Knowledge, Quality of Life and Adaptation Level among Patients with Thalassemia

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Abstract

Thalassemia is a chronic disease that presents a diverse range of serious clinical and psychological challenges. These challenges not only do effect on the patients' physical, emotional and social functioning but also their quality of life so patients needed to adapted with these disease. **Aim of the study:** To assess Knowledge, quality of Life and adaptation level among patients with thalassemia. **Research design:** A descriptive design was used. **Setting:** The study was conducted at general medicine department and the blood transfusion unit in Fayoum university hospital**. Methods:** A purposive sample of 80 adult patients from both genders with thalassemia. **Tools**: four tools were utilized for data collection. **Tool (I):** Structured interview questionnaire, **Tool (II):** patient's knowledge assessment questionnaire, **Tool (III):** World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire **Tool (IV):** Roy's Adaptation Model questionnaire. **Results:** There was unsatisfactory level of knowledge and moderate quality of life and adaptation related to patients with thalassemia**. Conclusion:** It can conclude that, the highest percentage of patients had unsatisfactory knowledge and moderate level of adaptation and quality of life related to thalassemia. **Recommendations:** Based on research data application of the educational program based on Roy's adaptation model had a positive effect on the outcomes of patients with thalassemia

Key words: *Adaptation, Knowledge, Quality of life, Thalassemia.*

Introduction

Thalassemia is one of the most common genetic diseases in the world. It is an inherited blood disorder characterized by decreased Hb production. Symptoms can vary from mild to severe anemia which includes fatigue, bone deformities, and growth retardation. Effective management includes a multidisciplinary approach involving blood transfusions, chelation therapy, possible hematopoietic stem cell transplantation, and continuous monitoring of organ function. The chronic nature of the disease and complications associated with clinical signs of the disease and its treatment make multiple physical, psychological and social problems and effects on the quality of life in these patients. **(Wangi et al., 2025).**

Knowledge plays a vital role in enhancing the quality of life for patients with thalassemia, as it empowers them to manage their condition more effectively and make informed decisions regarding their health. The Roy Adaptation Model provides a useful framework for understanding how individuals with chronic illnesses like thalassemia adapt to their condition through four adaptive modes: physiological, self-concept, role function, and interdependence. Adaptation to life with thalassemia involves coping with long-term treatment regimens, managing side effects, and maintaining social and educational roles. In this context, nurses play a pivotal role in patient education, psychosocial support,

and coordination of care. They help empower patients and families through self-care strategies, adherence to treatment, emotional support, and by acting as advocates to enhance both health outcomes and quality of life **Hassani, et al., (2024)**,

Significance of the study

Thalassemia is one of the most common genetic diseases in the world. Worldwide, it is estimated that 7 % of the population carries the thalassemia gene. The World Health Organization (WHO) has listed thalassemia as a major public health problem. Thalassemia has clear regional characteristics and group specificity, mainly occurring in the Mediterranean region, Southeast Asia, India, the Middle East, Africa, and southern China. With the flow of migrants, thalassemia has spread from the Mediterranean region, Africa, Asia to Europe, America, and Australia, becoming a serious global public health problem **(Su, et al., 2025)**.

In spite of the treatment measures that increase the survival of these patients, its clinical signs adversely affect the physical and mental health of the patients and their family. These physical and psychological problems lead to disappointment, decreased function, and ultimately reduced the quality of life. Not only factors such as insufficient knowledge, course duration of the disease and treatment, hospitalization, repeated laboratory tests for monitoring therapy and for early detection of any side-effects or complications and increased medical costs, mental status, and social problems cause stress in patients with chronic disease and their family, but also its effects on the patient's quality of life and adaptation with their disease **(Korany et al, 2022)**. So, when there are enough definite knowledge with those pre-existing factors, patient's quality of life and adaptation level likely to be improved.

Aim of the study

The study aimed to assess knowledge, quality of life and Adaptation level among patients with thalassemia through:
- Assess patient's knowledge regarding thalassemia.
- Assess patient's quality of life regarding thalassemia**.**
- Assess patient's Adaptation level regarding thalassemia**.**

Research question
- What is the patient's level of knowledge regarding thalassemia?
- What is the patient's quality of life regarding thalassemia?
- What is the patient's adaptation level regarding thalassemia?

Subject and Method

Research Design

A descriptive Correlational study design was utilized to conduct the study. It's a non-experimental quantitative research design used to: Describe the current status of variables in a population and examine the relationships (correlations) between two or more variables without manipulating them. **(Olawale et al., 2023; Devi et al., 2022)**.

Setting

This study was conducted at general medicine department and the blood transfusion unit in Fayoum university hospital.

Subject

Based on sample size equation 80 adult patients with thalassemia from both genders, recruited from the previously mentioned setting participate in this study. The sample size was calculated by adjusting the power of the test to 80% and the confidence interval to 95% with margin of error accepted, adjusted to 5% **(Chow, et al., 2007)**

$$n = \frac{N \times p(1-p)}{\left[\left[N-1 \times \left(d^2 \div z^2\right)\right] + p(1-p)\right]}$$

	=(180*(0.20*(1-
Nxp(1-p)	0.20)))/
N-1	=(180-1)*
d²/z²	=0.0025 / 3.8416+
p(1-p)	=0.20*(1-0.20)
N	=80

- P= 0.5
- N= Total population
- Z= Z value "1.96"
- D= Standard Error
- n= sample size

Inclusion criteria

Patients of both genders diagnosed with thalassemia, who consent to participate in the study and are able to communicate verbally

Exclusion criteria

Patients suffering from other types of anemia and Psychiatric patients.

Tools of Data Collection

Four tools were used to collect the data according to the following :

Tool I: Interview Patient's assessment Questionnaire

This tool was developed by the researcher in English and Arabic language after reviewing relevant recent literatures **(Choudhury, et al., 2025)** to collect baseline data pertinent to the current study. It was consist of two parts as follow: **Part I: Patients' demographic data:** This part concerned with assesses patients' socio-demographic characteristics which include patients' age, sex, marital status, educational level and occupation, residence and income.

Part II: Patients' present, past and family history: This part aimed to assess patients' medical history that includes information about the present history, duration of the disease, past history, previous hospitalization and family history of thalassemia.

Tool II: patients' knowledge assessment questionnaire.

It was developed by the researcher in the light of related literatures (**Asa, et al., 2021; Korany, et al., 2022**) to assess knowledge of patient regarding thalassemia. It includes questions about definition, causes, signs and symptoms, diagnostic test, prognosis, complications, treatment, iron therapy, diet and activity. It consisted of 40 questions in form of multiple-choice questions.

Scoring system: Patient's knowledge assessment questionnaire consisted of 40 questions, the correct answers were predetermined according to literature review, a correct answer was scored 1 point and incorrect answer was scored 0 point, The score were categorized according **Wahidiyat et al., (2021)** into:
-   Satisfactory knowledge level ≥75%
-   Unsatisfactory knowledge level < 75 %

Tool (III): World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire:

The WHOQOL-BREF was developed by **GENEVA, 1996.** It was used to assess quality of life for patient with thalassemia. It was translated into an Arabic language and back translated into English. The tool included (26) questions. The items of the WHOQOL-BREF questionnaire are divided into 4 domains (Physical health domain, psychological domain, social relationships domain, and environmental domain).

Scoring system:

WHOQOL-BREF composed of 26 items, which assess the following broad domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environmental factors (8 items), as well as the overall quality of life and general health (2 items). Each item is rated on a five-point likert scale that ranged from 1 to 5 where 1 is the lowest score and 5 are the highest score.

The score were categorized according **Skevington et al., (2004)** into:
-   Good quality of life: ≥75%
-   Average quality of life: 50<75%
-   Poor quality of life: <50%

Tool (IV): Roy's Adaptation Model questionnaire:

It was adapted from (**DeSanto& Fawcett, 2009**). It is consisted of four modes physiological, self-concept, role function, and interdependence 10 items for each mode. Each mode composed of 10 questions which are used for assessment level of adaptation among studied patients. The answers was measured and given a score based on five-point Likert scale as the following: Strongly Disagree (1) Disagree (2), Neither Agree or Disagree (3), Agree (4), and Strongly Agree (5). The total grade for this questionnaire is 200 grades that represent 100%. The total score ranged from 40- 200 with the higher score indicated more adaptive behavior for thalassemia patients.

The studied patients'adaptation can be classified according Abdelrahman et al.. (2023) into:
-   High adaption: ≥75%
-   Moderate adaption: 50<75%
-   Low adaptation: <50%

Validity

The content validity of the tools was done by a panel of 5 experts, who reviewed the content of the tools for comprehensiveness, accuracy, clarity, relevance and applicability. Suggestions were given and modifications were done.

Reliability

Reliability of the tool was tested to determine the extent to which the questionnaire items are related to each other. The Cronbach's alpha model, which is a model of internal consistency, was used in the analysis. Statistical equation of Cronbach's alpha reliability coefficient normally ranges between 0 and 1. Higher values of Cronbach's alpha (more than 0.7) denote acceptable reliability.

Cronbach's Alpha reliability analysis of the study tool

Construct	Cronbach's Alpha	P value
Tool (I): Part II: Patients' present, past and family history	0.767	<0.001*
Tool (II): Patients' Knowledge Assessment Questionnaire regarding thalassemia	0.814	<0.001*
Tool (III): World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire	0.765	<0.001*
Tool (IV): Roy's Adaptation Modes Scale" (RAMS)	0.805	<0.001*

*: Significant at $P \leq 0.05$

Ethical consideration

An official permission was obtained from the administrative authority of the selected setting for the current study. The researcher obtained consent from the studied patients, explaining the purpose and nature of the study, stating the possibility to withdraw at any time. Confidentiality of data assured by using codes to identify participants.

Pilot study

A Pilot study was carried out with 10% (not less than 10 patients) of the sample under study to test the applicability, clarity and efficiency of the tools, then the tools modified according to the results of the pilot study. Modifications included: rephrasing and rearrangement of some questions. After modification, the final form of the tools was developed. Patients who shared in pilot study excluded from the study sample.

Field Work

- Study was conducted within six months from July 2024 to the end of January 2025.
- The researcher visited the study setting 2 days; Monday and Thursday the days which selected according the hospital policy to thalassemia patients for blood transfusion per week from 9 am to 3 pm, range of cases about 1 to 3 per day from the two days of working field to gather data using the previously mentioned tools.

- The time consumed to fill in the tool by the researcher was 20 minutes for each tool.
- Before starting in data collection; the purpose of the study was simply explained to the patients and their families who agree to participate in the study prior to any data collection.

- An oral consent was obtained from each participant prior to data collection

- The researcher started the interview with each patient individually using the data collection tools.

Results

Table 1. Distribution of demographic data for the studied patients (n=80).

demographic data	Study group (n=80)	
	N	%
Age		
Mean±SD	27.3±7.07	
Gender		
Male	42	52.5
Female	38	47.5
Social Status		
Single	58	72.5
Married	16	20
Widowed	2	2.5
Divorced	4	5
Level of Education		
Can't read and write	42	52.5
Primary education	16	20
Secondary education	16	20
University education	6	7.5
Occupation		
Work	26	27.5
Doesn't work	54	72.5
Place of residence		
Urban	22	27.5
Rural	58	72.5
Income		
Sufficient	26	32.5
Insufficient	54	67.5

Table 1. illustrated that, as regard demographic characteristics, the mean age of the studied patients was 27.3±7.07. As regard to gender 52.5% were males and 47.5% were females. Regarding social status; 72.5% the studied patients were single. 52.5% of studied patients were can't read and write, A large proportion didn't work, live in rural areas 72.5 % and had insufficient income 67.5%.

Table 2. Distribution of past health and family history for the studied patients (n=80).

Past health history and family history	Study group (n=80)	
	N	%
Suffering from Chronic Disease		
No	4	5
Diabetes	16	21.05
Hypertension	18	23.6
Heart problems	32	42.1

Chest sensitivity	2	2.6
Diabetes, hypertension and Heart problems	4	5.2
Diabetes and Heart problems	4	5.2
Family history for thalassemia		
Yes	58	72.5
No	22	27.5
Degree of relationship		
First	38	65.5
Second	20	34.4

In relation to presence of chronic disease, **table 2shows that** 21.05% of patients had diabetes mellitus, 23.6% of patients had hypertension, 42.1% of patients had heart problems and 2.6 of them had chest sensitivity. As regard to family history of thalassemia, the table shows that 72.5% of patients under study had family history of thalassemia and 65.5% of them stated that the family history of thalassemia was from the first degree.

Table 3. Distribution of knowledge levels for patients patients with thalassemia (N=80).

Variable	Studied patient (N=80)	
Knowledge	**No.**	**%**
Unsatisfactory level	46	57.5
Satisfactory level	34	42.5

Table 3. showed that; there was a high percentage of unsatisfactory level of knowledge 57.5% regarding thalassemia among studied patients.

Table 4. Distribution of quality of life levels for patients with thalassemia (N=80).

Variable	Studied patients (N=80)	
Quality of life	**No.**	**%**
Poor	10	12.5
Average	60	75
Good	10	12.5

Table 4: illustrated that, 75% of the studied patients had average level of quality of life regarding thalassemia, while 12.5% had poor and good level of quality of life respectively.

Table 5. Distribution of adaptation levels for patients with thalassemia (N=80).

Variable	Study group (n=80)	
	N	%
Roy adaptation modes		
Low adaptation.	26	32.5
Moderate adaptation.	50	62.5
High adaptation.	4	5

Table 5. illustrated that, 62.5 of the studied patients had moderate level of adaptation regarding thalassemia, while 32.5% had low level of adaptation and 5% had high level of adaptation.

Table 6. Correlation between total knowledge score, total quality of life and total adaptation among patients with thalassemia (N=80).

Items	Total knowledge score	
	R	P-value
Total quality of life score	0.279	**0.01***
Total adaptation	0.338	**0.00***

Table 6. illustrated that, there was a highly statistically significant positive correlation between total knowledge, quality of life and adaptation score among patients with thalassemia with p-value 0.01

Discussion

Thalassemia is the most common form of inherited anemia worldwide. The chronic nature of the disease and complications associated with clinical signs of the disease and its treatment make multiple physical, psychological and social problems and effects on the quality of life in these patients **(Wangi t al., 2025)**.

The present study findings revealed that, the mean age of the studied patients in was (27.3±7.07). This result is similar to **Hossain et al., (2023)** who reported that the mean age of the studied patients was (19.75 ± 8.02) in a study titled "Health-related quality of life among thalassemia patients in Bangladesh using the SF-36 questionnaire.

Regarding to social status, the study results showed that more than two thirds of the studied patients were single. These results may be due to most patients are fear of passing the disease to their children by heredity. These results is in the same line with **Khodashenas et al., (2021)** who revealed that majority of the participants were single in their study that entitled "Quality of life and related paraclinical factors in Iranian patients with transfusion-dependent thalassemia".

Concerning education level, occupation, residence and income of the studied subjects, half of studied patients, can't read and write and more than two thirds of patients doesn't work, live in rural areas and had insufficient income. This result may be due to that the thalassemia is a chronic disease which affect the patient's, physical, psychological and social status of patients and cause severe level of fatigue which interfere with the patient's ability to study is go through their education in addition to frequent

hospitalization of patients due to the chronic nature of the disease and frequent receiving of treatment such as blood transfusion, which make patients in ability to work. Therefore, patients' income is insufficient.

This result is similar to **Hossain et al., (2023)** who reported that the majority of the studied patients were unemployment and low income. This result also agree with **Badur et al., (2021)** who revealed that more than half of patients were illiterate in their study that titled "Evaluation of the relationship between sociodemographic characteristics, quality of life, depression, drug compliance and biochemical parameters in patients with thalassemia major in Isparta".

In relation to past health history, chronic diseases in this study showed that about less than one quarter of patients suffer from diabetes mellitus and hypertension, less than half of patients had heart problem. These results may be due to pancreatitis which leads to diabetes mellitus and iron accumulation in the heart can cause cardiomyopathy. These results is agree with **Hamdy et al., (2021)** who revealed that more than one third of patients had diabetes mellitus and cardiomyopathy and most of the studied patients underwent splenectomy in their study that titled "Assessment of quality of life among beta-thalassemia major patients attending the hematology outpatient clinics at Cairo university hospital"

In relation to family history, the current results found that nearly two thirds of the studied patients had family history for thalassemia from first degree relation. This result may be due to that thalassemia is genetic disease that can be transferred through heredity. This result go in the same context with **Al-Abbass et al,, (2024)** who reported that two thirds of patients had family history of thalassemia in a study that titled " Epidemiological characteristics and disease complications in thalassemia syndrome patients in Babylon, Iraq"

The findings of the present study showed that, the more than half of the studied patients had unsatisfactory level of knowledge; this finding may be due to the high proportion of the studied patients live in rural areas that had lack of knowledge. In that context, **Abd elAziz et al. (2022)** who stated that, more than half of studied patients had unsatisfactory knowledge about thalassemia in a study that titled "Knowledge of adolescents with beta thalassemia major about their disease" This result also contradicted with **Korany et al., (2022)**. Who reported that nearly three quarters of patients had satisfactory level of knowledge regarding thalassemia.

The findings of the present study showed that, the three quarters of the studied patients had average level of quality of life, This might be due to early-onset of the disease in the childhood period and time over, the quality of life of patients was affected due to the absence of self-care concepts, among patients under study. In that context, This result was in supported by **Uçar & Taştan, (2025).** Who revealed that the quality of life of patients with thalassemia is at a moderate level.

The findings of the present study showed that, less than two third of the studied patients had moderate level of adaptation, This might be due to ongoing treatment stressors such as regular transfusions, chelation therapy, and chronic fatigue strain adjustment capacity. These stressors keep adaptation at a moderate level, not optimal; this result was in supported by **Mediani & Fuadah, (2025).** Who revealed that the studied patients had moderate levels of anxiety and adaptation, in a study that titled "Factors contributing to anxiety in adolescents surviving thalassemia major in Indonesia "

The present study findings indicated that, there was a statistical significant positive correlation between knowledge score, quality of life score and adaptation score, which indicated that an increase in knowledge level will associated with an increase in quality of life and adaptation level. The findings was supported by **Hasanah, et al., (2022),** illustrated that there were positive significant correlations between patients' knowledge, quality of life and adaption.

Conclusion

Based on the current findings, it can conclude that, the highest percentage of patients had unsatisfactory knowledge and moderate level of adaptation and quality of life related to thalassemia

Recommendations

Based on the findings of the present study, the following are recommended:

- Apply designated educational program Based on Roy's Adaptation Model to patients with thalassemia.
- Simple booklet written in simple Arabic language recommended to developed, and be available for all patients with thalassemia included all information and adaptation practice about the disease.

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