Dietary Intake, Nutritional Status, and Quality of Life in Patients with Thalassemia Major

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Abstract

Background: Impaired growth and inadequacy of dietary intake in thalassemia patients may affect the quality of life. This study aimed to determine and examine the relationship between dietary intake, nutritional status, and quality of life in in patients with thalassemia major.

Methods: This study was a cross-sectional descriptive study conducted from February to October 2020. Twelve respondents who were registered at the *Yayasan Thalassemia Indonesia* and the blood transfusion unit at Fatmawati Hospital participated. This study conducted a physical examination and distributed food record questionnaires and WHOQOL-BREF. Data analysis was performed using Nutrisurvey 2007 and Fisher's exact test.

Results: The majority of the respondent were male (58.3%), categorized in the age group 5–18 years (58.3%), had normal nutritional status (50%) and quality of life. Interestingly, the respondents had an excess intake of protein and fats, while the intake of energy and carbohydrates was normal. Respondents had less intakes of all micronutrients.

Conclusion: The majority of respondents have normal nutritional status and quality of life but have a low intake of micronutrients. Both patients and parents need to be further educated on dietary intake to meet their nutritional needs.

Keywords: Dietary intake, impaired growth, thalassemia, quality of life

Introduction

Thalassemia is a genetic red blood cells disorder that interferes with the synthesis of a specific globin chain and makes the age of red blood cells shorter than normal.[1] The highest incidence rate is in Asia, which reaches 40%. In Indonesia, the number of patients is over 15,000 thalassemia major patients, with the second-highest prevalence (12.3%) in Jakarta after West Java.[2]

Thalassemia patients experience impaired growth caused by decreased appetite due to anemia.[1] Recommendations for nutritional intake for thalassemia patients are high in protein, potassium, zinc, and B vitamins. It is recommended to reduce iron and vitamin C. Unbalanced nutritional adequacy can affect the nutritional status.[3] Most thalassemia patients have malnutrition.[4,5] However, another study reported otherwise; most patients have normal nutritional status even though they have less dietary intake than recommended daily allowance (RDA).[6] Some factors can influence diary intake and nutritional status, such as education, knowledge, eating habits, socioeconomic status, age, gender, height, weight and psychiatric problems.[4,6]

Prolonged medication treatments, various psychiatric pressures from the community, and difficulties in socio-educational activities can severely affect their general health, psychological health and quality of life.[7] A study in Iran[7] showed that quality of life is standard in physical health, psychological health, and environmental health, but less in the social relationship dimension.

This study aimed to determine and examine the relationship between dietary intake, nutritional status, and quality of life in thalassemia major patients.

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Methods

This study was a cross-sectional descriptive study conducted in February 2020. Thalassemia patients from the blood transfusion unit at Fatmawati Hospital and registered at the Yayasan Thalassemia Indonesia were invited to the WE ACT 'Atma Jaya Care for Thalassemia' activity. The thalassemia patients were informed about the study, followed by an online procedure via chat messenger and sending the Food Record Questionnaire to respondents to fill out. The respondents themselves signed informed consent, and those less than 18 years old signed by their mothers who came along in the event. Ethical clearance was granted by the Committee of Research Ethics Commission, Faculty of Medicine Atma Jaya no. 44/11/KEP-FKUAJ/2019.

Samples were obtained by total sampling and passed the inclusion and exclusion criteria. The inclusion criteria were subjects registered at the Indonesian Thalassemia Foundation who agreed to participate in this study. The exclusion criteria were subjects with comorbidities such as digestive, cardiovascular, respiratory, and psychological disorder. The total sample who participated in this study was 12 patients.

Data collection of thalassemia major patients included gender, age, and last education, while physical examinations such as weight and height were measured to determine nutritional status. Furthermore, the Food Record Questionnaire about the intake of macronutrients (carbohydrate, protein, fats, and energy/calories) and micronutrients (calcium, potassium, zinc, iron, vitamin A, vitamin B1, vitamin B2, vitamin B6, vitamin B9, vitamin C, vitamin E.) as well as the WHOQOL-BREF questionnaire on quality of life based on four domains (physique, psychosocial, social relation and environment) was distributed in G-form, filled out via mobile phones due to the Covid-19 restrictions.

In brief, the Food Record Questionnaires were collected from 3 different days (2 weekdays and 1 weekend) and was supported by photos of food that the respondents sent when filling the questionnaires. Then, the data from the questionnaires were calculated using the Nutrisurvey 2007 according to the Recommended Daily Allowance (RDA), and further analyzed using SPSS version 25.0.

The WHOQOL-BREF questionnaire was used to measure the patients' quality of life based on four domains (physique, psychosocial, social relation, and environment).[8] Individuals with a score above 50 were defined as having a standard quality of life. Fisher's exact test was used to analyze the relationship between adequate food intake, nutritional status, and quality of life.

The nutritional status category was merged into less categories (less and very less) and normal categories. Therefore, the categories of nutritional intake variables were also merged into normal (normal, excess) and less (mild, severe) categories. The nutritional status variable referred to the body mass index based on the regulations of the Ministry of Health of the Republic of Indonesia in 2013, for respondents aged over 18 years,[9] or the Z-score weight for the height index of respondents under 18 years.[10] It aimed to simplify the explanation of procedures and data collection due to the online procedures.

Results

In total, 12 thalassemia major patients were included in this study, with a mean age of 16.63 years (SD=4.48), and distributed normally using the Shapiro Wilk test with a significant result above 0.05 (Table 1).

Data on macronutrient and micronutrient intake in thalassemia major patients were distributed normally using the Shapiro Wilk test showed a significant result above 0.05. Overall, the average dietary intake of energy and carbohydrates was normal, while the average dietary intake of protein and fats was in the excess category. The average intake of all the micronutrients was in the deficiency category (Table 2). The nutritional status data in thalassemia major patients were distributed normally using the Shapiro Wilk test, which showed a significant result above 0.05.

Furthermore, from the relationship between dietary intakes (macro-micronutrient) and

Table 1 Distribution of Thalassemia Major Patients' Characteristics in Jakarta (n=12)

Characteristics		n
Gender	Male	7
	Female	5
Age	5–18 years old	7
	>18 years old	5
Last education	Elementary school	4
	Junior high school	6
	Senior high school	2

Table 2 Macro and Micronutrient Intake in Thalassemia Major Patients based on Recommended Daily Allowance (n=12)

Intake	Mean total RDA	SD	Mean % RDA	SD	Category	n
Energy (kcal)	2159.84	265.54	103.25*	1.28*	Normal	5
					Excess	7
Carbohydrate(g)	211.81	24.80	106.28	28.00	Less	5
					Normal	5
					Excess	2
Protein (g)	64.60	10.77	156.48	44,44	Normal	4
					Excess	8
Fats (g)	119.15	23.30	241.88*	1.41*	Normal	-
					Excess	12
Potassium (mg)	1189.94	350.62	41.30*	1.66*	Less	11
					Normal	1
Calcium (mg)	257.41	142.39	24.55	14.17	Less	12
Iron (mg)	6.23*	1.27*	54.41	17.01	Less	12
Zinc (mg)	5.98*	1.22*	75.78	26.87	Less	9
					Normal	3
Vitamin A (mg)	487.60	218.67	54.08	28.77	Less	11
					Normal	1
Vitamin B1 (mg)	0.48*	1.2*	42.26	12.60	Less	12
Vitamin B2 (mg)	0.73	0.21	58.63	21.06	Less	12
Vitamin B6 (mg)	0.89*	1.26 *	76.90	32.65	Less	8
					Normal	3
					Excess	1
Vitamin B9 (µg)	97.98	30.65	26.03	9.15	Less	12
Vitamin C (mg)	14.55*	2.32*	15.10*	2.32*	Less	12
Vitamin E (mg)	3.95	1.54	31.37	13.57	Less	12

Note: RDA= Recommended Daily Allowance, * Geometric mean value

nutritional status of thalassemia major patients, it was found that there was no significant relationship between energy intake, carbohydrate, protein, potassium, zinc, vitamin A, and vitamin B6 on nutritional status in thalassemia major patients. Several variables such as fat intake, calcium, iron, vitamin B1, vitamin B2, vitamin B9, vitamin C, and vitamin E were not obtained in the calculation due to the constant data (Table 4).

Most respondents had a normal quality of life based on four domains including physique, psychology, social relation, and environment. All domains had a mean score above 50, which was categorized as a normal quality of life. It found that there was no significant relationship between nutritional status and each domain on quality of life.

Discussion

The result regarding the macronutrients intake was consistent with the study that states an increase in calorie intake. The recommendation for nutritional intake is to consume high protein.[4,6] Thalassemia patients have ineffective erythropoiesis, which tends to consume more than normal people to compensate for excessive energy expenditure; therefore, patients tend to consume more calories to compensate.[3,11] A high protein intake can help regenerate and repair cells in the body due to red blood cells' destruction.[11]

Thalassemia major patients have a lower micronutrients intake; this is in line with previous studies.[4,6] Recommendations for nutritional intake are to reduce vitamin

Table 3 Nutritional Status of Thalassemia Major Patients (n=12)

Nutritional Status	Mean	SD	n
Weight (W; kilogram)	34.12	8.90	
Stature (S; centimetre)	140	13.05	
Category*			
Severe malnutrition			2
Mild malnutrition			2
Normal			8

Note: * Category designated as Body Mass Index (W/(S2.100)) for patients >18 years old, and Z-score (W/S) for patients 5-18 years old

Table 4 Relationship between Macro-micronutrients' Intake and Nutritional Status of Thalassemia Major Patients (n=12)

Nutrient Intake	RDA Category	Nutritional Status		p-value
		Less n	Normal n	
Energy (kcal)	Normal	2	3	1.00
	Excess	2	5	
Carbohydrate(g)	Less	1	4	0.576
	Normal	3	4	
Protein (g)	Less	3	1	0.067
	Normal	1	7	
Fats (g)	Excess	4	8	-
Potassium (mg)	Less	4	7	1.00
	Normal	-	1	
Calcium (mg)	Less	4	8	-
Iron (mg)	Less	4	8	-
Zinc (mg)	Less	3	6	1.00
	Normal	1	2	
Vitamin A (mg)	Less	4	7	1.00
	Normal	-	1	
Vitamin B1 (mg)	Less	4	8	-
Vitamin B2 (mg)	Less	4	8	-
Vitamin B6 (mg)	Less	3	5	1.00
	Normal	1	3	
Vitamin B9 (µg)	Less	4	8	-
Vitamin C (mg)	Less	4	8	-
Vitamin E (mg)	Less	4	8	-

Note: *p-value for combined category for 2x2 Fisher test, (normal + excess) vs less

C and iron consumption, and increase the consumption of zinc and vitamin B.[3] Patients' knowledge about iron intake was good. Most thalassemia patients avoid iron consumption because the iron accumulation of iron consumption can lead to zinc reduction.[11] Severe zinc deficiency can lead to impaired growth, inhibition of sexual maturation, immune deficiency, and impaired wound healing.[5,12] Folic acid (Vitamin B9) and cobalamin (B12) play roles in erythropoiesis and maintaining the function of peripheral

Table 5 Quality of Life in Thalassemia Major Patients (n=12)

Quality of Life	Mean	SD	Category	n
Physique	56.83	10.74	Less	2
			Normal	10
Psychology	51.75	17.49	Less	2
			Normal	10
Social Relation	56.25	12.02	Less	2
			Normal	10
Environment	56.75	13.97	Less	4
			Normal	8

Table 6 Relationship between Nutritional Status and Quality of Life in Thalassemia Major Patients (n=12)

Quality of Life		Nutritional Status		P-value
		Less	Normal	
		n	n	
Physique	Less	2	-	0.091
	Normal	2	8	
Psychology	Less	3	1	1.00
	Normal	1	7	
Social Relation	Less	2	-	0.091
	Normal	2	8	
Environment	Less	1	1	0.067
	Normal	3	7	

nerves. Therefore, these deficiencies may create a risk for peripheral neuropathy in beta-thalassemia major patients.[13] Effective delivery of dietary information to patients and caregivers is essential to choosing a healthy diet for their condition.[14]

There was no significant relation between macro and micronutrient intake on nutritional status. The nutritional status was normal but patients had inadequate micronutrients intake, which is in line with the previous study.[6] It is influenced by several factors such as dietary restrictions on certain foods (iron and vitamin C), insufficient consumption of additional supplements, knowledge, eating habits, socioeconomic status and ecological factors.[6,15,16] Nutritional status assesses a person's body condition by comparing weight, height, and age. Still, it does not look at the nutritional adequacy of daily food intake, so it is possible to have differences in nutritional status and nutritional intake adequacy, especially in thalassemia patients who have specific nutritional intake recommendations.[3,17]

Respondents had a normal quality of life, which contradicts previous studies in Iran and Qatar.[7,18,19] Based on four domains, the result showed no significant relationship between nutritional status and quality of life. In general, thalassemia patients have various psychiatric pressure from the community, such as depression, anxiety, psychosocial disorder, and impaired school functioning. Thalassemia patients require long and frequent home care treatment that can affect their general health, and psychological health, which is expected to have a negative impact on the patients' quality of life.[7,18,20] Screening for psychiatric disorders, facilitated access to oral iron chelators, and regular monitoring of complications especially cardiac disease and hepatitis along with strict quality control of blood products were also mandatory to improve quality of life.[18]

Overall, this study has several limitations due to the COVID-19 pandemic, which has caused various problems , especially in terms of time and communication. The sample did

not reach the required minimum number, so it might not provide an optimal description. This study used body mass index to simplify the procedure and data collection due to the online procedure. However, it was not an option for people with organomegaly, such as thalassemia patients.[10]

This research is a preliminary study; if a similar study will be carried out, it requires further analysis with a much larger sample of respondents and select other methods in collecting the data, especially in nutritional status, to reduce bias from self-report. Further study is needed to determine the risk of malnutrition despite normal nutritional status and monitor psychological problems due to the COVID-19 pandemic.

In conclusion, thalassemia patients tend to have normal nutritional status, quality of life, and low intake of micronutrients. Several factors such as education, knowledge, environment, and socioeconomic status may affect the results. Thalassemia patients and their families require monitoring and education on dietary intake to control the daily nutrient intake, fulfil the nutrition needs based on Recommended Daily Allowance, and increase the quality of life.

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