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The Quality of Life of Adolescents with Type 1 Diabetes in Malang



Aloysia Ispriantari¹, Dian Pitaloka Priasmoro², Musthika Wida Mashitah³

^{1,2,3}Faculty of Nursing, Poltekkes RS dr. Soepraoen Malang

Article Information

Article History:

Received, 05/01/2019

Accepted, 19/02/2019

Published, 01/04/2019

Keywords:

Adolescents, Quality of Life, Type 1 Diabetes

Abstract

Type 1 diabetes is a disease that can't be cured but the quality of life of the patients can be maintained as much as possible. This study aimed to analyze the quality of life of adolescents with type 1 diabetes in Malang. This study used cross sectional design. The sampling technique used total sampling by taking all adolescents (10-19 years) with type 1 diabetes who are still active in IKADAR Malang which were 24 adolescents. The quality of life of adolescents with type 1 diabetes was measured by the quality of life for youth questionnaire. The result showed that the total score of the quality of life of adolescents with type 1 diabetes was 74.4 ± 11.4 with the highest score was the impact on activities (92.3 ± 12.4) and the lowest score was the parent issues (57.3 ± 29.2). Higher score quality of life was in boys (75.5 ± 12.9), age 10-14 years (75.3 ± 11.7), disease duration 1-5 years (83.0 ± 3.5) and last HbA1c was $<7.5\%$ (83.3 ± 4.2). Healthcare providers especially nurse are expected to keep monitoring and improving the quality of life of adolescents with type 1 diabetes.

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✉ Correspondence Address:

Poltekkes RS dr. Soepraoen, Malang- East Java, Indonesia

Email: aloyisia.tari@gmail.com

DOI: [10.26699/jnk.v6i1.ART.p001-005](https://doi.org/10.26699/jnk.v6i1.ART.p001-005)

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P-ISSN : 2355-052X

E-ISSN : 2548-3811

INTRODUCTION

Diabetes occurs when there is lack of insulin or the body's cells unable to respond insulin and caused raised levels of glucose in the blood (DeFronzo, Ferrannini, Zimmet, & Alberti, 2015). Based on the latest estimate of International Diabetes Federation (IDF), there were 450 million people living with diabetes in the world in 2017. In 2045, it is estimated that the number will increase to 691 million people. There are three main categories of diabetes which are type 1, type 2 and gestational diabetes. Type 1 diabetes is a result from autoimmune reaction when the body produces none to very little insulin and more common in children and adolescents (IDF, 2017).

The number of children and adolescents with type 1 diabetes (0-19 years) was 1,106,500 and there were 132,600 newly diagnosed cases happened every year (IDF, 2017). In Indonesia, the number of children and adolescents with type 1 diabetes is still unclear. There were 825 children with type 1 diabetes in Indonesian Pediatric Society' registration during 1991-2012. Incidence rate of type 1 diabetes from 2000 to 2010 is increase from 0.0038 per 100.000 populations to 0.02819 per 100.000 populations (Pulungan, 2013).

In order to survive, people with type 1 diabetes need daily insulin injection, regular blood glucose monitoring, healthy diet and maintenance a good lifestyle (IDF, 2017). Disease and its treatment which affect the functional, psychological and social health and well-being of person with diabetes are defined as quality of life. Quality of life is an individual's perception of their position in life and the cultural context and value system in which they live in relation to individual goals, expectations, standards and concerns (WHO, 2014).

Adolescence is a transitional period from children to adulthood where physical, social and psychological changes occur. WHO defines adolescence as a period of human growth and development that occurs after childhood and before adulthood, beginning at age 10 to 19 years (WHO, 2016). They experience physical changes that lead to increased insulin resistance so they need a change of insulin dose that leads to more complicated self-management due to fluctuating blood sugar (Keough, Sullivan-Bolyai, Crawford, Schilling, & Dixon, 2011).

In Malang, the second biggest city in province East Java, most of the children with diabetes join a group called IKADAR (Ikatan Keluarga Diabetesi

Anak dan Remaja/Association of Child and Adolescent's Family with Diabetes). The aim of this group is to support children and their family within diabetes management, physic and psychologic support. This group has 82 children and mostly has type 1 diabetes.

The International Society for Pediatric and Adolescent Diabetes (ISPAD) explains that the goals of diabetes management are optimal health, social happiness and have a good quality of life (Swift, 2009). Based on the facts above, assessing quality of life is important for health professional to planning management to improve or maintain quality of life adolescents with type 1 diabetes.

METHODS

This study used cross sectional design. The study was conducted in IKADAR Malang in July 2017 after received ethical approval recommendation from The Ethic Committee of Polytechnic of Health The Ministry of Health Malang (Reg: 031/KEPK-POLKESMA/2017) and written informed consent was obtained from parents. This study was using total sampling technique with the criteria of respondents were adolescents (10-19 years) who joined and still active in IKADAR Malang.

The candidate of respondents data were provided by the committee of IKADAR Malang. There were 24 adolescents who still active in IKADAR Malang and data collection was conducted by door to door.

A structured interviewing questionnaire was used to collecting demographic data (gender and age) and diabetes characteristics (disease duration and latest glycated hemoglobin/HbA1c).

The quality of life adolescents with type 1 diabetes was measured using the Quality of Life for Youth Questionnaire. The Quality of Life for Youth questionnaire is a revision of 52 items of the Diabetes Quality of Life for Youth (Skinner, Hoey, McGee, & Skovlund, 2006).

The Quality of Life for Youth Questionnaire consists of 21 items and divided into sections: impact of symptoms relating to diabetes (3 items), impact of treatment (3 items), impact on diabetes (5 items), parent issues (3 items), worries about diabetes (7 items). For each item was scored by Likert scale 0-4 (0 representing 'all the time' and 4 'all never'). Then the score every section and total quality of life were calculated to a range 0-100 and categorized as: poor <60, fair 60-80 and good >80.

The validity and reliability of this questionnaire were tested before being used with Pearson Correlation Product Moment with $r_{count} > r_{table}$ $df = (10-2)$ that is 0.549 and reliability of Chronbach Alpha $0.834 > 0.6$. It can be concluded the instrument was valid and reliable.

Statistical analysis was performed with SPSS for windows (version 23). The characteristics of respondents were presented in the form of frequency distribution and percentage. The score of quality of life were tabulated and presented in the form of mean and standard deviation.

RESULT

The characteristics of respondents as shown in Table 1 below.

Table 1 The Characteristics of Respondents

Characteristics	Value	%
Gender		
Boy	8	33
Girl	16	67
Age (Year)		
10-14	11	46
15-19	13	54
Disease Duration (Year)		
< 1	3	12
1-5	5	21
> 5	16	67
Last HbA1c (%)		
< 7.5	3	8
7.5-9	4	13
> 9	17	79

Table (1) shows most of the respondents were girl (66.7%) with most of the age were 15-19 years and nearly half (33%) had primary high school of education level. Most of the disease duration' respondents were > 5 years and last HbA1c were > 9%.

Table 2 Quality of Life

Aspects	Score
Impact of symptoms relating to diabetes	72.6 ± 15.4
Impact of treatment	75.4 ± 14.8
Impact on activities	92.3 ± 12.4
Parent issues	57.3 ± 29.2
Worries about diabetes	69.4 ± 20.4
Total Score	74.4 ± 11.4

Table (2) shows the quality of life adolescents with type 1 diabetes were fair with total score 74.4 ± 11.4 . Most of the aspects quality of life was fair except the impact on activities that good (92.3 ± 12.4) and the parent issues that poor (57.3 ± 29.2).

Table 3 Characteristics of Respondents and Quality of Life

Characteristics	Score
Gender	
Boy	75.5 ± 12.9
Girl	73.9 ± 11.0
Age (Year)	
10-14	75.3 ± 11.7
15-19	73.7 ± 11.6
Disease Duration (Year)	
< 1	72.0 ± 17.3
1-5	83.0 ± 3.5
> 5	72.2 ± 11.2
Last HbA1c (%)	
< 7.5	83.3 ± 4.2
7.5-9	78.8 ± 5.9
> 9	71.8 ± 12.3

Table (3) shows that higher score quality of life is in boy (75.5 ± 12.9), age 10-14 years (75.3 ± 11.7), disease duration 1-5 years (83.0 ± 3.5) and last HbA1c was < 7.5% (83.3 ± 4.2).

DISCUSSION

The quality of life is defined as the individual's perception of his position in life, in relation to the local cultural and value systems and relates to his ideals, expectations and views, which are multidimensional measurements, not limited to physical or psychological effects of treatment (Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011)

Delamater stated that diabetes can affect both psychosocial and neurocognitive functions that potentially affect the quality of life of adolescents and entire families (Monazea, Talha, El-Shereef, El-Megeed, & Eltony, 2012). Children and adolescents with type 1 diabetes have a lower quality of life than children and adolescents who do not have diabetes (Faulkner & Chang, 2007).

Based on this study, the quality of life in adolescents with type 1 diabetes in Malang were fair (74.4 ± 11.4). This result was in line with Abolfotouh, Kamal, El-Bourgy, and Mohamed (2011)

that the same result that adolescents with type 1 diabetes in Alexandria have fair quality of life (76.4±9.8).

Quality of life of adolescents with type 1 diabetes in every aspects quality of life also can be categorized as fair and good except the parent issues. The parent issues aspect's score was 57.3±29.2 which categorized as poor. This poor quality could be a result the feeling of adolescents that their parents are too protective, worry too much and even act like diabetes is the parent's disease.

Erikson stated the psychosocial development during adolescence develops into increased self-responsibility and increased self-reliance (Zinn, 2012). According to Gardiner, during this period, adolescents develop their self-identity, choose their lifestyle and gradually part ways from their parents. They are start to think that their parents are too much interfere their life (Zinn, 2012).

In this study, it was found that girl respondents had lower score in quality of life but the difference was slight (73.9±11.0 and 75.5±12.9) and considered as not significant. This result was in line with the study of Abolfotouh et al. (2011) and Monazea et al. (2012) which stated that the difference quality of life between boy and girl respondents was not significant

This study also shown the difference between score quality of life in younger adolescents and older adolescents was slight (75.3±11.7 and 73.7±11.6). This result was in line with the study of Vanelli, Chiarelli, Chiari, and Tumini (2003) and Laffel et al. (2003) which stated that there was no association between age and quality of life in adolescents with type 1 diabetes.

This study reported that respondents with disease duration 1-5 years had more score quality of life than the respondents who had disease duration less than a year and more than 5 years. It was in line with the study of Monazea et al. (2012). The less disease duration (< 1 years), the adolescents with type 1 diabetes still adapt with their condition and had remission period which can decrease the quality of life (Costa & Vieira, 2015). The longer disease duration associated with the age when adolescents will try to being accepted by their peers and do not want to perform the diabetes management in front of their peers which caused they have more diabetes complication and lower quality of life (Zinn, 2012).

HbA1c as metabolic control become indicator to evaluate the quality of diabetes treatment and

also the quality of life. Target level of HbA1c based on ISPAD and IDF (IDAI & WDF, 2015) is optimal (<7.5%), sub optimal (7-5-9%) and high risk (>9%).

Good metabolic control was associated with better quality of life in adolescents with type 1 diabetes in (Monazea et al., 2012) and was in line with the result of this study. This study found that respondents with optimal HbA1c had the best score of quality of life (83.3±4.2) and respondents with high risk HbA1c had the worst score of quality of life (71.8±12.3).

CONCLUSION AND SUGGESTION

CONCLUSION

Quality of life adolescents with type 1 diabetes in Malang was fair (74.4±11.4). The aspect of quality of life impact in activities was good (92.3±12.4) and the highest one. The aspect of quality of life impact of symptoms relating to diabetes, impact on treatment and worries about diabetes were fair (72.6±15.4, 75.4±14.8, 69.4±20.4). And the aspect of quality of life parent issues was poor (57.3±29.2).

SUGGESTION

Healthcare providers especially nurse are expected to enhance the quality of life of adolescents with type 1 diabetes and help adolescents with their parents to make a good communication in diabetes management. Further research is needed to examine other factors related to the quality of life of adolescents with type 1 diabetes by using a larger sample.

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