descriptive Respondents) and bivariate analysis (Correlation Analysis using Chi-Square).

Results: The results showed that the factors that are significantly associated with the quality of life of children are the type of disease and the child's nutritional status (p -value= 0.005; $0.009 < \text{Level of Significance} = 0.05$) while other factors such as age, gender, parents' knowledge, and education background, duration of disease, parents' social and economic condition and several children are not significantly associated with the quality of life.

Conclusion: The factors that are significantly associated with the quality of life of children were the type of disease and nutritional status.

Keywords: children's quality of life, PedsQL™, chronic disease.

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INTRODUCTION

Chronic disease is known to be a condition that affects daily function and daily activity for longer than 3 months causing the patient to be hospitalized for over one month or when the diagnosis was made they tend to be hospitalized.¹ A chronic disease in children may affect their development and quality of life. According to Boyse² a child with chronic disease will have more health check-up visits, treatments, and hospitalizations. Several examples of chronic disease in children are type 1 diabetes mellitus, congenital hyperthyroidism, obesity, nephrology syndromes, thalassemia, short bowel syndrome, hemophilia, immunologic deficiency, kidney disease, cerebral palsy, brain tumors, rheumatoid fever, leukemia, asthma, and many more.¹ Several factors that can affect the quality of life of children with chronic disease are global conditions, external conditions,

interpersonal conditions, and personal conditions.

The World Health Organization has determined the standards of quality of life assessment which include physical, mental, and social aspects.³ The pediatric quality of life inventory™ (PedsQL™) is an instrument to assess the quality of life that meets the standards. This instrument is comprised of generic and specific modules for a disease. The generic PedsQL™ 4.0 instrument has been used in 25.000 children and parents and has been adapted to 60 languages. The PedsQL™ instrument has good reliability with a Cronbach score of 0.73-0.94, and with a wide age range which is 2-18 years old. In a study by Varni³, the results proved the reliability and validity of PedsQL™ 4.0 Generic Core Scales. A good generic PedsQL™ 4.0 can be used in clinical trials, studies, clinical practice, and health care management in schools, and community populations.

The impact of chronic disease in

children depends on the child's view of their body organs, disease, the treatments received, and their view of death. The long-term impact of a chronic health condition can affect the patient and their family. The impact on children can be observed in their psychosocial development, involvement with peers, and school achievements. While the impact on the family may include the parents' psychosocial status, the family's activity, and economic status, and the role of the family in the community.⁴

In Indonesia, thalassemia is the most common genetic disorder. In the Thalassemia Center of the Department of Pediatric Health Faculty of Medicine Universitas Indonesia Rumah Sakit Cipto Mangunkusumo (RSCM) until the end of 2008, there were 1,455 patients. It is estimated that every year in Indonesia there are 2,500 children born with thalassemia. The prevalence of asthma in Indonesia is unclear, however, it is estimated that 2-5%

of Indonesian citizens suffer from asthma. The result of the International Study on Asthma and Allergies in Childhood showed that in Indonesia, the prevalence of asthma increased from 4.2% in 1995 to 5.4% in 2003. DKI Jakarta has a higher prevalence of asthma which was 7.5% in 2007. The incidence of asthma in children is around 10-85%.⁴

The high incidence of chronic diseases in children showed that there are many impacts for children with chronic diseases, such as stress, fear, and pain. Many factors are associated with the quality of life of children with chronic diseases. The quality of life of children with chronic disease should be evaluated therefore an intervention can be given as early as possible to achieve an optimal quality of life and children are treated well by the family and health care providers, since according to the Children's Right Convention in 1989 it was noted that every child has a right for sufficient physical, mental, spiritual, moral, and social development. For this reason, we conducted a study to determine the quality of life of children with chronic disease in Malang city using PedsQL™.

METHODS

This study is categorized as analytic observational with a cross-sectional design. The study subjects are 82 respondents. The study population is children aged 2-18 years old with chronic disease in Malang city. The sample of this study was taken from a population that met the inclusion criteria as follows: 1) Children aged between 2-18 diagnosed with chronic diseases such as Asma, Diabetes Mellitus Type 1, ADHD, thalassemia, and epilepsy. 2) From Malang City. 3) Only parents or proxies can fill out the questionnaire 4) Parents of patients given consent or agreed voluntarily for their children to be included or be part of the study after getting an explanation. And the exclusion criteria: 1) Children with mental retardation 2) Parents or proxy who do not consent or agree to be a part of the study. The Sampling technique was using purposive sampling (non-probability). The study was carried out using a generic PedsQL™ version 4.0 questionnaire with a google form. Data analysis using univariate analysis for each

variable of the study results. The data obtained were recorded and collected then presented as a frequency distribution table. Descriptive statistics and frequency will be analyzed for the total sample and each group of diseases. The Chi-Square test will be used to analyze the factors (type of disease, gender, age, parent's education background, socio-economic, number of children, nutritional status, and duration of disease) associated with the quality of life of children with chronic disease in Malang City. Data were analyzed using SPSS for Windows IBM25.

RESULTS

Univariate Analysis (Descriptive Respondents)

Results of the study on 82 respondents who met the inclusion and exclusion criteria, the characteristics of respondents including age and gender are presented in the following Table 1.

According to Table 1 it was found that most of the subjects are male which was 43 (52.4%) respondents and the largest proportion was from the 5-18-years age group which was 80 (97.6%) respondents. The study result data for factors associated with the quality of life of children including

parents' educational background, socioeconomic status, type of disease, number of children, nutritional status, and duration of disease are presented in Table 2.

According to Table 2 it was found that the largest proportion of parent's education background was from higher education, which was 36 (43.9%) respondents, the largest proportion of socioeconomic status was from middle-class which were 39 (47.6%) respondents, the most common type of disease was type 1 DM which were 32 (39.0%) respondents, most respondents are from the 2 (two)-children group which were 50 (61%) respondents, the largest proportion of nutritional status was from the normal category which was 40 (48.8%) respondents, and the largest proportion of disease duration was from the not long (<6 years) category which was 42 (51.2%) respondents.

According to Table 3 it was found that most respondents had a normal quality of life 80 (97.6%).

Bivariate Analysis (Correlation Analysis using Chi-Square)

The result of data analysis between factors associated with the quality of life of

Table 1. Characteristics of Respondents of Children with Chronic Disease in Malang.

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	43	52.4
Female	39	47.6
Age (yrs)		
< 5 years	2	2.4
5-18 years	80	97.6

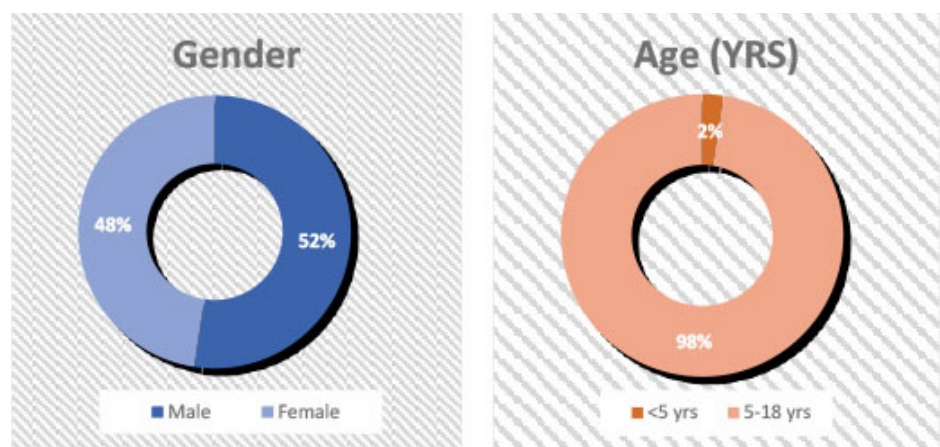


Figure 1. Graphic of Gender and Age Distribution of Children with Chronic Disease.

children with chronic disease in Malang is presented in Table 4 below.

According to Chi-Square analysis, it was found that the p-value for the type of disease and nutritional status was 0.005 and 0.009, therefore it can be interpreted that there is a significant association

between the factors of type of disease and nutritional status with quality of life. The factors of age, gender, parental knowledge and education, disease duration, socioeconomic condition, and several children were not significantly associated with quality of life.

Table 2. Factors Associated with Quality of Life of Children with Chronic Disease in Malang.

Factors Associated with the Quality of Life of Children	Frequency (n)	Percentage (%)
Parents' Education Level		
Elementary	20	24.4
Middle	26	31.7
High	36	43.9
Socioeconomic Status		
Low	26	31.7
Middle	39	47.6
High	17	20.7
Type of Disease		
Asthma	10	12.2
ADHD	12	14.6
T1DM	32	39.0
Epilepsy	7	8.5
Thalassemia	21	25.6
Number of Children		
2 children	50	61.0
> 2 children	32	39.0
Nutritional Status		
Normal	40	48.8
Underweight	38	46.3
Obese	4	4.9
Disease Duration		
Not long (<6yrs)	42	51.2
Long (>6years)	40	48.8

Note: ADHD: Attention-deficit hyperactivity disorder; T1DM: type 1 diabetes mellitus

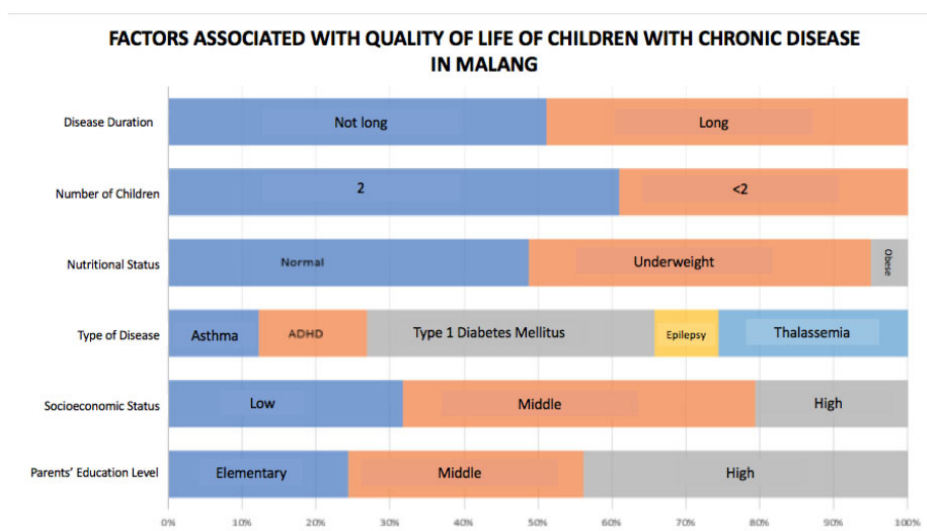


Figure 2. Graphic of Factors Associated with Quality of Life of Children with Chronic Disease in Malang.

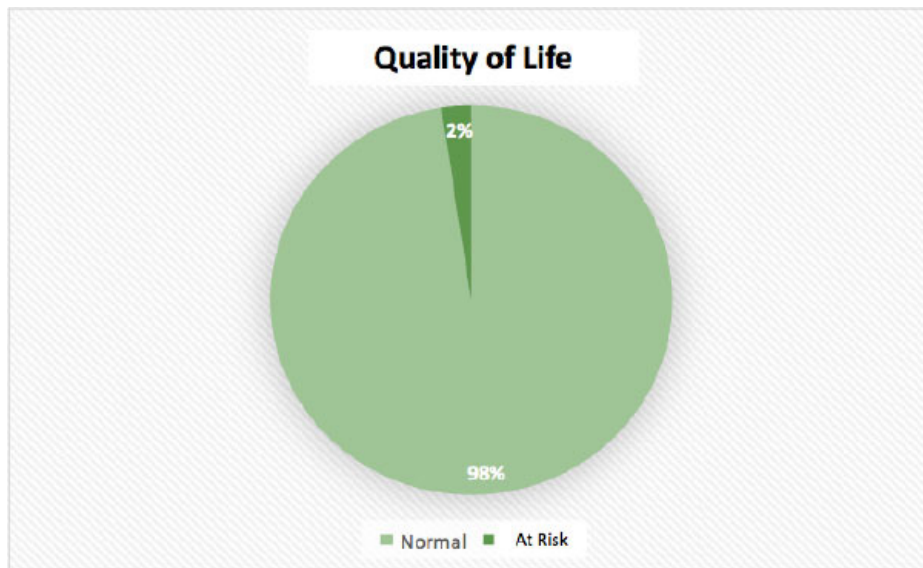
DISCUSSION

Most respondents in this study were male which was 43 (42.4%) respondents. Gender can have a different effect on a person's behavior, including in daily life. In living daily quality of life, females tend to more easily feel anxious than males.⁵ According to Nofitri⁶ gender is one of the factors that affect the quality of life. They found a difference in the quality of life between males and females, in which the quality of life of males was better than females. Notable characteristics in children and adolescents are rapid physical growth, development of secondary sexual characteristics, menstruation, and psychological changes.⁷ At this age, normal individuals are receiving education at the school level. Most adolescents of school age will spend most of their time at school, therefore the influence of peers will be stronger than that of parents for them.⁸

Most respondents are in the 5-18-years age group which were 80 (97.6%) respondents. This showed that respondents of children with chronic disease in Malang are mostly children to mid-adolescence age. A study by Suryono⁹ found that children with chronic disease are mostly from the 5-18-years age group which was 90.4%. The stages of growth and development of school-age children include physical, motor, cognitive, and psychosocial development. Physical growth and development in school-age children tend to be slow and uniform until there is a sign of pubertal changes. Motor changes at this age became more fine and coordinated compared to the early childhood stage such as: running, jumping, and balancing. In cognitive development at this age, children became to be able to differentiate what is visible to the eyes and reality. In psychosocial development at this age, children can face and resolve tasks or perform actions that produce results.¹ Early adolescence is a period of rapid physical growth and pubertal development, while mid-adolescence and late adolescence will have more dominant cognitive and psychosocial development. Puberty and adolescent growth spurt cause many metabolic changes in adolescents with

Table 3. Quality of Life of Children with Chronic Disease in Malang.

Quality of Life	Frequency (n)	Percentage (%)
Normal	80	97.6
At Risk	2	2.4

**Figure 3.** Graphic of Quality of Life of Children with Chronic Disease.

chronic diseases. For example, increasing levels of growth hormones in adolescence will cause increased insulin resistance, and adolescence tends to develop a sense of wanting to lose dependence on their parents and wanting to try many new things.

Most respondents are from the high parent education level group which were 36 (43.9%) respondents, most respondents were from the middle-class category of socioeconomic status which was 39 (47.6%) respondents, most respondents were with type 1 DM 32 (39%) respondents, most respondents were from the 2-children category which was 50 (61.0%) respondents, most respondents were from the normal nutritional status category which was 40 (48.8%), and most respondents were from the not long (<6 years) category of disease duration which was 42 (51.2%). The results of this study are supported by a study by Varni¹⁰ which showed that most respondents were from parents with high education levels, most respondents were from the middle socioeconomic status, most respondents had type 1 DM, and most respondents were from the 2 children category. According to the Indonesian Association of Pediatricians (*Ikatan Dokter Anak*

Indonesia/ IDAI)¹¹, the most influential factor in the quality of life of children with chronic disease is their treatments, because if they received good treatments then the patients' quality of life will be better. Several factors that generally can affect the quality of life of children with chronic disease are global conditions, including government regulation and societal norms that give protection for children; external conditions, including the neighborhood, family's socioeconomic status, health care system, and parental educational background; and interpersonal condition, including social relationship in the family and family support. The personal condition includes the physical, mental, and spiritual dimensions, the level of education of the child and their parents, and the income of the parents.

Most children had a normal quality of life, which were 80 (97.6) respondents. The results of this study are supported by a study by Varni¹⁰ which showed that most subjects had a good quality of life. According to a study by Suryono⁹, the highest percentage with good quality of life were 30 respondents (57.7%) and the lowest percentage with poor category was 22 respondents (42.3%). The quality of life of children with chronic disease was

affected because they appear to be afraid and feel pressured by their condition. According to Suryono⁹, family support that can be given to children with a chronic condition is advocacy, instructional support, information, instrumental support, and emotional support. A study by Mariani¹² described that there is a significant association between family support and the quality of life of children. Psychosocial support from the family can reduce emotional problems in children with chronic disease, therefore it can be explained that psychosocial support can reduce emotional distress, increase the efficacy of iron chelation and strengthen the coping approach to be better in living daily life and also improve the quality of life of children.

Type of disease and nutritional status had a significant association with quality of life (p-value= 0.005 & 0.009). while gender, age, parent's education level, disease duration, socioeconomic status, and the number of children were not significantly associated with quality of life (p-value > 0.05). the results of this study are supported by a study by Varni³ which showed that there is an association between the type of disease and nutritional status with quality of life. Most respondents in this study were with type 1 DM and according to the chi-square test, the subjects with low quality of life were from the Asthma category of type of disease. According to the data from Persi, diabetes cases in Indonesia are currently the fourth highest after the United States, China, and India with 13.7 million diabetic patients in 2003 and it is estimated to increase to 20.1 million patients in 2030, with prevalence of 14.7% in an urban area and 7.2 % in the rural area. Meanwhile, according to reports, type 1 diabetes cases in children in early 1990, in one year approximately 10 cases. Since the 2000s, almost every month there was a new type 1 DM case and in 2009, every month there were more than 2 new cases detected. The management of type 1 DM according to the national consensus is to optimize the quality of life of patients. The complexity of problems in children with type 1 DM will cause new problems to occur including physical, psychological, or social problems which will interfere with the daily activity of children, both

Table 4. Factors Associated with Quality of Life of Children with Chronic Disease in Malang.

Factors	Quality of Life		p-value
	Normal n (%)	At Risk n (%)	
Age			
< 5 years	2	0	1.000
5-18 years	78	2	
Gender			
Male	43	0	0.223
Female	37	2	
Parents' Education Level			
Elementary	19	1	0.544
Middle	26	0	
High	35	1	
Socioeconomic Status			
Low	25	1	0.361
Middle	39	0	
High	16	1	
Type of Disease			
Asthma	8	2	0.005*
ADHD	12	0	
DM	32	0	
Epilepsy	7	0	
Thalassemia	21	0	
Number of Children			
2 Children	49	1	1.000
> 2 Children	31	1	
Nutritional Status			
Normal	39	1	0.009*
Underweight	38	0	
Obese	3	1	
Disease Duration			
Long (>6 years)	40	0	0.162
Not long (<6 years)	40	2	

at home and at school. Children may have difficulty and delays in following school activities because they have to rest at home. Children may also feel stressed and inferior because they need insulin treatments their whole life.¹¹ Indonesia is in the 13th position in the world and fifth in Asia with the highest percentage of death in asthma patients. In the province of Bali, there were 5.370 asthma patients with 20% of them children. Good asthma control is expected to be understood and practiced by patients, especially parents. According to a study by Miranty¹³, 75% of subjects with good nutritional status had a good quality of life and 25% had a poor quality of life. While for those with poor nutritional

status, 35.7% had a good quality of life and 64.3% had a poor quality of life. Therefore, nutritional status is one of the factors that affect the quality of life of children. A study by Rumahorbo¹⁴ also found that subjects with good nutritional status had a better quality of life than those with poor nutritional status. Keshavarzi¹⁵ described that respondents with malnutrition or at risk of malnutrition had a significantly lower quality of life than respondents with good nutritional status. As well as a study by Istutiningum¹⁶ studied the association between nutritional status and quality of life and found that there was a significant association between nutritional status and quality of life.

CONCLUSION

The majority of respondents were children of male gender and aged 5-18-years old. The results of the study showed that most children had a normal quality of life. The factors that are significantly associated with the quality of life of children were the type of disease and nutritional status (p-value = 0.005, 0.009 < Level of Significance = 0.05), while age, gender, parental knowledge and education, disease duration, socioeconomic condition, and the number children were not significantly associated with quality of life (p-value ≥ Level of Significance = 0.05).

ETHICAL CLEARANCE

This research received a certificate of ethical acceptance from the Ethics Commission of the Faculty of Medicine, the University of Brawijaya with the number No.145/EC/KEPK-S1-PD/08/2022 before the research was conducted.

AUTHOR CONTRIBUTION

All authors have contributed to all processes in this research, including preparation, data gathering, analysis, drafting, and approval for publication of this manuscript.

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CONFLICT OF INTEREST

None of the authors had any relevant conflict of interest to declare.

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