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The Comparison of Quality of Life in Children with Type 1 Diabetes Mellitus Based on Parents and Children Report

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ABSTRACT

Background: The primary goal of current diabetes management for children and adolescents has shifted from purely medical to optimal glucose control, normal psychological development, and increase QoL. Parents who accompany their children in the routine treatment of diabetes also have their own perceptions of their children's quality of life. The study regarding the QoL of T1D according to parents and children still vary. This research intends to compare between the QoL of T1D according to parents and children report in Indonesia. **Methods:** This is a cross sectional, conducted in a pediatric endocrine outpatient clinic, Dr. Soetomo Hospital, Surabaya, during November 2020 to August 2021. Comparison between variables were analyzed using an independent t-test and $P < 0.05$ was statistically significant. **Result:** The overall average quality of life score from parents is 71, while from children is 73,14. From parents report, in each domain, the average scores regarding the disease; treatment I; treatment II; worries; communications are 66,1; 74,3; 81; 60,8; 72,8 respectively. while from children, in each domain, the average scores regarding the disease; treatment I; treatment II; worries; communications are 68,5; 75,8; 80,6; 61,7; 79,1 respectively. The P score in each domain regarding the disease; treatment I; treatment II; worries; communications are ($P=0.978$); ($P=0.728$); ($P=0.766$); ($P=0.641$); ($P=0.531$) respectively. **Conclusion:** There is no difference between parents and children report on the QoL of children with T1D for each domain.

Keywords: diabetes; diabetes mellitus type 1; quality of life; children; parents; Indonesia

INTRODUCTION

Type 1 diabetes (T1D) is an autoimmune illness caused by the destruction of pancreatic β -cells, which results in insulin insufficiency, hyperglycemia, and a risk of ketoacidosis. Type 1 diabetes (T1D) treatment is based on frequent blood glucose monitoring and insulin administration that is tailored to the patient's blood glucose level, meals, exercise, and overall health. These consequences affected children's Quality of Life (QoL).

Children with Type 1 Diabetes Mellitus (T1DM) are becoming more common worldwide, including in Indonesia. In 2018, the Indonesian Pediatric Society (IDAI) recorded 1120 children with T1DM. The significant number of T1DM children with diabetic ketoacidosis upon presentation, which reached 71 percent in 2017, reflects low public and healthcare awareness of T1DM.

Improving the quality of life and well-being of children with diabetes is just as important as controlling their blood sugar levels in preventing secondary morbidity. And Parents who accompany their children in the routine treatment of diabetes also have their own perceptions of their children's quality of life. As a result, the primary goal of current diabetes management for children and adolescents has shifted from purely medical to optimal glucose control, normal psychological development, and maximum QOL.

In the COVID-19 pandemic, people with Diabetes Mellitus are very susceptible to the SARS-CoV-2 virus due to high glucose levels. The pandemic phase is marked by poor glycemic management in many patients. As a result, COVID-19 infection is risky for kids with T1DM. Patients with T1DM may have a further decline in their Quality of Life (QoL) in pandemic conditions as a result of their decreased ability to interact with doctors due to a fear of going to the hospital.

because study on the quality of life of children with T1D from the point of view of parents and children is still rarely done, and during the covid pandemic, parents and children were staying at home longer than before the pandemic. Therefore, further discussion is needed regarding the QoL of T1D children according to parents and children. The research intend to compare between the QoL of T1D children according to parents report and children report in Indonesia, especially in Dr. Soetomo Hospital, Surabaya.

METHODS

The type of research conducted by the researcher is an analytic study with cross sectional to compare the perception from the parents and their children about the Quality of Life of the children with their disease (T1D), in the Pediatric Endocrine Outpatient Clinic in Dr. Soetomo Hospital, Surabaya with a period from December 2021 until August 2022.

The inclusion criteria were patients aged 8–18 years, that diagnosed as having T1DM who regularly control in Pediatric Endocrinology Outpatient Clinic and their parents. A total of 20 patients and 20 parents were included in this study.

The SPSS 25.0 program was utilized to analyze our data using a comparison test (IBM SPSS). The mean and standard deviation of each component were utilized for the initial characteristics and the clinical characteristics. Because the study sample was less than 30, the one-sample Kolmogorov-Smirnov test was used for each data's normality test. The independent t-test was used for the comparison test. $P < 0.05$ was regarded as statistically significant. The ethics committee managing the health research team at the Dr. Soetomo General Hospital in Surabaya, Indonesia gave their clearance for this study with ethical clearance number 1030/105/3/X/2021.

This research data measurement tool uses a g-form filled out online via smartphone, consisting of parent's perspective and children's perspective of the QoL of patients with T1D. Collecting data using PedsQL Diabetes Module version 3.2 with 33-item diabetes-specific HRQoL instrument that includes five a priori scales that measure Diabetes Symptoms (15 items), Treatment Barriers (5 items), Treatment Adherence (6 items), Worry (3 items), and Communication (4 items). For the choices, 0 (never), 1 (rarely), 2 (sometimes), 3 (often), 4 (always). Scores are transformed on a scale from 0 to 100. Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. The sum of the items is divided by the number of items answered to arrive at a summary score. Higher scores indicate lower problems. Overall, the higher the score, the better the QoL. Score 70 or higher shows good result for QoL. A study on the validity of the PedsQL 3.2 Diabetes Module has been published. The reliability and validity had been tested by various study. Therefore, the validity will not be tested in this research.

RESULT

This study involved 20 children with DMT1 during the COVID-19 pandemic at Dr. Soetomo Surabaya. All respondents who entered the inclusion criteria were aged 8 to 18 years with their parents who were both willing to be involved in the study. the average quality of life score of children from parents as a respondent is 71 with the lowest score being 30,34 and the highest score being 98. From each domain, the average statement regarding the disease is 66,1. The average statements regarding treatment I and II are 74,3 and 81 respectively. Also, the average statements regarding worries and communication are 60,8 and 72,8. And the average quality of life score of children from children as respondents is 73,14 with the lowest score being 30 and the highest score being 97,66. From each domain, the average statement regarding the disease is 68,5. The average statements regarding the treatment I and II are 75,8 and 80,6 respectively. Also, the average statements regarding worries and communication are 61,7 and 79,1.

TABLE 1: Distribution of parents as respondent

| Characteristic | n (%) |
|-----------------|----------|
| Gender | |
| male | 4 (20%) |
| female | 16 (80%) |
| Age | |
| 31-35 years old | 3(15%) |
| 36-40 years old | 7(35%) |
| 41-45 years old | 6(30%) |
| 46-50 years old | 4(20%) |

TABLE 2: Distribution of children as respondent

| Characteristic | n (%) |
|---------------------------|----------|
| Male | 8 (40%) |
| Female | 12 (60%) |
| Age | |
| 8-12 years old | 12(60%) |
| 13-18 years old | 8 (40%) |
| Level of Education | |
| Elementary school | 11 (55%) |
| Middle school | 8 (40%) |
| High school | 1 (5%) |

TABLE 3: Mean and Comparison of Quality of Life Scores of Children from Parents and Children as Respondent

| Quality of Life Domain | mean | | P Sig.2 |
|-----------------------------|---------|----------|---------|
| | parents | Children | |
| Regarding the disease | 66,1 | 68,5 | 0.978 |
| Regarding the treatment I | 74,3 | 75,8 | 0.728 |
| Regarding the treatment II | 81 | 80,6 | 0.766 |
| Regarding the Worries | 60,8 | 61,7 | 0.641 |
| Regarding the Communication | 72,8 | 79,1 | 0.531 |
| Mean score | 71 | 73,14 | |

DISCUSSION

in our study shows that children report and parents report about the QoL were found to be no different. While in study conducted by Bekele about Health-Related Quality-of-Life and Associated Factors Among Children and Adolescents with type I diabetes Mellitus: A Cross-Sectional study in Ethiopia, the result shows children report and parents report about the QoL were found to be significantly different.4 Demographics where the samples taken and COVID-19 pandemic can be the factors of the different results between both studies.

In our study of children with DMT1, the score of Quality of Life that perceived by children is higher than what perceived by parents. While In study Agustini conducted about The Type 1 Diabetic Children's Quality of Life from Children and Parents Perspective in Cipto Mangunkusumo Hospital, Jakarta.3 The results of this study showed that the score of Quality of Life that perceived by children is lower than what perceived by parents. This is due to differences in conditions and situations, namely before and shortly after the COVID-19 pandemic, which can be a strong indicator of whether or not the quality of life of children with autoimmune disease in the local area is good or bad.

In study conducted by Nur Rochmah about Quality of Life Differences in Pre- and Post-Educational Treatment in Type 1 Diabetes Mellitus During COVID-19 in Surabaya, parents had lower QoL compared with children, It could be brought on by the parents' responsibility to care for and guide their T1DM patients who are children and adolescents.15 The result of our study also shows that parents had lower QoL compared to their children.

In this study, most of the subjects aged 8–12 years (60%). This study is in line with that of Abdul-Rasoul et al., who claimed that the majority of the age group is between the ages of 8 and 12.1

However, there is a limitation to this study. Despite the fact that the study was carried out at a referral hospital in East Indonesia, the number of T1DM cases in this study is lower than that in Caucasians. There are other factors that have not been studied and may affect the quality of life of children with DMT1. In addition, the results of this study describe the quality of life of children with DMT1 in a small scope. For a wider population and different characteristics, further research is needed.

CONCLUSION

The majority of QoL of children with T1D based on parents report showing good result. The majority of QoL of children with T1D based on children report showing good result. There is no difference between parents report and children report on QoL of children with T1D for all the domain.

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