An-Najah National University
Faculty of Graduate Studies

ASSESSMENT OF ADHERENCE TO IRON CHELATION THERAPY AMONG PALESTINIANS WITH THALASSEMIA AT AL-WATANI GOVERNMENTAL HOSPITAL, NABLUS, PALESTINE

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Dedication

To my family, who have always been my source of strength and inspiration, this thesis is dedicated to you. Your unwavering faith in my abilities has been the driving force behind my academic journey.

To my professor Hamzah, thank you for your guidance and wisdom. Your expertise and dedication to my education have been invaluable.

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Finally, I would like to thank all the participants who generously shared their time and experiences for this study. Without their contribution, this research would not have been possible.

Declaration

I, the undersigned, declare that I submitted the thesis entitled:

ASSESSMENT OF ADHERENCE TO IRON CHELATION THERAPY AMONG PALESTINIANS WITH THALASSEMIA AT AL-WATANI GOVERNMENTAL HOSPITAL, NABLUS, PALESTINE

Unless otherwise referenced, I declare that the work provided in this thesis is the researcher's work and has not been submitted elsewhere for any other degree or qualification.

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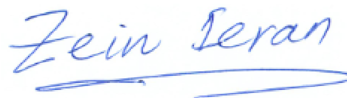
Signature:	
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ASSESSMENT OF ADHERENCE TO IRON CHELATION THERAPY AMONG PALESTINIANS WITH THALASSEMIA AT AL-WATANI GOVERNMENTAL HOSPITAL, NABLUS, PALESTINE

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Abstract

Introduction: Adherence to iron chelation therapy is a crucial step in reducing excess iron levels in the body. Factors such as age, having a sibling with thalassemia, lack of parental supervision, lower family income, infrequent blood transfusions, and psychological issues are likely to be investigated as significant predictors of nonadherence. The relationship between disease knowledge and adherence status will be examined. It is important for healthcare providers to be aware of the high prevalence of poor adherence to iron chelation therapy among patients.

Aim: To assess different barriers to adherence patients with Beta thalassemia included patient-related factors, medications-related factors, sociocultural-related factors, environmental context and resources, and patient–health care provider relationship factors

Method: A descriptive cross-sectional design is adopted to assess the adherence for thalassemia patients of the National Thalassemia Center at the National Hospital, Nablus. The sample size of 120 thalasemia patients. Data was collected using an direct interview or by phone that composed questionnaire of three parts. The first part of the questionnaire Sociodemographic and clinical characteristics of the samples in Thalassemia center the second part of the questionnaire included Assessment of disease knowledge gaps among thalassemia patients. And the third part of the questionnaire on adherence patient to iron chelation therapy.

Results: Nearly equal gender distribution (63% males, 57% females) and a predominant age range of 18 to 26 years were studied. Adherence to iron chelation therapy correlated with lower ferritin levels, indicating treatment efficacy. Both adherent and non-adherent patients demonstrated a good understanding of thalassemia, suggesting sufficient disease

knowledge. However, adherence positively influenced patient satisfaction with hospital treatment and medical services, highlighting the importance of patient education and support systems in enhancing treatment adherence and overall healthcare experience.

Conclusion: The study concluded that many patients at the National Governmental Hospital in Nablus show adherence to iron chelation therapy. Challenges remain including difficulties in obtaining medication and external influences that affect adherence despite adequate knowledge. The role of health care providers is important in strengthening relationships between the patient and the service provider, providing multidisciplinary care, highlighting the importance of education and continuous support for patients.

Keywords: Thalassemia, Adherence, Iron Chelation Therapy, Beliefs, deferasirox (Exjade)

Chapter One

Introduction and Theoretical Background

1.1 Introduction

Beta (β)-thalassemia is an autosomal recessive blood disorder caused by a defect in the synthesis of the beta (β)-globin chain of hemoglobin [1]. It is prevalent worldwide, including in Palestine, where approximately 801 patients suffer from thalassemia in Palestine without effective treatment. The disease represents a financial and social burden on patients and their families, as well as on the national health system. It is prevalent due to the high rate of consanguineous marriages in Palestine, estimated at about 45% in marriages contracted after 1980 [2].

Patients with beta-thalassemia major (β-TM) develop severe anemia that requires lifelong blood transfusions to maintain life. Repeated blood transfusions eventually lead to an accumulation of iron called chronic iron overload [3], [4]. Chronic iron overload is a potentially fatal condition because excess iron is particularly toxic to the heart and liver. Heart disease is the leading cause of premature death in patients with chronic iron overload [5]. Patients are at increased risk for heart failure, stroke, and endocrine diseases [1], [3].

There are a few medications available to treat iron overload, all of which act as chelating agents. Since the mid-1970s, deferoxamine has been the main chelation therapy for patients with iron overload [6]. Despite its effectiveness, deferoxamine must be given as a continuous slow subcutaneous injection over 8–12 hours every night, at least 5 nights per week. This treatment is cumbersome and invasive and therefore rarely followed by patients [4], [7].

There is significant evidence to support the use of the oral iron chelators deferiprone (L1) and deferasirox (Exjade). Although both are effective in reducing iron burden, several characteristics favor deferasirox [5], [8]. Deferasirox (Exjade) is a relatively new and effective chelation therapy that has the advantage of being easy to administer as a once-daily oral dose [6],[8]. However, deferasirox may require frequent dose adjustments due to increased serum creatinine, which requires close monitoring [6], [9]. The availability

of deferasirox is a promising alternative to DFO and has a positive impact on adherence to treatment [8], [10].

Treatment of thalassemia major requires an intensive treatment plan to survive, and adherence to treatment to prevent iron overload and regular medical monitoring are essential. Adherence to the treatment regimen is a major challenge in chronic diseases [11], [12]. Patients should be followed from their developmental stage, as they seek independence and dependence on others, and childhood characteristics and maturational desires increase the threshold for non-adherence. Other factors known to complicate adherence include family aspects (size, income, parental education, presence of a sibling with the disease, parental involvement in their child's treatment and monitoring) and demographic and clinical variables such as age, disease severity, and knowledge of the disease [13], [14], [15]. Thus, we need to propose approaches to reduce the influence of these factors to maximize adherence.

The previous study highlighted the importance of psychological and social factors in adolescents with type 1 diabetes and their impact on self-management habits, especially with regard to exercise practices, dietary practices, adherence to medication (insulin) and control of glucose levels, as the study found simple to moderate relationships in its results, which indicates the impact of psychological factors related to self-management. Eating behaviors and social anxiety (especially in men) were higher than others in females, as well as between eating habits, conscience and intrinsic motivation. In addition, practicing positive habits such as exercise and improving self-management, especially among with type 1 diabetes, all helped patients adhere, which confirms the importance of psychological effects [16].

Finally, a previous study showed the importance of identifying the quality of life and its associated factors among thalassemia patients at the national level, as it was shown that the quality of life of thalassemia patients is affected by a number of factors, including (environmental, social and personal). Therefore, improving and enhancing the quality of life of thalassemia patients helps reduce the negative consequences of the disease and also reduces patients' non-adherence to treatment. To achieve this, effective health and social

policies must be developed, and this requires obtaining comprehensive and clear information about the various aspects of the patient's life. This can be achieved by establishing multidisciplinary teams that include (doctors, nurses, psychologists, and nutritionists), to help understand the individual needs of thalassemia patients. These strategies help enhance adherence to treatment [17].

1.2 Problem statement

Many thalassemia patients struggle with adhering to iron chelating therapy due to the complexity of the treatment regimen, side effects of the medication, and other personal factors. This can result in iron overload and organ damage, which can have a significant impact on the quality of life and overall health outcomes for these patients.

Non-compliance of Palestinian with thalassemia in the Al Watani hospitalin Nablus in taking chelation and often they require frequent blood transfusions, which can lead to iron overload in the body. Horwever, adherence to iron chelating therapy can be a challenge for thalassemia patients, as the treatment requires regular and long-term use of medications that can have side effects.

1.3 Aim of the Study

1.3.1 General objective

To assess different barriers to adherence among patients with Beta thalassemia included patient-related factors, medications-related factors, sociocultural-related factors, environmental context and resources, and patient–health care provider relationship factors.

1.3.2 Specific objectives

1. To study the rates of patient’s adherence to ICT and to know the insights of their illness.
2. To determine the interventions for better Iron Chelation Therapy adherence and health outcomes of patient’s adherence. Study the rates of patients’ adherence to iron chelation therapy when receiving treatment in the hospital.

3. Study the rates of patients' adherence to iron chelation therapy when receiving medical services provided in the hospital.
4. Study the rates of patients' adherence to iron chelation therapy with the surrounding community.
5. Studying patients' compliance rates with iron chelation therapy when interacting with medical staff.

1.4 The importance of the Study

Understanding the factors that contribute to adherence to ICT, helps the healthcare staff to improve patient outcomes and reduce the burden of disease and the complications of frequent blood transfusionan as iron overload can cause significant damage to body organs such as the liver, heart, and endocrine system, which will lead to a reduced quality of life and potentially life-threatening complications.

Moreover this could reduce healthcare costs as thalassemia pathients needs frequent follow up, blood transfusion and treatments which can be costly for both patients and healthcare systems. Poor adherence to ICT can lead to end organ damage such as heart failure which will reflect as increased healthcare costs due to hospitalizations, costly medical therapy, and long-term managment. Thus understanding the importance to adhere to treatment could help reduce these costs and make treatment more accessible for patients.

Studying adherence rate to ICT could also help the healthcare team to understand the challenges and break down barriers that patients usually face. This in turn will reflect to patient-centered care when dealing with chronic condition like thalassemia that requires long-term management and struggles.

Lastly, identifying factors associated to poor adherence to ICT could guide us to future research, and help in implaminting of multiple-target interventions aimed at resolving adherence barriers and the use of different measures of adherence to be included in different care plans.

1.5 Hypotheses of study

Hypothesis 1: There is a significant relationship between patient-related factors, sociocultural factors, and patient-provider relationships on adherence to iron thrombolytic therapy among β-thalassemia patients.

Hypothesis 2: Improved education, especially regarding patient knowledge and support, is associated with increased adherence to iron thrombolytic therapy among β-thalassemia patients, leading to improved health and reduced morbidity and mortality among β-thalassemia patients.

Hypothesis 3: Thalassemia patients, especially those at a young age, who receive support from family, peers, and the community are more likely to adhere to iron thrombolytic therapy than those who lack such support.

Hypothesis 4: There is a significant relationship between patient and provider relationships that critically influence adherence to ICT, as many patients who reported higher levels of satisfaction and support from medical staff led to greater adherence to treatment protocols.

These main hypotheses form the fundemental multifaceted nature of adherence to ICT in beta-thalassemia patients, which includes main factors such as patient education, social support, medication side effects, and interactions with health care providers.

1.6 Concepts and operational definition

First of all, identifying the key term and definition related to the current study, such as adherence to treatment and knowledge about the disease, and moreover to discuss about the contents of the socio-demographic characteristics file related to this study.

Adherence to treatment:

Adherence to treatment is the degree to which an individual's actions align with the agreed-upon recommendations of a healthcare provider. This includes aspects like medication intake, following a prescribed diet, executing lifestyle changes, and in addition to the patient's satisfaction when receiving treatment in the hospital or his

satisfaction with the availability of the medical services received. It goes beyond just taking the prescribed doses and also includes following instructions regarding timing, frequency, and other relevant guidelines. In our study, the researcher focused on patients' perceptions that help them adhere to iron chelation in the hospital and answered questions on a scale (0: no, 1: yes), starting with questions 36 to 82 in the third part of the questionnaire.

Knowledge about the disease:

Knowledge about the disease refers to the understanding and awareness an individual has regarding a particular medical condition. This includes knowledge about the causes, symptoms, risk factors, diagnostic methods, treatment options, and potential outcomes associated with the disease. Individuals who have good knowledge about a disease can empower self and others to make decisions about their health and treatment options in better way. In our research, the emphasis was on patients' understanding of the disease and its role in their adherence to ICT during hospital stays. Responses were recorded on a scale where 0 indicated "no," 1 indicated "yes," and 0.5 indicated "I don't know." These questions were found in the second section of the questionnaire, spanning from question 21 to question 35.

The socio-demographic characteristics related to the current study:

The socio-demographic characteristics related to the current study refer to the social and demographic factors of the participants that are relevant to the research. These characteristics may include age, gender, education level, marital status, employment status, income level, and other similar factors. Grasping and understanding these points could help researchers to analyze and relate tp how they may influence the study outcoms. Our research will focus on patients' socio-demographic characteristics and its major role in their adherence to ICT. This part about socio-demographic charactaristics is found in the first section of the questionnaire, from question 1 to question 20.

1.7 Previous Studies and Theoretical Background

A summary of some studies at the global, regional and local levels on the extent of thalassemia patients' adherence to iron chelation therapy is presented.

1.7.1 Global Studies

We reviewed the literature on thalassemia patients' adherence to iron chelation therapy. Clear evidence has been identified that non-adherence to treatment is influenced by multiple factors belonging to several different areas and includes patient knowledge about their disease, education, social support, dosing regimens, and side effects.

The role of social and family support was reviewed in this qualitative study conducted by [18]. The study was conducted on 20 Iranian patients, and the researchers' goal was to delve deeper into identifying the obstacles that affect patients' non-adherence to treatment. Barriers included a lack of support from health care providers, including family support, medication side effects, and financial constraints. The study also emphasised how psychological variables such as anxiety and despair affect compliance practices. These findings highlight the need for personalised treatments to target the unique problems faced by Iranian patients with thalassemia major. Improving access to healthcare and psychosocial support networks have been identified as critical approaches that have been suggested to improve treatment adherence in this population.

Another study conducted by Saifuddin et al in 2019 in Malaysia highlighted the important role of social support and its relationship to anxiety among patients. This research project was adopted in a mixed, non-experimental method. Collecting qualitative and quantitative data through a set of questions through an online survey. This article, entitled "A Study of Social Support and its Relationship to Anxiety in Malaysia," emphasized the relationship between anxiety in individuals and social support. Through analyzing the data, it was found that there are different factors that affect patients, including a number of aspects (social, emotional, and informational), and they have an effective impact on anxiety levels. The study showed that with high levels of social support, patients have a low level of anxiety, and this helps them adhere to treatment. By chelating iron, the effective role of social, emotional and cultural support was also emphasized in reducing

the level of anxiety among patients and increasing the rate of adherence among patients, which emphasized the importance of family and community networks in Malaysia. These views emphasise the importance of promoting strong psycho-emotional and social support systems, tailored to cultural contexts, as a correlate of alleviating anxiety and promoting psychosocial well-being among individuals in Malaysia [19].

A study published on Iran Public Health article on adherence of patients with thalassemia major The major narrative review “Thalassemia major and its associated psychosocial problems” was published and presented a synoptic overview of the psychosocial challenges faced by individuals with thalassemia major. The multifaceted impact of this condition on the nature of patients’ lives and their relational health was emphasized, and many social and psychological issues were investigated, such as emotional disturbance, anxiety, social stigma, and depression that affect a number of individuals with thalassemia major. The study demonstrated the importance of addressing these social and psychological problems. Through multidisciplinary care systems that include psychological support, education and guidance to improve the general health of elderly thalassemia patients. Furthermore, the review addresses the role of psychosocial interventions in supporting patients with thalassemia major. It emphasizes the importance of comprehensive care approaches that include not only medical management, but also psychosocial support to improve the overall well-being of patients [20].

At the same time, conducted a cross-sectional study in Babil Governorate, “Evaluating adherence to iron chelation therapy among patients with thalassemia major in Babil Governorate.” It measured the extent of adherence of patients with thalassemia major and was conducted on 100 patients. It was found through the study that 79% adhered to iron chelation therapy, while 21% of them were adherent to treatment.did not adhere to it. The most common reason for non-adherence was gastrointestinal side effects of the medications and the second reason was lack of interest and discomfort or bitter taste of the medication. The other reasons were due to forgetfulness, some psychological problems, and taking other medications. The results suggest that adherence to ICT among these patients is inadequate, with many failing to adhere to the prescribed regimen. Factors contributing to non-adherence include forgetfulness, inconvenience of ICT

management, and lack of awareness of its importance.The study emphasizes the need for interventions to enhance adherence in this population. He points out that educational and counseling initiatives aimed at increasing awareness and addressing barriers can improve treatment outcomes for major thalassemia patients in Babylon Governorate [21].

Lastly, Senol et al., 2023, conducted This single-center observational study was conducted in Larissa, Greece among 37 pediatric patients and 35 affected adult patients. The article covers "Quality of life, clinical effectiveness, and satisfaction in patients with beta-thalassemia major and sickle cell anemia receiving deferasirox chelation therapy" and the impact of deferasirox chelation therapy on quality of life (QoL), clinical outcomes, and patient satisfaction in individuals. With beta thalassemia major and sickle cell anemia.

The study evaluates quality of life through standardized questionnaires, clinical effectiveness through laboratory parameters, and patient satisfaction through interviews and studies. The results show that deferasirox treatment improves quality of life, reduces complications associated with iron overload, and enhances patient satisfaction among individuals with beta thalassemia major and anemia Sickle cell. The study found that patients receiving deferasirox had significantly better QoL scores compared to those receiving deferiprone or deferoxamine. Research and support for effective iron chelation therapy in this population must continue [22].

In conclusion, adherence to iron chelation therapy is important for the management of thalassemia. It included patient education, social support, side effects, and dosing regimens as they affect their adherence to treatment. In addition, healthcare professionals must take these factors into consideration when developing treatment plans for thalassemia patients.

1.7.2 Regional Studies

A descriptive cross-sectional design used in this study, was conducted in Jordan on 73 patients. The article covers “Beliefs of Jordanian children with thalassemia toward the use of iron chelation therapy”. The aim of the study is to examine the beliefs, knowledge, and commitment of Jordanian children with thalassemia to treatment. The study showed that patients are highly aware of the importance of chelation therapy and the complications associated with not using the treatment [23].

Another cross-sectional study in Dubai among A total of 351 patients The article covers the “demographic and clinical profiles of patients with beta thalassemia major who were treated at the Thalassemia Center in Dubai”, where a clear difference was noted between the previous study in 2007 in the number of young people, as the data reflected that the effect of education and the conduct of medical examinations and consultations before marriage reduced the Consanguineous marriage and the marriage of thalassemia patients, and the UAE government’s vision was that there was a clear hope of reducing the incidence of thalassemia major, and this will certainly affect other neighboring countries that suffer from similar health concerns. The study also showed that in patients who take iron chelates orally, the low ferritin level in the blood is better than the serum ferritin level, especially in the young group [24].

1.7.3 Local studies

Retrospective cohort study conducted in the West Bank on 309 patients The article covers the “Health Status of Patients With β-Thalassemia in the West Bank: A Retrospective-Cohort Study" The study showed that there is an urgent need to develop comprehensive and necessary evaluation protocols to reduce the rates of morbidity and mortality associated with beta thalassemia. It also strongly recommends regular evaluation and follow-up with a focus on blood transfusions to improve the clinical picture of patients. Establishing programs aimed at increasing patients' adherence to treatment programs and follow-up is a top priority. This can be achieved through collaboration with a national multidisciplinary team consisting of a group of hematologists, endocrinologists, cardiologists, ophthalmologists, dentists, psychologists, social workers, and nutritionists [25].

1.8 Summary

In this section, the researcher presented the available studies that supported the study method used. The opposite studies have been demonstrated. After presenting the studies and reviewing all the previous studies, it was proven that there is a lack of research on this topic in general, and its lack and almost reaching the point of lack of research on this topic in Palestine in particular.

Chapter Two
The Method

2.1 Study design

A descriptive cross-sectional design is adopted to assess the adherence for thalassemia patients of the National Thalassemia Center at the National Hospital, Nablus.

2.2 Study setting

The study was performed at the Thalassemia Department at the National Hospital, Nablus.

2.3 Study population

This study was conducted by selecting a purposive sample of

1. Palestinian between the ages of 3 and 33 years.
2. Diagnosed with β-TM.
3. Patients receiving Deferoxamine (Desferal) IV or Deferasirox (Exjade) by mouth with iron chelation.

2.4 Study sample

The researcher used the sampling method for this cross-sectional study by interviewing all patients receiving treatment at the Thalassemia Center, where the total number of patients was 120 patients, knowing that the Ministry of Health adopted the premarital medical examination in 2008, but there were rare cases in which the law was not adhered to, especially in rural areas and villages, where the youngest age of patients in the study was 3 years, so the medical examination became mandatory in 2000 and was closely followed up by the Ministry of Health, and the oldest age in the study was 33 years, as non-compliance negatively affects their health and causes diseases such as heart disease, which leads to the premature death of patients.

2.5 Inclusion and exclusion criteria

Inclusion Criteria:

- Palestinian Patients aged 3–33 years.
- Diagnosed with β-TM.
- Treated with deferoxamine iron chelating therapy. Palestinian Patients who fulfilled the inclusion criteria and accepted to participate were enrolled in the current study.

Exclusion Criteria:

- Any patients who refused to participate in the study were excluded from the study.
- Any patients with thalassemia- unrelated co-morbidities. (Example malignancy, renal failure, mental illness, chronic liver disease).

2.6 Study timeframe

The study was conducted between the start of July 2023 and the end of July 2023. This study took place at the National Thalassemia Center at the National Hospital, Nablus.

2.7 Data collection tool

Data was collected by communicating with thalassemia patients through a direct interview or by phone to fill out the questionnaire, and data was collected starting from July 2023, and thalassemia patients were contacted via a direct interview or by phone to fill out the questionnaire, and the data will be provided.

The questionnaire used in the research is composed of three parts. The first part of the questionnaire Sociodemographic and clinical characteristics of the samples in Thalassemia center the second part of the questionnaire included Assessment of disease knowledge gaps among thalassemia patients. And the third part of the questionnaire on adherence patient to iron chelation therapy

The questionnaire has been translated into Arabic, adapted, and validated for implementation.

Section 1: The first part of the questionnaire introduced the Sociodemographic and clinical characteristics of the samples in Thalassemia center:

- Sex
- Age
- Place of residence
- The questionnaire has already been filled out
- Relationship between the parents
- Father's education
- Mother’s education
- Patients education
- Status
- Job
- Family members affected by thalassemia
- Family member died of thalassemia
- Social and economic status of the family
- Monthly income/ shekels
- Diagnose
- Iron chelation therapy treatment period
- Treatment type of iron chelation therapy
- Any other disease

Do you have bad habits such as smoking and others management/personal skills. The adherence to ICT was assessed using Likert Scale where 1 represented “never missed a dose”, 2 represented “some of the time” (missed <25% of total doses), 3 represented “most of the time” (missed 25-50% of total doses) and 4 represented “all of the time” (missed >50% of total doses). Patients taking >75 % of the prescribed doses (score of 1

and 2) were considered to be adherent, whereas those with <75% (score 3 and 4) were considered non-adherent.

The knowledge regarding thalassemiawas analyzed using a 15-point questionnaire. The knowledge of the patients was then scored. A score of 1 was given for each correct response, a score of 0.5 was given when the patient was uncertain about the answer, and a score of 0 was given for each incorrect response. The knowledge regarding the disease and the prevalence of iron overload related complications were compared between the adherent and non-adherent groups, and The knowledge of the patients was then scored. and the extent of the patient's compliance with iron chelation treatment was analyzed, which included several aspects (when receiving treatment, when receiving medical service, when dealing with the community, and finally the medical staff). was analyzed using a 45-point questionnaire. A score of 1 was given for each correct response, and a score of 0 was given for each incorrect response [26].

2.8 Validity and Reliability of the Questionnaire

The questionnaire was approved by the doctors supervising thalassemia patients for a period of not less than 20 years, and the questionnaire was reviewed by the dissertation supervisor, Professor Hamzeh Al Zabadi and 2 other academic public health specialist.

We contacted the Friends of Thalassemia Patients Society and was provided with attachments containing information about nurses' adherence to treatment and using the information to form questions to complete the survey. In addition, more than one study was reviewed to complete the questionnaire [27].

Reliability:

Information regarding the study in general and the objectives of the study in particular was provided to participants, and a consent form was signed. Earlier, before adopting the questionnaire, the researcher conducted a pilot study and observed the results. This indicates that the questionnaire was clear to participants and easy to understand for all participants. It also provided good interpretation of the data and fewer errors for participants.

2.9 Study procedures

The following steps were taken:

- Initially, a research proposal for the current study was prepared, and the study tool (questionnaire) was presented to the experts and a group of arbitrators before being submitted on May 30, 2023.
- Official approvals were obtained from the Faculty of Graduate Studies and IRB at An-Najah National University and from official authorities to facilitate carrying out the field study by distributing questionnaires to collect data between July 2023 and the end of October 2023.
- A review of previous studies and theoretical frameworks in the field of research to build the theoretical framework for the current study has been published.
- The study tool was applied to the study sample, and the data was collected, analyzed, and converted into information through special tables between November 1, 2023, and April 24, 2022.
- Finally, interpreting and discussing results and formulating recommendations, proposals, and conclusions

2.10 Data Analysis

The researcher reviewed the questionnaire in all details and checked for completeness and consistency. The information was processed, given codes, entered into the system, cleaned, interpreted, and analysed. Using the Statistical Package for the Social Sciences (SPSS V21.0). Data were entered and double-checked for outliers or errors.I explained that all domains were not normally distributed with $P < 0.05$.

The data from thalassemia patients was analyzed based on ferritin levels, which were categorized into two groups. The first group consisted of patients who Never missed a dose or Some of the time, with ferritin levels less than or equal to 2500. The second group included patients who forgot most of the time or did not adhere to taking the doses at all, with ferritin levels equal to or greater than 2501.

2.11 Ethical considerations

Ethical considerations were taken into the study through postgraduate approval (dated 19/03/2023) Appendix A. Ethical approval was obtained from the Institutional Review Board “IRB” at An-Najah National University in Nablus - Palestine (dated 08/05/ 2023) Appendix (B), and official books obtained by postgraduate studies was distributed to At Al-Watani Governmental Hospital The purpose of the books was to obtain permission to distribute the questionnaire and information sheet. Approval was obtained for the questionnaire in English and Arabic.

Filling out the questionnaire and participating was by the person’s choice and not for rent, i.e. voluntary, as shown in Appendices (D, E, F, F). . Information about the purpose of this study was provided to participants. The focus was on privacy throughout, and therefore the right to withdraw from the study at any time was allowed without consequences. They were also informed that they could withdraw from the study at any time without any penalty, and serial numbers were also used to collect and save the questionnaire.

Chapter Three
Results

Our study included 120 patients from Thalassemia department At Al-Watani Governmental Hospital, Nablus. In this section of the study, the collected data then tabulated, analyzed, and then interpreted individually using statistical programs and tests. Below, this section begins with the characteristics of those studied

3.1 Demographic characteristics of the participants

All participants in the study responded, with 120 questionnaires distributed and returned. In terms of participant demographics, the gender distribution was nearly equal, with 63% male and 57% female respondents. Thalassemia patients were assessed through a questionnaire regarding their adherence to chelation therapy. The study noted that the majority of participants fell within the 18 to 26 age range (52%). Patients were asked about the frequency of missed doses of iron chelation therapy, with response options including "never missed a dose," "some of the time," "most of the time," and "all of the time."

Data analysis involved grouping patients who had either never missed a dose or had occasionally missed one as those adherent to treatment. This conclusion was supported by assessing the body's iron levels, which were found to be below 2500. Patients who frequently missed doses or consistently missed them were classified as non-adherent, with their ferritin levels exceeding 2501.

Further examination showed that 75% of adherent patients maintained a blood ferritin level of less than or equal to 2500, along with their questionnaire responses. Conversely, 45% of non-adherent patients exhibited ferritin levels equal to or greater than 2501.See table (1)

Table 1

Socio-demographic and clinical characteristics of participants

Variable	Adhered N (%)	Not adhered N (%)	Total	Chi-Square P-value
Ferritin levels				
• Less than and/ or equal 2500	75 (100)	0 (0.0)	75	<0.001
• Equal and/or above 2501	0 (0.0)	45 (100)	45	
Gender				
• Male	42 (66.7)	21 (33.3)	63	0.322
• Female	33 (57.9)	24 (42.1)	57	
Age (years) (mean±SD)	19.253±7.038	21.288±7.393	---	0.135*
Age				
• 0-8 years	8 (10.7)	3 (6.7)	11	0.064
• 9-17 years	23 (30.7)	9 (20)	32	
• 18-26 years	34 (45.3)	18 (40.0)	52	
• 27-33 years	10 (13.3)	15 (33.3)	25	
Place				
• City	18 (54.5)	15 (45.5)	33	0.348
• Village	36 (62.1)	22 (37.9)	58	
• Camp, refugee	21 (72.4)	8 (27.6)	29	
The questionnaire has been filled out				
• Patient himself	50 (61.0)	32 (39.0)	82	0.612
• Patient relative	25 (65.8)	13 (34.2)	38	
Relationship between the parents				
• No	9 (52.9)	8 (47.1)	17	0.380
• Yes	66 (64.1)	37 (35.9)	103	
Father's education				
• Primary	10 (62.5)	6 (37.5)	16	0.788
• Preparatory	27 (65.9)	14 (34.1)	41	
• Secondary	31 (57.4)	23 (42.6)	54	
Mother’s education				
• Primary	10 (62.5)	6 (37.5)	16	0.486
• Preparatory	21 (55.3)	17 (44.7)	38	
• Secondary	37 (71.2)	15 (28.8)	52	
Patients education				
• Primary	10 (58.8)	7 (41.2)	17	0.293
• Preparatory	13 (61.9)	8 (38.1)	21	
• Secondary	30 (63.8)	17 (36.2)	47	
• Diploma	4 (36.4)	7 (63.6)	11	
• Bachelor's	18 (75.0)	6 (25.0)	24	

3.2 Cont. demographic characteristics of the participants

When analyzing the rest of the socio-demographic and clinical characteristics of the participants from several aspects related to different factors such as the number of family members, socio-economic status, monthly income, diagnosis, it was noted that there is a correlation between the number of family members and the thalassemia infection status, as the percentage increases with the increase in the number of family members. As for the socio-economic status and income, they affect the infection rate, in addition to the type of diagnosis and the treatment period, which play an important role in the results.

In terms of family size, adherence rates were higher for individuals with smaller families (1-3 people) than for those with larger families (6-8 members). Adherence was influenced by job type, with employees and students exhibiting higher adherence than self-employed or non-students. The influence of family thalassaemia was also significant; adherence was stronger in households without any afflicted members.

Interestingly, there was no discernible variation in adherence between income levels. But the kind of diagnosis did, with the maximum adherence found in patients with thalassaemia mild. The form of treatment had a greater effect on adherence than the length of iron chelation therapy; oral tablets were more adhered to than intravenous therapy. Adherence was significantly impacted by bad behaviours like smoking, with non-smokers exhibiting somewhat greater adherence rates. See table (2)

Table 2

Cont. Socio-demographic and clinical characteristics of participants

Variable	Adhered N (%)	Not adhered N (%)	Total	Chi-Square P-value
Family members				
• Less than 3	7 (63.6)	4 (36.4)	11	0.609
• (3-5)	37 (59.7)	25 (40.03)	62	
• (6-8)	25 (62.5)	15 (37.5)	40	
• More than 8	6 (85.7)	1 (14.3)	7	
Job				
• Student	33 (64.7)	18 (35.3)	51	0.087
• College	8 (72.7)	3 (27.3)	11	
• Not studying	5 (31.3)	11 (68.8)	16	
• Personal job	21 (67.7)	10 (32.3)	31	
• Employee	8 (72.7)	3 (27.3)	11	
Family members affected by thalassemia				
• No body	28 (75.7)	9 (24.3)	37	0.120
• (1-2)	43 (55.8)	34 (44.2)	77	
• More than 2	4 (66.7)	2 (33.3)	6	
Family member died of thalassemia				
• No body	68 (64.8)	37 (35.2)	105	0.176
• One or more	7 (46.7)	8 (53.3)	15	
Social and economic status of the family				
• Low	6 (100.0)	0 (0.0)	6	0.143
• Medium	68 (60.7)	44 (39.3)	112	
• High class	1 (50.0)	1 (50.0)	2	
Monthly income/ shekels				
• Less than(2000)	21 (77.8)	6 (22.2)	27	0.063
• More than (2000)	54 (58.1)	39 (41.9)	93	
Diagnosis				
• Thalassemia minor	2 (100.0)	0 (0.0)	2	0.013
• Thalassemia medium	38 (76.0)	12 (24.0)	50	
• Thalassemia major	35 (51.5)	33 (48.5)	68	
• Sickle-cell anemia – thalassemia	0 (0.0)	0 (0.0)	0	
Iron chelation therapy treatment period				
• Less than a year	5 (71.4)	2 (28.6)	7	0.833
• (1-3) years	9 (60.0)	6 (40.0)	15	
• (3-5) Years.	10 (71.4)	4 (28.6)	14	
• More than 5 y	51 (60.7)	33 (39.3)	84	
Treatment type of iron chelation therapy				
• Oral tablet	73 (61.9)	45 (38.1)	118	0.269
• IV	2 (100.0)	0 (0.0)	2	
Do you have bad habits such as smoking and others				
• No	61 (61.0)	39 (39.0)	100	0.614
• Yes	14 (70.0)	6 (30.0)	20	

3.3 Assessment of disease knowledge gaps among thalassemia patient's questions

Patients were found to have sufficient information about the disease, including its symptoms, causes, and negative consequences associated with non-adherence to treatment, as well as the positive effects of full adherence. This was demonstrated by assessing the knowledge gaps in the questionnaire, which included 15 questions. The results shown in the table reveal the correct answers to each question in percentage, which indicates that many patients have sufficient information about the disease. In addition, the incorrect answers to each question are shown in percentage, which indicates that some patients have gaps in their knowledge about the disease, which can be improved through education and continuous support from the medical staff and family as well, which leads to better patient adherence to treatment and better health outcomes..See table (3).

The results of the questionnaire indicate that there are no significant knowledge gaps among thalassemia patients. A brief explanation of some of the questions will be provided: Sufficient information about thalassemia: Patients who have sufficient information constitute more than half of the patients with 73.3% and patients who do not have sufficient information constitute 26.7%.

Thalassaemia as a genetic disease: Patients' knowledge was high, constituting 93.3%.

Iron accumulation and its effect on the heart: Patients showed that they have high knowledge of the effect of iron accumulation on cardiomyopathy by 73.3%, but 26.7% lack this knowledge. Thalassaemia and its effect on red blood cells: Patients showed that they have high knowledge of the effect of iron accumulation on the number of red blood cells by 70.8%, but 29.2% do not know this.

Diet for thalassemia patients: Patients showed that they should follow a healthy diet containing a low percentage of iron by 92.5%, which reflects a high level of awareness.

The effect of iron accumulation on the glands: The question showed that patients are fully aware of the effect of iron accumulation on the glands, which constituted 64.2%, but there is a large percentage (35.8%) who do not know. The importance of genetic counseling: Patients realize the importance of genetic counseling before marriage by 97.5%, which shows good awareness of this aspect. In avoiding having new children suffering from the same disease.

Table 3

Assessment of disease knowledge gaps among thalassemia patient's questions

	Assessment of disease knowledge gaps among thalassemia patient's questions	No N (%)	Yes N (%)	I don't know. N (%)	Correct Answer (%)	Incorrect Answer (%)
1	Do you have enough information about thalassemia?	12 (10.0)	88 (73.3)	20 (16.7)	73.3	26.7
2	Thalassemia is a genetic disease.	7 (5.8)	112 (93.3)	1 (0.8)	93.3	6.7
3	When a couple has a child with thalassemia, both parents carry the genetic trait for thalassemia	4 (3.3)	111 (92.5)	5 (4.2)	92.5	7.5
4	Consanguineous marriage plays an important role in the transmission of thalassemia to the next generatio	8 (6.7)	111 (92.5)	1 (0.8)	92.5	7.5
5	Thalassemia affecting growth and physical activity	11 (9.2)	102 (85.0)	7 (5.8)	85.0	15.0
6	Symptoms of thalassemia appear several months after birth	13 (10.8)	75 (62.5)	32 (26.7)	62.5	37.5
7	An accumulation of iron in the blood leads to cardiomyopathy	10 (8.3)	88 (73.3)	22 (18.3)	73.3	26.7
8	Thalassemia leads to a decrease in the number of red blood cells	1 (0.8)	85 (70.8)	34 (28.3)	70.8	29.2
9	The diet of thalassemia patients should contain a low percentage of iron	7 (5.8)	111 (92.5)	2 (1.7)	92.5	7.5
10	Matched bone marrow/stem cell transplantation is the only known method of treating thalassemia at present	4 (3.3)	99 (82.5)	17 (14.2)	82.5	17.5
11	To prevent thalassemia, genetic counseling and investigations must be carried out before marriage	0 (0.0)	117 (97.5)	3 (2.5)	97.5	2.5
12	To maintain the health of patients with major thalassemia, iron chelation therapy should be given	9 (7.5)	108 (90.0)	3 (2.5)	90.0	10.0
13	Treating you with iron chelation therapy should stop the iron overload from getting worse	6 (5.0)	108 (90.0)	6 (5.0)	90.0	10.0

In assessing disease knowledge gaps among thalassemia patients, a series of questions were asked. A significant majority, 73.3%, felt they had enough information about thalassemia, while 93.3% correctly identified it as a genetic disease. 92.5% were aware that both parents must carry the genetic trait for their child to have thalassemia, and the same percentage knew consanguineous marriages increase transmission risk.

85.0% recognized that thalassemia affects growth and physical activity, while 62.5% knew symptoms appear months after birth.

Additionally, 73.3% were aware that iron accumulation leads to cardiomyopathy, and 70.8% knew it reduces red blood cells. Regarding diet, 92.5% understood it should be low in iron, and 82.5% knew matched bone marrow or stem cell transplantation is a treatment method. Iron overload's impact on gland disorders was known by 64.2%, and its effect on growth by 85.0%. 97.5% correctly answered that genetic counseling before marriage is crucial to prevent thalassemia. For major thalassemia health maintenance, 90.0% knew iron chelation therapy is essential, and the same percentage understood its role in preventing further iron overload.

3.4 Assessment of variables for patients with adherence and non-adherence to iron chelation in hospital

Evaluation of variables for patients with adherence and non-adherence to ICT in hospital. In this table, patient variables were classified based on adherence and non-adherence to medication and categorized into good and poor. A survey was conducted to assess patient with iron chelation to disease knowledge gaps. This section consisted of 15 questions. In the analysis. Patients who answered "yes" were assigned 1 point, while those who answered "no" received 0 points.

The analysis used a cut of point 6, and patients in Section were classified into two groups based on their scores: scores ranging from 0 to 6 were considered poor, while scores greater than 6 were considered good.The study found that 98.7% of committed patients gave good answers, whereas 100% of non-adherent patients gave good answers. Only of committed patients gave poor answers in the rate 1.3%, while of non-adherent patients

gave weak answers in the rate of 0%.A survey was conductedWhen assessing satisfaction with receiving hospital treatment among thalassemia patients.

This section consisted of 8 questions. In the analysis. Patients who answered "yes" were assigned 1 point, while those who answered "no" received 0 points. The analysis used a cut of point 2, and patients in Section were classified into two groups based on their scores: scores ranging from 0 to 2 were considered poor, while scores greater than 2 were considered good.The study found that 98.7% of committed patients gave good answers, whereas 75.6% of non-adherent patients gave good answers.

Only of committed patients gave poor answers in the rate 1.3%, while of non-adherent patients gave weak answers in the rate of 24.4%.A survey was conducted to assess patient satisfaction with iron chelation when receiving the treatment with community at the hospital. This section consisted of 6 questions. In the analysis. Patients who answered "yes" were assigned 1 point, while those who answered "no" received 0 points. The analysis used a cut of point 3, and patients in Section were classified into two groups based on their scores: scores ranging from 0 to 3 were considered poor, while scores greater than 3 were considered good.

The study found that 82.7% of committed patients gave good answers, whereas 28.9% of non-adherent patients gave good answers. Only of committed patients gave poor answers in the rate 17.3%, while of non-adherent patients gave weak answers in the rate of 71.1%.and A survey was conducted to assess patient satisfaction with iron chelation when medical staff at the hospital. This section consisted of 16 questions. In the analysis.

Patients who answered "yes" were assigned 1 point, while those who answered "no" received 0 points. The analysis used a cut of point 8, and patients in Section were classified into two groups based on their scores: scores ranging from 0 to 8 were considered poor, while scores greater than 8 were considered good. The study found that 98.7% of committed patients gave good answers, whereas 8.9% of non-adherent patients gave good answers. Only of committed patients gave poor answers in the rate 1.3%, while of non-adherent patients gave weak answers in the rate of 91.1%.

In conclusion, the results indicate a strong relationship between patient satisfaction when receiving treatment in the hospital and their commitment to iron chelation therapy. Although patients have good knowledge of the disease, it does not significantly affect commitment, as all non-adherent patients have good knowledge.

Therefore, it is necessary to enhance programs that aim to improve patients' satisfaction with the medical services provided in the hospital and their satisfaction with the medical staff, in addition to satisfaction with treatment in the community by enhancing patient confidence and encouraging them to confront and continue, and these factors help to increase levels of commitment to treatment.See table (4).

Table 4

Assessment of variables for patients with adherence and non-adherence to iron chelation in hospital

Variable	Adhered N (%)	Not adhered N (%)	Total	Chi-Square *P*-value
Disease knowledge				
• Good	74 (98.7)	45 (100)	119	0.439
• Poor	1 (1.3)	0 (0.0)	1	
Satisfaction receiving the treatment in the hospital				
• Good	74 (98.7)	34 (75.6)	108	<0.001
• Poor	1 (1.3)	11 (24.4)	12	
Satisfaction receiving the medical service				
• Good	75 (100)	8 (17.8)	83	<0.001
• Poor	0 (0.0)	37 (82.2)	37	
Satisfaction receiving the treatment with community				
• Good	62 (82.7)	13 (28.9)	75	<0.001
• Poor	13 (17.3)	32 (71.1)	45	
Satisfaction with the medical staff				
• Good	74 (98.7)	4 (8.9)	78	<0.001
• Poor	1 (1.3)	41 (91.1)	42	

In examining variables related to adherence, disease knowledge, nearly all participants with good knowledge adhered 98.7%, while adherence was universal among those with poor knowledge 100%, though this group was very small. Satisfaction with hospital treatment showed a significant relationship; 98.7% of those satisfied adhered, compared to 75.6% among the dissatisfied.

Satisfaction with medical service was crucial; all satisfied patients adhered (100%), while only 17.8% of dissatisfied patients did. Community treatment satisfaction followed a similar trend; 82.7% adherence for the satisfied and only 28.9% for the dissatisfied. Finally, satisfaction with medical staff was highly influential; 98.7% of satisfied patients adhered, compared to just 8.9% of those dissatisfied.

3.5 Association of disease knowledge and participant characteristics

The data indicate health outcomes based on multiple variables, with emphasis on P-values and Chi-Square testing. A brief analysis of the data is as follows, including gender, age, place of residence, parental relationship, and education, and including parents and children. High P-values ($P>0.05$) across all variables indicated no significant effect for each of the aspects presented in the table, demonstrating good health outcomes prevalent in all groups, reflecting a high level of health awareness and care. See table (5).

When analyzing the association of the degree of knowledge of the disease with the socio-demographic and clinical characteristics of the study among the study participants, some of them will be clarified. Gender: Males constituted 98.4% and 100% of females were rated as good. There were no "bad" cases among females, which is a good indication that positive outcomes are higher among females.

Education has a clear effect: All parents with primary education received a good evaluation, while parents who completed middle school were better, but parents who completed secondary education were rated as good and had a better positive effect.

Exploring adherence in relation to various demographic and educational variables: Gender showed a minor difference, with 98.4% of males and 100% of females demonstrating good adherence. Age didn't significantly impact adherence, with high rates

across all age groups. Place of residence revealed similarly high adherence in cities, villages, and refugee camps. The source of questionnaire completion also showed minor differences, with patients themselves having a 100% adherence rate, and relatives filling out the questionnaire showing 97.4% adherence. Parental relationship status didn't affect adherence significantly.

Educational background of parents and patients alike showed high adherence rates, with minor variations: Fathers' and mothers' education levels yielded nearly perfect adherence rates, with slight differences. Similarly, patients' education levels showed consistently high adherence, regardless of whether they were in primary, preparatory, secondary, or bachelor's level studies.

Table 5

Association of disease Knowledge degree with the study socio-demographic and clinical characteristics among the participants of study subjects

Variable	Good	Poor	Total	Chi-Square P-value
Gender				
• Male	62 (98.4)	1 (1.6)	63	0.339
• Female	57 (100)	0 (0.0)	57	
Age				
• 0-8 years	11 (100)	0 (0.0)	11	0.428
• 9-17 years	31 (96.9)	1 (3.1)	32	
• 18-26 years	52 (100)	0 (0.0)	52	
• 27-33 years	25 (100)	0 (0.0)	25	
Place				
• City	32 (97)	1 (3)	33	0.265
• Village	58 (100)	0 (0.0)	58	
• Camp, refugee	29 (100)	0 (0.0)	29	
The questionnaire has been filled out				
• Patient himself	82 (100)	0 (0.0)	82	0.140
• Patient relative	37 (97.4)	1 (2.6)	38	
Relationship between the parents				
• No	17 (100)	0 (0.0)	17	0.683
• Yes	102 (99.0)	1 (1.0)	103	
Patients education				
• Primary	17 (100)	0 (0.0)	17	0.815
• Preparatory	21 (100)	0 (0.0)	21	
• Secondary	46 (97.9)	1 (2.1)	47	
• Bachelor's	24 (100)	0 (0.0)	24	

3.6 Cont. Association of disease knowledge and participant characteristics

The table shows an analysis of the association between the level of knowledge about the disease and the socio-demographic and clinical characteristics of the study participants. The table shows that factors such as age, gender, parental education level, place of residence, and number of family members do not significantly affect participants' knowledge of the disease. However, clear correlations were observed through the analysis, such as patients' employment with a ratio of (P = 0.041), socioeconomic status with a ratio of less than (P = 0.001), and whether the patient suffers from other diseases with show statistically significant of (P = 0.006), in addition to that monthly income with show statistically significant of (P = 0.062). The table shows that patients from families with a higher economic status show a better level of knowledge, and patients who do not suffer from other diseases show advanced knowledge. The table showed that the work also has an impact, as it showed that students in particular have sufficient information about their disease, as these results confirmed the importance of taking into account social and economic factors in health educational efforts that aim to enhance awareness and improve disease management.

Job types, including students, non-students, and those with personal jobs, all showed a 100% adherence rate. Family members affected by thalassemia and those with deceased family members didn't significantly influence adherence rates, with minor deviations. Social and economic status, however, showed variability; low-status families had an 83.3% adherence rate, while medium and high-status families had 100% adherence. Monthly income also influenced adherence slightly, with higher income showing better adherence.

Diagnosis types revealed minor differences; thalassemia minor and major had perfect adherence, while thalassemia medium showed a slight drop. Duration of iron chelation therapy didn't impact adherence significantly, and treatment type showed nearly perfect adherence for oral tablet users. Other diseases slightly influenced adherence, with 100% for those without and 92.9% for those with additional diseases.

Table 6

Cont. association of disease Knowledge degree with the study socio-demographic and clinical characteristics among the participants of study subjects

Variable	Good	Poor	Total	Chi-Square P-value
		Job		
• Student	51 (100)	0 (0.0)	51	0.041
• Not studying	16 (100)	0 (0.0)	16	
• Personal job	31 (100)	0 (0.0)	31	
		Family members affected by thalassemia		
• No body	37 (100)	0 (0.0)	37	0.755
• (1-2)	76 (98.7)	1 (1.3)	77	
		Social and economic status of the family		
• Low	5 (83.3)	1(16.7)	6	<0.001
• Medium	112 (100)	0 (0.0)	112	
• High class	2 (100)	2 (100)	2	
		Diagnose		
• Thalassemia minor	2 (100)	0 (0.0)	2	0.494
• Thalassemia medium	49 (98)	1 (2.0)	50	
• Thalassemia major	68 (100)	0 (0.0)	68	
		Iron chelation therapy treatment period		
• Less than a year	7 (100)	0 (0.0)	7	0.934
• (1-3) years	15 (100)	0 (0.0)	15	
• (3-5) Years.	14 (100)	0 (0.0)	14	
• More than 5 y	83 (98.8)	1 (1.2)	84	
		Treatment type of iron chelation therapy		
• Oral tablet	117 (99.2)	1 (0.8)	118	0.896
• IV	2 (100)	0 (0.0)	2	
		Any other disease		
• No	106 (100)	0 (0.0)	106	0.006
• Yes	13 (92.9)	1 (7.1)	14	

3.7 Satisfaction with hospital treatment and participant characteristics

The table shows the analysis of the relationship between hospitalization recipients and the sociodemographic and clinical characteristics of the study participants. The table shows that factors such as age, gender, level of education of parents, place of residence, and number of family members do not significantly affect participants' knowledge of the disease. However, clear correlations were observed through the analysis, such as the socio-economic status show statistically significant of (P = 0.121), and the treatment period with iron chelation therapy. Patients have a longer treatment period. They know the risk of failing to take the medication and are more committed than others. The medication adherence rate for all patients was show statistically significant (P = 0.091). The table shows that patients from families with Higher economic status shows a better level of knowledge, as these results confirmed the importance of taking into account social and economic factors in health education efforts aimed at encouraging patients to adhere to medication.

When analyzing the remaining variables such as thalassemia diagnosis, iron treatment period, and bad habits, we note that they do not significantly affect the results. Thalassemia diagnosis: Patients suffering from any type of thalassemia (simple, moderate, severe) according to age have good health. There is no significant statistical significance here (p-value = 0.760). Iron treatment period: Individuals who receive treatment for (less than a year, or (1-3) years or more than 5 years enjoy good health. This is clear as the differences are not statistically significant (p-value = 0.091). Bad habits: Individuals, whether they practice bad habits or not, such as smoking, do not affect their commitment to treatment, but they affect the health of patients.

Table 7

Association of degree of satisfaction in receiving the treatment in the hospital with the study socio-demographic and clinical characteristics among the participants of study subjects.

Variable	Good	Poor	Total	Chi-Square P-value
Family members affected by thalassemia				
• No body	34 (91.9)	3 (8.1)	37	0.589
• (1-2)	68 (88.3)	9 (11.7)	77	
• More than 2	6 (100)	0 (0.0)	6	
Family member died of thalassemia				
• No body	94 (89.5)	11 (10.5)	105	0.645
• One or more	14 (93.3)	1 (6.7)	15	
Social and economic status of the family				
• Low	6 (100)	0 (0.0)	6	0.121
• Medium	101 (90.2)	11 (9.8)	112	
• High class	1 (50)	1 (50)	2	
Monthly income/ shekels				
• Less than (2000)	25 (92.6)	2 (7.4)	27	0.610
• More than (2000)	83 (89.2)	10 (10.8)	93	
Diagnose				
• Thalassemia minor	2 (100)	0 (0.0)	2	0.760
• Thalassemia medium	44 (88)	6 (12)	50	
• Thalassemia major	62 (91.2)	6 (8.8)	68	
Iron chelation therapy treatment period				
• Less than a year	7 (100)	0 (0.0)	7	0.091
• (1-3) years	11 (73.3)	4 (26.7)	15	
• (3-5) Years.	12 (85.7)	2 (14.3)	14	
• More than 5 y	78 (92.9)	6 (7.1)	84	
Treatment type of iron chelation therapy				
• Oral tablet	106 (89.8)	12 (10.2)	118	0.635
• IV	2 (100)	0 (0.0)	2	
Any other disease				
• No	96 (90.6)	10 (9.4)	106	0.570
• Yes	12 (85.7)	2 (14.3)	14	
Do you have bad habits such as smoking and others				
• No	89 (89)	11 (11)	100	0.414
• Yes	19 (95)	1 (5.0)	20	

3.8 Satisfaction with hospital medical service and participant characteristics

The table presents an analysis of the association between various socio-demographic and clinical characteristics and the degree of satisfaction with receiving medical services in the hospital among the study participants. The Chi-Square test and associated P values were used to assess the statistical significance of these associations. A P value of less than 0.05 indicates a significant association between the level of characteristics and satisfaction, highlighting potential factors influencing patients' satisfaction with medical care.

The table shows that factors such as age, gender, level of education of parents, place of residence, and number of family members do not significantly affect participants' knowledge of the disease. However, clear correlations were observed through the analysis, such as the patient's status, whether he is married or single, which constituted show statistically significant of (P = 0.056), and monthly income also has an impact on patients' commitment when receiving services, and constituted show statistically significant of (P = 0.014), and it was noted if there is more than one person in the family suffering from thalassemia, as They have a clear idea of the necessity of adhering to the medication, and it formed show statistically significant of (P = 0.095).

Table 8

Association of degree of satisfaction in receiving the medical service in the hospital with the study socio-demographic and clinical characteristics among the participants of study subjects

Variable	Good	Poor	Total	Chi-Square P-value
		Status		
• Married	14 (53.8)	12 (46.2)	26	0.056
• Single	69 (73.4)	25 (26.6)	94	
		Family members		
• Less than 3	7 (63.6)	4 (36.4)	11	0.775
• (3-5)	43 (69.4)	19 (30.6)	62	
• (6-8)	27 (67.5)	13 (32.5)	40	
		Job		
• Student	36 (70.6)	15 (29.4)	51	0.188
• College	8 (72.7)	3 (27.3)	11	
• Personal job	23 (74.2)	8 (25.8)	31	
		Family members affected by thalassemia		
• No body	30 (81.1)	7 (18.9)	37	0.095
• (1-2)	48 (62.3)	29 (37.7)	77	
• More than 2	5 (83.3)	1 (16.7)	6	
		Social and economic status of the family		
• Low	6 (100)	0 (0.0)	6	0.211
• Medium	76 (67.9)	36 (32.1)	112	
		Monthly income/ shekels		
• Less than (2000)	23 (85.2)	4 (14.8)	27	0.014
• More than (2000)	60 (64.5)	33 (35.5)	93	
		Diagnose		
• Thalassemia medium	39 (78.0)	11 (22.0)	50	0.107
• Thalassemia major	42 (61.8)	26 (38.2)	68	
		Iron chelation therapy treatment period		
• (1-3) years	11 (73.3)	4 (26.7)	15	0.729
• (3-5) Years.	10 (71.4)	4 (28.6)	14	
• More than 5 y	56 (66.7)	28 (33.3)	84	
		Treatment type of iron chelation therapy		
• Oral tablet	81 (68.6)	37 (31.4)	118	0.341
• IV	2 (100)	0 (0.0)	2	
		Any other disease		
• No	74 (69.8)	32 (30.2)	106	0.674
• Yes	9 (64.3)	5 (35.7)	14	
		Do you have bad habits such as smoking and others		
• No	68 (68.0)	32 (32.0)	100	0.536
• Yes	15 (75.0)	5 (25.0)	20	

3.9 Satisfaction with community treatment and participant characteristics

The table presents an analysis examining how various socio-demographic and clinical characteristics relate to the satisfaction levels of study participants when receiving the treatment in community. The statistical significance of these associations was evaluated using Chi-Square tests and corresponding P-values. A P-value below 0.05 indicates a significant association between specific characteristics and satisfaction, highlighting factors that potentially influence patient satisfaction with the treatment in community.

The analysis revealed that variables such as age, gender, parents' education levels, place of residence, and family size did not show significant impacts on participants' satisfaction levels. However, notable correlations were observed in other factors. For instance, Any other diseas,show statistically significant (P = 0.106). Do you have bad habits such as smoking and others as a significant factor affecting satisfaction show statistically significant (P = 0.206). These findings underscore the complexity of factors influencing patient satisfaction in commintiy settings and suggest areas where targeted interventions enhance the patient in community.

When analyzing the remaining variables such as gender and age, we note that they do not significantly affect the results.

Gender: The results show that there are slight differences between males (61.9%) and females (63.2%) in health status, which does not significantly affect the results.

Age: Children aged 0-8 years show excellent health status (100%). The same is true for the age groups 9-17 (90.6%) and 18-26 (88.5%), where it is noted that there is a significant decrease in the age group 27-33 (88.0%), indicating that young people at younger ages suffer less from health problems, due to education and regular follow-up.

Location: Individuals from the city (60.6%) show a lower health status compared to individuals from villages (58.6%)

Work: People who work as employees (81.8%) have a better health status compared to students (62.7%) and others.

Table 9

Association of degree of satisfaction when receiving the treatment in community with the study socio-demographic and clinical characteristics among the participants of study subjects.

Variable	Good	Poor	Total	Chi-Square P-value
Gender				
• Male	39 (61.9)	24 (38.1)	63	0.887
• Female	36 (63.2)	21 (36.8)	57	
Age				
• 0-8 years	11 (100)	0 (0.0)	11	0.686
• 9-17 years	29 (90.6)	3 (9.4)	32	
• 18-26 years	46 (88.5)	6 (11.5)	52	
• 27-33 years	22 (88.0)	3 (12.0)	25	
Place				
• City	20 (60.6)	13 (39.4)	33	0.441
• Village	34 (58.6)	24 (41.4)	58	
• Camp, refugee	21 (72.4)	8 (27.6)	29	
Job				
• Student	32 (62.7)	19 (37.3)	51	0.683
• College	7 (63.6)	4 (36.4)	11	
• Not studying	9 (56.3)	7 (43.8)	16	
• Personal job	18 (58.1)	13 (41.9)	31	
• Employee	9 (81.8)	2 (18.2)	11	
Family members affected by thalassemia				
• No body	24 (64.9)	13 (35.1)	37	0.904
• (1-2)	47 (61.0)	30 (39.0)	77	
• More than 2	4 (66.7)	2 (33.3)	6	
Family member died of thalassemia				
• No body	67 (63.8)	38 (36.2)	105	0.433
• One or more	8 (53.3)	7 (46.7)	15	
Social and economic status of the family				
• Low	3 (50)	3 (50)	6	0.449
• Medium	70 (62.5)	42 (37.5)	112	
• High class	2 (100)	0 (0.0)	2	
Any other disease				
• No	69 (65.1)	37 (34.9)	106	0.106
• Yes	6 (42.9)	8 (57.1)	14	
Do you have bad habits such as smoking and others				
• No	65 (65.0)	35 (35.0)	100	0.206
• Yes	10 (50.0)	10 (50.0)	20	

3.10 Satisfaction with hospital staff and participant characteristics

The table presents an analysis examining how different socio-demographic and clinical characteristics are associated with the levels of satisfaction of study participants with the hospital's medical staff. The statistical significance of these associations was assessed using chi-square tests and corresponding p-values. A p-value of less than 0.05 indicates a significant association between the specific characteristics and satisfaction, highlighting factors that may influence patient satisfaction with treatment in the community. The analysis revealed that variables such as:

Age: The younger age groups, children aged 0-8 years, show clear positive results (81.8% good). It was also noted that the proportion of individuals with poor health conditions increases with age, especially in the age group of 27-33 years, where the percentage reaches only 40% in good condition.

Gender: When analyzing the data, it was shown that males have a high percentage (71.4%) compared to females (57.9%). These differences show social or biological influences that affect public health.

Marital status: Single patients (69.1%) were in better health compared to married patients (50%).

Occupation: Students and professional practitioners showed better health outcomes compared to those who did not receive education (not studying) (25%). This indicates that education and participation in academic activities or work are very important in contributing to improving mental and physical health.

However, significant associations were observed in other factors. For example, patients' status was a significant factor (P = 0.070). Patients' occupation was a significant factor (P = 0.011), and thalassemia diagnosis was a significant factor (P = 0.017). These results emphasize the complexity of factors that influence patients' satisfaction with hospital staff and point to areas where targeted interventions could be used to enhance patients' adherence to iron chelation therapy by hospital staff.

Table 10

Association of degree of satisfaction when with the medical staff in the hospital with the study socio-demographic and clinical characteristics among the participants of study subjects

Variable	Good	Poor	Total	Chi-Square P-value
Gender				
• Male	45 (71.4)	18 (28.6)	63	0.121
• Female	33 (57.9)	24 (42.1)	57	
Age				
• 0-8 years	9 (81.8)	2 (18.2)	11	0.014
• 9-17 years	25 (78.1)	7 (21.9)	32	
• 18-26 years	34 (65.4)	18 (34.6)	52	
• 27-33 years	10 (40.0)	15 (60.0)	25	
Status				
• Married	13 (50.0)	13 (50.0)	26	0.070
• Single	65 (69.1)	29 (30.9)	94	
Job				
• Student	36 (70.6)	15 (29.4)	51	0.011
• College	8 (72.7)	3 (27.3)	11	
• Not studying	4 (25.0)	12 (75.0)	16	
• Personal job	22 (71.0)	9 (29.0)	31	
• Employee	8 (72.7)	3 (27.3)	11	
Family members affected by thalassemia				
• No body	28 (75.7)	9 (24.3)	37	0.123
• (1-2)	45 (58.4)	32 (41.6)	77	
• More than 2	5 (83.3)	1 (16.7)	6	
Social and economic status of the family				
• Low	6 (100)	0 (0.0)	6	0.169
• Medium	71 (63.4)	41 (36.6)	112	
• High class	1 (50.0)	1 (50.0)	2	
Diagnose				
• Thalassemia minor	2 (100)	0 (0.0)	2	0.017
• Thalassemia medium	39 (78.0)	11 (22.0)	50	
• Thalassemia major	37 (54.4)	31 (45.6)	68	

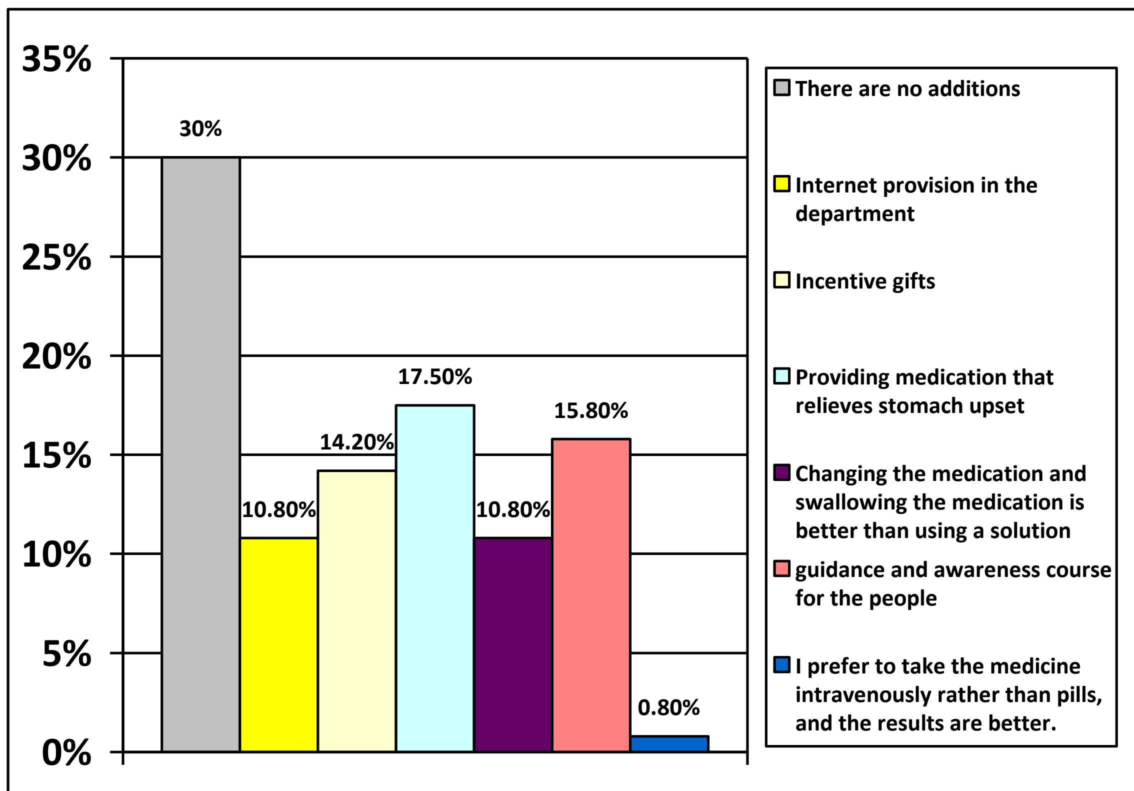
3.11 Suggestions to help you adhere to a better way to take the medication continuously

It describes recommendations made by patients to ensure they follow iron chelation therapy. Analytics provide solutions. The most prominent of these recommendations is that the majority of patients (17.5%) stated that they need specific medications to reduce the side effects caused by Exjade.

Patients also need awareness and counseling sessions. Psychological disorders represented 15.8% of the total, and some individuals said they needed additional support, such as distributing motivational and encouraging gifts to them See figure (1).

Figure 1

Suggestions to help you adhere to a better way to take the medication continuously



3.12 Barriers to adherence to iron chelation therapy among thalassemia patients

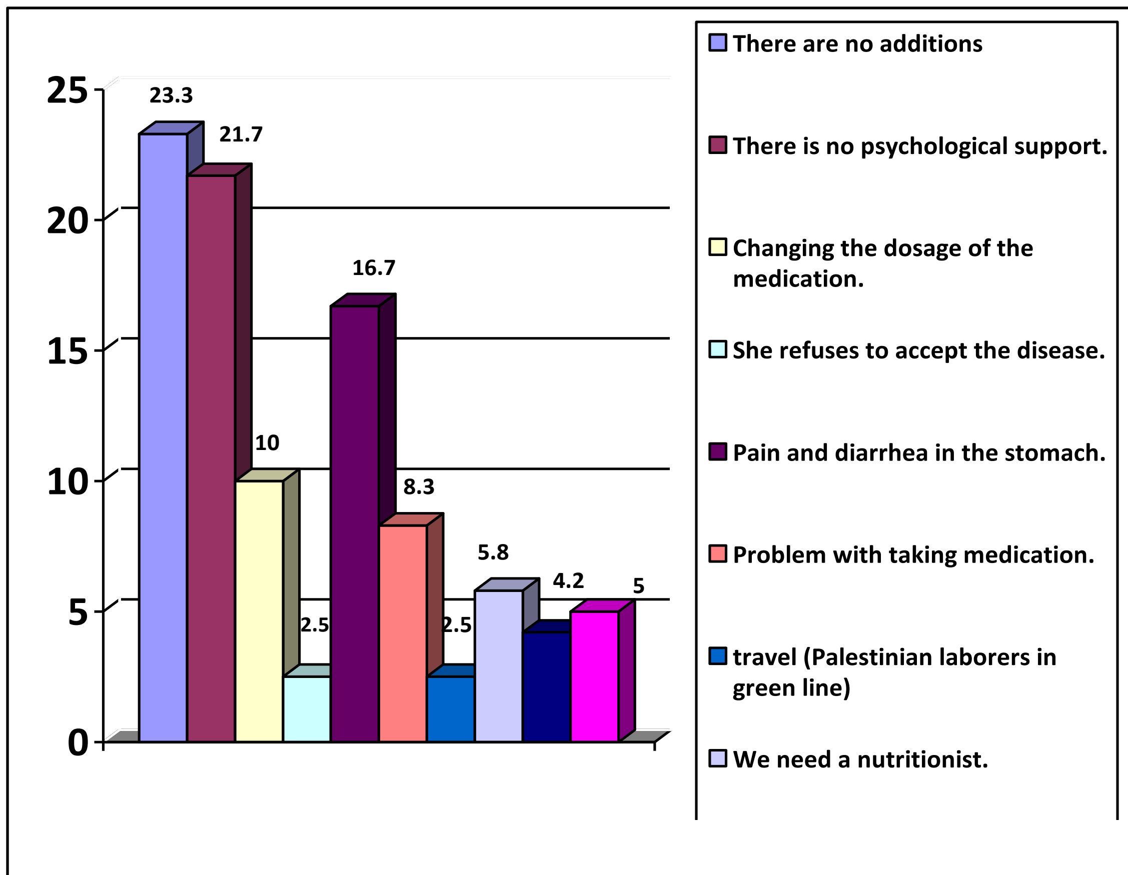
A study showed that many patients do not adhere to taking their medications as prescribed, and an analysis of patients' answers showed that there are several main reasons for this behavior. The most prominent of which is the urgent need for psychological support, which reached (21.7%).

Therefore, support for patients by doctors and health care providers, including the provision of psychological support services and psychological counseling, is necessary and has an effective positive impact. Therefore, a group of different adherence techniques must be implemented to improve the patient's adherence to the treatment prescribed to him. In addition, the pain associated with taking the medication, such as stomach pain and diarrhea, appeared as an influencing factor and accounted for 16.7%.

Changing the dosage of the medication also had an impact on patients' adherence, and its rate was (10%) See figure (2).

Figure 2

Barriers to adherence to iron chelation therapy among thalassemia patients

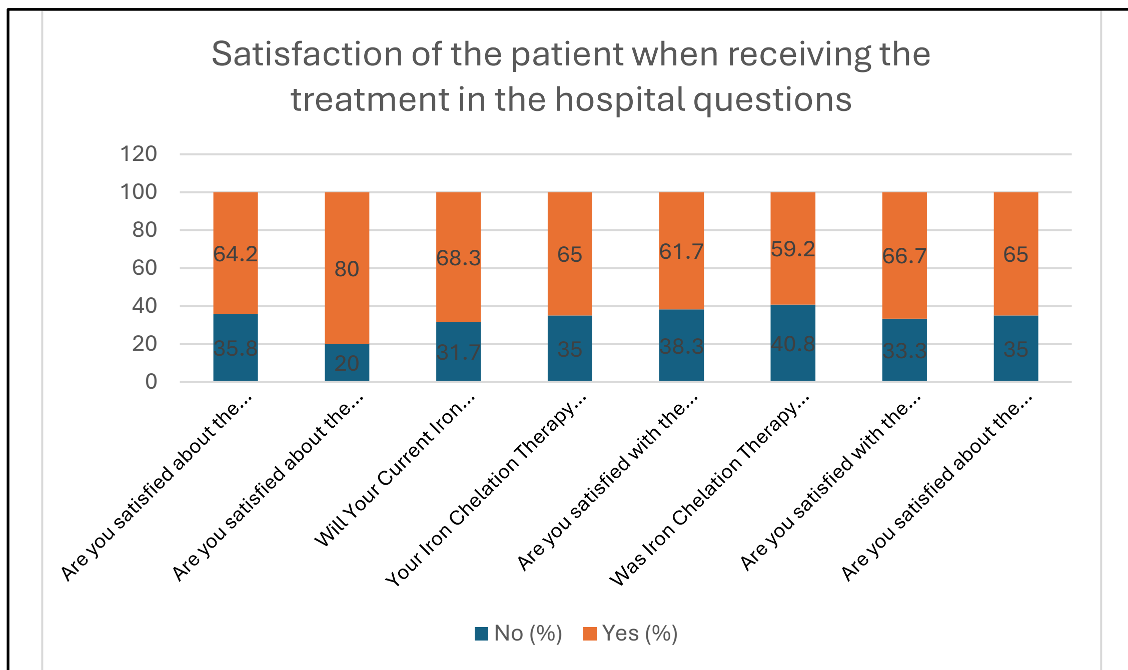


3.13 Satisfaction of the patient when receiving the treatment in the hospital questions

Data on patient satisfaction with hospital treatment showed that (64.2%) of patients were satisfied with the cost of transportation to and from the hospital, but (35.8%) were still dissatisfied with the cost of getting to the hospital, which led us to explore options to improve access to the hospital and provide transportation for patients. Patients expressed their satisfaction with the registration process in the department, which represented (80%), indicating the efficiency of the process and ease of registration. As for iron chelation therapy and its effect on lifespan, patients confirmed the benefits of the treatment by (68.3%), while (65%) considered the treatment effective. However, it was noted that only 61.7% were satisfied with adherence to treatment, which indicates the presence of challenges and obstacles that require additional support. Some patients expressed their satisfaction with the ease of treatment, which represented (59.2%). Although patients were satisfied with the time taken for treatment, which represented (66.7%), there is room for improvement. Finally, patients were satisfied with the treatment (oral or IV) and it was (65%). Based on these results, it is recommended to enhance communication with patients and encourage them to take the treatment and its importance and we must provide more support and awareness to ensure their adherence.

Figure 3

Satisfaction of the patient when receiving the treatment in the hospital questions

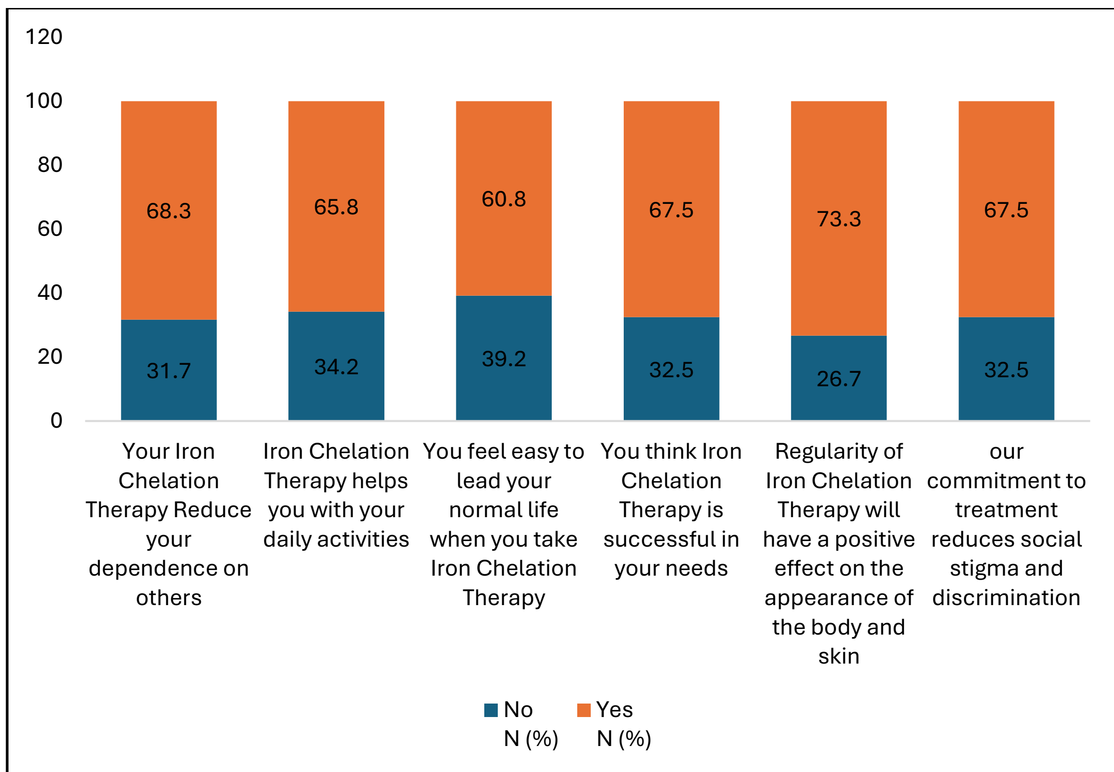


3.14 Satisfaction of the patient when receiving the treatment with community questions

The data showed patient satisfaction when receiving treatment with the community, where it constituted a percentage of (68.3%) when patients adhered to treatment, it reduced their dependence on others, and a percentage of (31.7%) of patients still depended on the community, where it was also noted that the percentage of patients (65.8%) when they adhered to treatment helped them in practicing their daily activities and also with ease, where it constituted a percentage of (60.8%), in addition to that, the patients' commitment helped in meeting their needs without the help of the community, which constituted a percentage of 67.5%, and this had a positive effect on the appearance of the body and skin and reduced social stigma and discrimination, which constituted a percentage of (67.5%).

Figure 4

Satisfaction of the patient when receiving the treatment with community questions



Chapter Four
Discussions and Conclusions

The research aimed to assess different barriers to the adherence among patients with Beta thalassemia. Knowing what help patients to adhere to treatment effectively, and identifying the dilemmas that prevent their adherence is clinicaly important and a key component of health outcomes in thalassemia patients due to the risks associated with iron overload.

We identified 120 tailored patients undergoing treatment Iron chelation therapy at the govermental hospital in Nablus, that assessed patient adherence through a variety of methods including patient-related factors, medications-related factors, sociocultural-related factors, environmental context and resources, and patient–health care provider relationship factors. Most participants reported adherence to chelation therapy, while others were non-adherent despite having sufficient knowledge of the disease. The percentage of adherent patients with adequate knowledge was 98.7%, while the percentage of non-adherent patients with sufficient knowledge was 100%. This suggests variety in measurement and definitions for adherence and didn’t reveal a relationship between their knowledge of thalassemia and their adherence to ICT. Thus, health care provider should not only educate patients about their disease and its treatment, but also listen to their beliefs in the necessity and concerns about medications as in a previous study conducted on thalassemia patients in Jordan [28].

Moreover the crucial role of medication use was associated with the degree of adherence in both categorical (IV vs. Oral) and availability as the majority of participants expressed their concerns regarding the medication in a few aspects, including recurrent changing of the dosage of the medication, which accounted for 10%, or difficulty when taking the medication, which accounted for 3.8%, and also interruption of the medication by MOH accounted for 10%. Impressively, third of the participants reported their strong fears of being dependent on ICH, and its affect on their lives.

Understanding these obstacles is critical for healthcare providers to develop strategies and plans that effectively support patients' adherence to their treatment regimen. The results

of the questionnaire confirmed the pivotal role of the medical team, as the percentage of patients' satisfaction with the medical staff and its role in motivating them to adhere to reached 98.7%. Lhaur-Yaigaiba Annette Ouattara (2023) reinforces the idea by highlighting the importance of the doctor-patient relationship in achieving optimal outcomes in terms of satisfaction and adherence to treatment. In addition, Lhaur-Yaigaiba Annette Ouattara (2023) suggested that providing simple advice can sometimes be enough to enhance treatment compliance [29].

Multidisciplinary approach to patient care means providing care to overcome the disease through different part of caregivers (psycologist, nurse, doctor, nutritionist) as our study confirmed the necessity of conducting psychological awareness courses and involving psychological and social support. Which is considered one of the most important obstacles that prevent patients from adhering to treatment by 21.7%.

Other studies such as [30] suggests, managing the quality of hemoglobinopathies requires a shift in therapeutic practice from a biomedical model to a holistic biopsychosocial model integrated into care [31]. In addition, a previous study in India confirmed that as most patients with thalassemia major reach adolescence, it is necessary to conduct periodic sessions of psychological and social support, as it is considered a very important part of patient and family management [32]. In addition the presence of nutrition specialist to assess dietary patterns and nutritional status is important as some of participants showed that they consume foods that is high in iron without knowing.

Adherence to iron chelation therapy in general among people with thalassemia is linked to a number of things, including low monthly family income. There was no correlation between knowledge of thalassemia and levels of adherence in our study when analyzing the correlation of the degree of knowledge of the disease with the study of social, demographic and clinical characteristics, with show statistically significant (P = 0.062) and the correlation of the degree of satisfaction with receiving medical service in the hospital with the study of social, demographic and clinical characteristics is show statistically significant (P = 0.014) which confirmed that the financial situation improves the patient's commitment and this is consistent with a previous study conducted in

Malaysia in the year 2022 which confirmed a close relationship between Monthly income and patient commitment is considered a very important part of patient and family management [33].

Our study showed an association between the degree of satisfaction when dealing with medical staff and patients' socio-demographic and clinical characteristics. Our study highlighted the necessity of effective communication with health care providers and patients, and establishing clear and open communication between them to encourage dialogue about treatment concerns and compliance barriers. This was clear to the patients when analyzing the data, as the percentage of patients' contributions varied according to the patient's type of work (student, college, not studying, working). Private, employee) with statistical significance (P = 0.011). This is what a previous study conducted in London in 2022 showed the importance of providing comprehensive and sufficient information about the importance of treatment, its benefits in reducing iron accumulation, and the potential consequences of non-compliance [34].

In addition, our study showed that some of the obstacles that prevent patients from adhering to treatment are forgetting the medication, and this percentage was 4.2%. Therefore, it is necessary to intervene using technology such as medication reminder apps or wearable devices to remind patients of medication appointments and the need to take them on time. A previous study in London also emphasized the importance of integrating technology into patients' lives to help them adhere [34].

Our study showed, when analyzing patient data, the degree of patient satisfaction with the medical staff, the community, service provision, adequate information about the disease, and others. It focused on certain factors, including the family's monthly income, economic and social background, the patient's educational status, nutritional support, and psychological counseling.

It was concluded that education and education are important. It is necessary for patients, as it has been noted that students have a good level of information and have good commitment, as it helps them make the right decisions and help confront problems in a positive way, and they have an ambition to become healthy, and also psychological,

emotional, and social health are the aspects that the patient needs most, and this is what was confirmed by a previous study conducted. In India in 2019, education and training contribute to achieving health independence for individuals, and lead to improving the quality of life in general, including emotional, social, and psychological health [35].

4.1 Limitations of the study

1. Shortage of literature review in the investigated field in Palestine,Or even globally.

2. Time limitations.

4.2 Strength of the study

This study addressed a critically important health issue – adherence to iron chelation therapy with patients thalassemia. This is particularly important in the context of managing a chronic condition such as thalassemia, where adherence to treatment plays a crucial role in patient outcomes.

The study comprehensively evaluated adherence, considering various factors such as patient-related, drug-related, social, cultural, and environmental factors, as well as the patient's relationship with healthcare providers. Additionally, the study incorporated insights from multiple specialties, including healthcare providers, psychologists, and nutritionists, to understand and address the complex factors influencing adherence to iron chelation therapy.

4.3 Conclusion

Although the study may conclude that a large portion of patients with Beta thalassemia at the National Governmental Hospital in Nablus, Palestine, show high adherence rates to iron chelation therapy. However the importance of increased education and ongoing support for patients are essential and should cover the nature of the disease, its potential complications, the benefits of treatment, and the consequences of non-adherence. Health care providers support were noticed to paly vital role in supporting medication adherence.

Building strong relationships between the patient and caregivers, and providing support and guidance helps enhance adherence rates. This included the quality of communication,

the level of trust, and the provider's attitude towards the patient. Patients who had a good relationship with their healthcare provider were more likely to adhere to their treatment regimen. Our results showed that multidisciplinary approach to patient care such as (psychologists, nutritionists, as well as health care providers) is lacking.

Further research is needed to develop and test interventions to improve adherence in this population and highlight the need for a comprehensive approach to improve adherence and ultimately, patient outcomes.

4.4 Recommendations of the Study

The following recommendations are made based on the results that need improvement, noting that the results are prominent in the current study.

1. Strengthen patient education: Create clear educational programmes that seek to increase patients' understanding of thalassemia and the importance of adherence to iron chelation therapy. It includes regular and recurring educational sessions, informational, educational, and cultural resources, in addition to individual personal consultations.
2. Innovative ways to increase access to medicines: The development and implementation of guidelines aim to improve the quality of health care, address barriers, and implement strategies for access to medicine, ensuring the continuous provision of specialised medicines for patients suffering from excess iron accumulation.
3. Multidisciplinary patient care teams aim to significantly improve the quality of patient care. The integration of all departments and professionals involved ensures complete and continuous support for patients during treatment and follow-up periods. The different members of the multidisciplinary team will provide precise symptom management, adequate nutritional support, psychological and social reinforcement, and individual follow-up. Comprehensive evaluation and monitoring of thalassemia patients by multidisciplinary teams will improve treatment adherence and tolerability and improve quality of life.

4. Monitoring and follow-up Regular: regular observation and recording to track patients' adherence to iron chelation therapy and implement follow-up protocols. Its aim is to routinely gather information on all aspects of patient care, including barriers, concerns, and ongoing communication between patients and health care providers.
5. Supporting community participation: stimulating social participation with patients' families to exchange experiences and strategies used to increase patients' commitment to treatment, as this community participation helps provide emotional and practical support.

These recommendations address the challenges and barriers faced by thalassemia patients and aim to enhance their adherence to iron chelation therapy. Therefore, these particular barriers and facilitators in iron chelation therapy among these patients must be understood, as they provide many interesting options for future multifaceted interventions, ultimately leading to improved quality of life and improved long-term health outcomes.

List of Abbreviations

Abbreviation	Meaning
ICT	Iron Chelation Therapy
B-TM	Beta-Thalassemia Major
QOL	Quality Of Life
DFO	Deferoxamine

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Appendices

Appendix A

Faculty of Graduate studies approval Appendix

Reload Page

نموذج تحديد عنوان الأطروحة و المشرف

*** يجب توفر جميع الشروط التالية لتحديد عنوان الأطروحة و المشرف :
- أن يكون مسار الطالب أطروحة ** الشرط متحقق **
- أن يتم الطالب 12 ساعة . ** الشرط متحقق ** ** عدد الفصول أقل أو يساوي 4 **
- أن لا يكون الوضع الدراسي للطالب "مفصول من البرنامج". ** الشرط متحقق **

اسم الطالب :	زين توفيق ابراهيم عيران	رقم التسجيل :	12053802
اسم البرنامج :	ماجستير إدارة الصحة العامة	مسار الدراسة:	أطروحة
عدد الساعات المعتمدة التي انجزت حتى الان:	33	المعدل التراكمي:	3.61
الوضع الدراسي :	يدرس		
عنوان الطالب :	نابلس	رقم الهاتف المحمول :	05993360811
البريد الالكتروني :	zein.ieran@najah.edu		
لغة الرسالة :	انجليزي		
عنوان الأطروحة باللغة العربية :	تقييم الالتزام بالعلاج بالاستخلاب لدى المراهقين الفلسطينيين المصابين بالثلاسيميا في المستشفى الوطني الحكومي ، نابلس ، فلسطين		
عنوان الأطروحة باللغة الانجليزية:	Assessment of adherence to iron chelation therapy among Palestinian adolescents with thalassemia at Al-Watani governmental hospital, Nablus, Palestine		
النسخة الإلكترونية من مقترح الاطروحة :	doc.12053802-1		

رقم المشرف الأول :	3507	اسم المشرف الأول:	حمزة محمد عبد الهادي الزبدي
المشرف الثاني :	يعمل في جامعة النجاح: --------------------		

ملاحظة المشرف :	مع الموافقة			التاريخ :	2023-04-11
ملاحظة المنسق :	لا مانع	رأي المنسق :	موافق	التاريخ :	2023-04-11
ملاحظة رئيس القسم :	موافق	رأي رئيس القسم :	موافق	التاريخ :	2023-04-11
ملاحظة مدقق الدراسات :	تعرض على مجلس الكلية - تم التواصل مع الطالب من اجل الغاء التاجيل على الفصل الثاني 2022/2023	رأي مدقق الدراسات :	موافق / عبء الاشراف : أدنى من الحد	التاريخ :	2023-04-18
ملاحظة عميد الدراسات العليا :	لا مانع - الاعتماد على الفصل الثاني 2022-2023 بعد الغاء التاجيل	رأي عميد الدراسات العليا:	موافق	التاريخ :	2023-04-18

قرار مجلس الكلية			
تم تغيير العنوان من قبل مجلس الكلية :	لا		
عنوان الأطروحة باللغة العربية :	تقييم الالتزام بالعلاج بالاستخلاب لدى المراهقين الفلسطينيين المصابين بالثلاسيميا في المستشفى الوطني الحكومي ، نابلس ، فلسطين		
عنوان الأطروحة باللغة الانجليزية:	ASSESSMENT OF ADHERENCE TO IRON CHELATION THERAPY AMONG PALESTINIAN ADOLESCENTS WITH THALASSEMIA AT AL-WATANI GOVERNMENTAL HOSPITAL, NABLUS, PALESTINE		
رقم المشرف:	3507	اسم المشرف:	حمزة محمد عبد الهادي الزبدي

المشرف الثاني :	يعمل في جامعة النجاح: --------------------		
فصل الاعتماد :	الثاني	سنة الاعتماد :	2022 ** ملاحظة : مثال العام الدراسي 2021-2022 يتم ادخاله على شكل 2021
رقم جلسة الكلية:	428		
تاريخ جلسة الكلية:	19/3/2023		

Appendix B

IRB approval

An-Najah National University
Faculty of Medicine & Health Sciences
Institutional Review Board

جامعة النجاح الوطنية
كلية الطب وعلوم الصحة
لجنة اخلاقيات البحث العلمي

Ref: Mas . May. 2023/8

IRB Approval Letter

Title of Research:

Assessment of adherence to iron chelation therapy among Palestinian adolescents with thalassemia at Al-Watani governmental hospital, Nablus, Palestine

Submitted by:
Zein Tawfeq Ieran

Supervisor:
Hamza Al Zabadi

Approved:
8th May. 2023

Your Study Title **"Assessment of adherence to iron chelation therapy among Palestinian adolescents with thalassemia at Al-Watani governmental hospital, Nablus, Palestine"** reviewed by An-Najah National University IRB committee and was approved on 8th , May . 2023.

Hasan Fitian, MD

IRB Committee Chairman

Nablus - P.O Box :7 or 707 | Tel (970) (09) 2342902/4/7/8/14 | Faximile (970) (09) 2342910| E-mail : IRB@najah.edu

Appendix C

Book to facilitate the task at Al-Watani governmental hospital in Nablus

State of Palestine Ministry of Health Education in Health and Scientific Research Unit		دولة فلسطين وزارة الصحة وحدة التعليم الصحي والبحث العلمي

Ref.: ……………… الرقم: ع ت/١١٠٤/٢٠٢١

Date:……………… التاريخ: ١٥/٦/٢٠٢١

ق. أ. الوكيل المساعد لشؤون المستشفيات والطوارئ المحترم،،،

تحية واحترام،،،

الموضـــوع: تسهيل مهمة بحث

يرجى تسهيل مهمة بحث الطالبة: **زين توفيق عيران– ماجستير ادارة صحة عامة** – جامعة النجاح،

لعمل بحث بعنوان:

"تقييم الالتزام بالعلاج بالاستخلاب لدى المراهقين الفلسطينيين المصابين بالثلاسيميا في المستشفى الوطني الحكومي– نابلس– فلسطين"

حيث ستقوم الطالبة بجمع معلومات من خلال تعبئة استبانة من قبل المرضى (بعد اخذ موافقتهم)، وذلك في:

- **مستشفى الوطني**

مع العلم أن مشرف الدراسة: د. حمزة الزبدي.

على ان يتم الالتزام بالمحافظة على اخلاقيات البحث العلمي وسرية المعلومات، وعدم استخدام المعلومات الشخصية للمرضى.

على ان يتم تزويد الوزارة بنسخة PDF من نتائج البحث.

مع الاحترام،،،

د. عبد الله القواسمي

رئيس وحدة التعليم الصحي والبحث العلمي

نسخة: نائب الرئيس للشؤوم الأكاديمية المحترم/ جامعة النجاح

Telfax.:09-2333901 scientificresearch.dep@gmail.com 09-2333901 :تلفاكس

Appendix D

Consent form (English version)

Greetings,

Thank you for allowing your children to participate in this questionnaire, which aims to collect information about the social, health, and psychological conditions of adolescent thalassemia patients aged between (13-19) years old. This information will contribute to conveying an accurate and documented picture to decision-makers with the aim of Assessment of adherence to iron chelation therapy, which will enhance their quality of life and improve their health indicators.

For any inquiries regarding the subject, please contact:

Researcher / Zein Tawfiq Ieran
An-Najah National University
Mobile: 0599613182
Email: zein.ieran@najah.edu

Guardian: ....

Signature: ....

Date: ....

Appendix E

Consent form (Arabic version)

أخي المواطن/ أختي المواطنة،

تحية وبعد،

شكرا للسماح لأبنائكم في المشاركة في هذا الاستبيان، والذي يستهدف لجمع معلومات حول الأوضاع الاجتماعية والصحية والنفسية لمرضى التلاسيميا المراهقين بين عمر (13−19) سنة إن هذه المعلومات ستساهم في إيصال صورة موثقة ودقيقة إلى صنَاع القرار بهدف تحسين التزام مرضى التلاسيميا المراهقين في العلاج عن طريق استخلاص الحديد والتي ستحسن من جودة الحياة ورفع المؤشرات الصحية لهم.

لأي استفسار بخصوص الموضوع الرجاء التواصل مع:

الباحث / زين توفيق عيران

جامعة النجاح الوطنية

جوال **0599613182**

بريد الكتروني zein.ieran@najah.edu

ولي الأمر: ....

التوقيع: ....

التاريخ: ....

Appendix F
Questionnaire (English version)

AN-Najah National University
Faculty Of Graduate Studies

جامعة النجاح الوطنية
كلية الدراسات العليا

Annexes

Annex 1: Disease knowledge about Thalassemia questionnaire .

بسم الله الرحمن الرحيم

أخي المواطن/ أختي المواطنة،
تحية وبعد،

شكرا لسماح لأبنائكم في المشاركة في هذا الاستبيان، والذي يستهدف لجمع معلومات حول الأوضاع الاجتماعية والصحية والنفسية لمرضى التلاسيميا المراهقين بين عمر (١٣-١٩) سنة إن هذه المعلومات ستساهم في إيصال صورة موثقة ودقيقة إلى صنَاع القرار بهدف تحسين التزام مرضى التلاسيميا المراهقين في العلاج عن طريق استخلاص الحديد والتي ستحسن من جودة الحياة ورفع المؤشرات الصحية لهم.

لأي استفسار بخصوص الموضوع الرجاء التواصل مع:

الباحث / زين توفيق عيران
جامعة النجاح الوطنية
جوال **0599613182**
بريد الكتروني **zein.ieran@najah.edu**

ولي الأمر: ....
التوقيع: ....
التاريخ: ....

1

Table 2: Assessment of disease knowledge gaps among thalassemia patients.

الجدول 2: تقييم الفجوات المعرفية عن المرض بين مرضى التلاسيميا.

* 0 (for no answers), 1 (for correct answers), and 2 (for don't know answers) * each branch has only one answer.		No (0)	Yes (1)	I don't know (0.5)
21.	Do you have enough information about thalassemia?			
22.	Thalassemia is a genetic disease.			
23.	When a couple has a child with thalassemia, both parents carry the genetic trait for thalassemia			
24.	Consanguineous marriage plays an important role in the transmission of thalassemia to the next generatio			
25.	Thalassemia affecting growth and physical activity			
26.	Symptoms of thalassemia appear several months after birth			
27.	An accumulation of iron in the blood leads to cardiomyopathy			
28.	Thalassemia leads to a decrease in the number of red blood cells			
29.	The diet of thalassemia patients should contain a low percentage of iron			
30.	Matched bone marrow/stem cell transplantation is the only known method of treating thalassemia at present			
31.	Iron overload can cause gland disorders			
32.	Iron overload can cause an effect on growth			
33.	To prevent thalassemia, genetic counseling and investigations must be carried out before marriage			
34.	To maintain the health of patients with major thalassemia, iron chelation therapy should be given			
35.	Treating you with iron chelation therapy should stop the iron overload from getting worse			

3

Table 1: Sociodemographic and clinical characteristics of the samples in Thalassemia cente

الجدول١: الخصائص الاجتماعية والديموغرافية والسريرية للعينات بمركز التلاسيميا

Part one : personal information							
1.	Sex	0. Male ☐		1. Female ☐			
2.	Age	year -----------					
3.	Place of residence	0. City ☐	1.Village ☐	2.Camp/refugee ☐			
4.	The questionnaire has already been filled out	0.Patient himself ☐		1.Patient+relative			
5.	Relationship between the parents	0. No ☐		1. Yes ☐			
6.	Father's education	0.Primary ☐	1.Preparatory ☐	2.Secondary ☐	3.Diploma ☐	4.Bachelor's ☐	5.Master ☐
7.	Mother's education	0.Primary ☐	1.Preparatory ☐	2.Secondary ☐	3.Diploma ☐	4.Bachelor's ☐	5.Master ☐
8.	Patients education	0.Primary ☐	1.Preparatory ☐	2.Secondary ☐	3.Diploma ☐	4.Bachelor's ☐	5.Master ☐
9.	Status	0.Married ☐	1.Single ☐	2.Widower ☐	3.Divorce ☐		
10.	Family members	0.Less than 3 ☐	1.(3-5) ☐	2.(6-8) ☐	3.More than 8 ☐		
11.	Job	0.Student ☐	1.College ☐	2.Not studying ☐	3.Personal job ☐	4.Employee ☐	
12.	Family members affected by thalassemia	0.No body ☐	1. (1-2) ☐	2.More than 2 ☐			
13.	Family member died of thalassemia?	0.No body ☐		1.One or more ☐			
14.	Social and economic status of the family	0.Low ☐	1.Medium ☐	2.High class ☐			
15.	Monthly income/ shekels	0.Less than (2000) ☐		1. more than(2000) ☐			
16.	Diagnose	0.Thalassemia minor ☐	1.Thalassemia medium ☐	2.Thalassemia a major ☐	3.Sickle-cell anemia – thalassemia ☐		
17.	Iron chelation therapy treatment period	0.Less than a year ☐	1. (1-3) years ☐	2.(3-5) Years ☐	3.More than 5 y ☐		
18.	Treatment type of iron chelation therapy	0.Oral tablet ☐		1. IV ☐			
19.	Any other disease	0. No ☐		1. Yes ☐			
20.	Do you have bad habits such as smoking and others	0. No ☐		1. Yes ☐			

2

Table ٣: Questionnaire on adherence patient to iron chelation therapy

الجدول ٣: استبيان حول التزام المريض بالعلاج باستخلاب الحديد

*** 0 (for no answers), 1 (for correct answers)** *** each branch has only one answer.**		**No (0)**	**Yes (1)**
The satisfaction of the patient when receiving the treatment in the hospital			
36.	Are you satisfied about the cost of transportation to and from the hospital		
37.	Are you satisfied about the registration process in the department for treatment		
38.	Will Your Current Iron Chelation Therapy Help You Live Longer		
39.	Your Iron Chelation Therapy was effective and worth to proceed		
40.	Are you satisfied with the results from your commitment to Iron Chelation Therapy		
41.	Was Iron Chelation Therapy Easy as You Expected		
42.	Are you satisfied with the time taken for Iron Chelation Therapy		
43.	Are you satisfied about the way of chelation therapy (oral -iv)		
The satisfaction of the patient when receiving the medical service			
44.	The hospital administration is committed of providing the necessary medicines and medical supplies permanently, in the hospital pharmacy		
45.	Available medication on regular basis affects your commitment of treatment		
46.	Are you satisfied with the availability of complementary therapies (vitamins and nutritional supplements) permanently and continuously		
47.	Oral Iron Chelation Therapy has increased your medication commitment		
48.	The hospital administration provides the necessary filtered, safe, and high-quality blood units in the hospital		
49.	The hospital administration provides the necessary laboratory tests in the hospital (iron, hormones, osteoporosis, etc.)		
50.	The hospital administration is committed providing the necessary treatment and care and allow admissions to the hospital when needed		
51.	The hospital administration is committed providing medical services at the wright time.		
52.	The hospital administration is keen on confidentiality and maintaining privacy during treatment		
53.	The hospital administration is interested in providing a comprehensive information system and database about the patient and his health condition		
54.	The hospital administration maintains a clean and comfortable environment in the center (sterilization of equipment, cleanliness of beds, sheets and corridors).		
55.	The hospital administration provides modern and advanced medical equipment and supplies.		

* 0 (for no answers), 1 (for correct answers) * each branch has only one answer.		No (0)	Yes (1)
56.	The hospital administration is keen on the staff's readiness to help patients		
57.	The hospital administration works to use medical equipment safely, quickly and skillfully		
58.	The hospital administration cares about the manner and form of work clothes for doctors and medical staff		
The satisfaction of the patient when receiving the treatment with community			
59.	Your Iron Chelation Therapy Reduce your dependence on others		
60.	Iron Chelation Therapy helps you with your daily activities		
61.	You feel easy to lead your normal life when you take Iron Chelation Therapy		
62.	You think Iron Chelation Therapy is successful in your needs		
63.	Regularity of Iron Chelation Therapy will have a positive effect on the appearance of the body and skin		
64.	our commitment to treatment reduces social stigma and discrimination		
The satisfaction of the patient when with the medical staff			
65.	Are you satisfied with the hospital management in providing a sufficient number of: doctors - staff - beds - equipment		
66.	Are you satisfied with the hospital management in providing a multidisciplinary medical staff of: hematologist, nurses, psychologist, social worker		
67.	Are you satisfied with the hospital administration for facilitating your access to emergency medical treatment when needed		
68.	The hospital administration works on sufficient working hours by the medical staff, as it suits the needs of the patients		
69.	Are you satisfied with the follow-up and supervision by the medical staff (routine check-ups, follow-up of the patient's condition in case of complications or complaints)		
70.	The medical staff is obligated to examine the patient and give him enough time to examine him and give him medical instructions and a clear explanation of his condition		
71.	The medical staff responds quickly to patients' requests and takes immediate action in any emergency situation		
72.	The medical staff puts the interests of the patients at the top priority their attention.		
73.	The hospital administration works on the confidence and insurance of the patients by doctors and staff		
74.	Is the hospital administration committed to ensuring safety and a sense of security in receiving health care?		
75.	The hospital administration is keen to treat the patient with respect and dignity		
76.	Is the hospital administration keen to create a fun atmosphere and make an effort to make the patient receive treatment comfortable		
77.	Is the medical staff interested in providing psychological and social support		

* 0 (for no answers), 1 (for correct answers) * each branch has only one answer.		No (0)	Yes (1)
78.	Are you encouraged by medical staff in self-care and adherence to treatment?		
79.	Is an evaluation made by the administrative staff in the hospital expressing your satisfaction with the medical service after receiving it		
80.	Are you satisfied with the hospital administration in meeting and understanding your needs when receiving treatment		
81.	Are you adherence to iron chelation therapy 0.Not-Adherence ☐ 1.Adherence ☐		
82.	How many times have you missed doses of iron chelation therapy. 1. Never missed a dose ☐ 2. Some of the time ☐ 3. Most of the time ☐ 4. All of the time ☐		
83.	Do you have suggestions to help you adhere to a better way to take the medication continuously? ________________________________ ________________________________ ________________________________		
84.	What are the obstacles that prevent you from committing to taking the medicine regularly that was not mentioned previously? ________________________________ ________________________________ ________________________________		

شكراً لتعاونكم

6

Appendix G
Questionnaire (Arabic version)

AN-Najah National University
Faculty Of Graduate Studies

جامعة النجاح الوطنية
كلية الدراسات العليا

Annexes

Annex 1: Disease knowledge about Thalassemia questionnaire .

بسم الله الرحمن الرحيم

أخي المواطن/ أختي المواطنة،
تحية وبعد،

شكرا لسماح لأبنائكم في المشاركة في هذا الاستبيان، والذي يستهدف لجمع معلومات حول الأوضاع الاجتماعية والصحية والنفسية لمرضى التلاسيميا المراهقين بين عمر (١٣-١٩) سنة إن هذه المعلومات ستساهم في إيصال صورة موثقة ودقيقة إلى صناع القرار بهدف تحسين التزام مرضى التلاسيميا المراهقين في العلاج عن طريق استخلاص الحديد والتي ستحسن من جودة الحياة ورفع المؤشرات الصحية لهم.

لأي استفسار بخصوص الموضوع الرجاء التواصل مع:

الباحث / زين توفيق عيران
جامعة النجاح الوطنية
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بريد الكتروني **zein.ieran@najah.edu**

ولي الأمر: ....
التوقيع: ....
التاريخ: ....

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Table 1: Sociodemographic and clinical characteristics of the samples in Thalassemia center

الجدول١: الخصائص الاجتماعية والديموغرافية والسريرية للعينات بمركز التلاسيميا

الجزء الأول: - معلومات شخصية:							
١.	الجنس	٠.ذكر ☐	١. أنثى ☐				
٢.	العمر	----------- سنة ☐					
٣.	مكان الإقامة	٠. مدينة ☐	1.قرية ☐	2.مخيم/لاجئين ☐			
٤.	تم تعبئة الاستبيان من قبل	٠. المريض نفسه ☐	١. المريض + شخص من العائلة ☐				
٥.	قرابة بين الوالدين	٠. لا ☐	١.نعم ☐				
٦.	المستوى التعليمي للأب	٠.ابتدائي ☐	١.اعدادي ☐	٢.ثانوي ☐	٣.دبلوم ☐	٤.بكالوريوس ☐	٥.دراسات عليا ☐
٧.	المستوى التعليمي للأم	٠.ابتدائي ☐	١.اعدادي ☐	٢.ثانوي ☐	٣.دبلوم ☐	٤.بكالوريوس ☐	٥.دراسات عليا ☐
٨.	المستوى التعليمي للمريض	٠.ابتدائي ☐	١.اعدادي ☐	٢.ثانوي ☐	٣.دبلوم ☐	٤.بكالوريوس ☐	٥.دراسات عليا ☐
٩.	الحالة الاجتماعية	٠.متزوج ☐	١.أعزب ☐	٢.أرمل ☐	٣.مطلق ☐		
١٠.	عدد أفراد الأسرة	٠.أقل من٣ أفراد ☐	١. (3-5) ☐	٢.(6-8) ☐	٣.أكثر من ٨ أفراد ☐		
١١.	المهنة	٠. طالب مدرسة ☐	١. طالب جامعي ☐	٢. لا يدرس ☐	٣. اعمل لحسابي الخاص ☐	٤. موظف ☐	
١٢.	عدد افراد العائلة المصابين في مرض التلاسيميا	٠. لا أحد ☐	١.(1-2) ☐	٢. أكثر من فردين ☐			
١٣.	هل توفى أحد افراد العائلة في مرض التلاسيميا	٠. لا أحد ☐	١. واحد او أكثر ☐				
١٤.	الوضع الاجتماعي والاقتصادي للعائلة	٠. الطبقة الدنيا ☐	١. الطبقة الوسطى ☐	٢. الطبقة العليا ☐			
١٥.	الدخل الشهري/ شيكل	٠. أقل من (2000) ☐	١. (2000) وأكثر ☐				
١٦.	التشخيص	٠. تلاسيميا صغرى ☐	١. تلاسيميا وسطى ☐	٢. تلاسيميا كبرى ☐	٣. انيميا منجلية-تلاسيميا ☐		
١٧.	مدة العلاج ب Iron Chelation Therapy	٠. اقل من سنة ☐	١. (1-3)سنوات ☐	٢. (3-5)سنوات ☐	٣. اكثر من 5سنوات ☐		
١٨.	نوع العلاج ب Iron Chelation Therapy	٠. الحبوب Oral ☐	١. الوريد IV ☐				
١٩.	هل تعاني من امراض أخرى	٠. لا ☐	١.نعم ☐				
٢٠.	هل تمارس عادات سيئة مثل التدخين وغيرها	٠. لا ☐	١.نعم ☐				

Table 2: Assessment of disease knowledge gaps among thalassemia patients.

الجدول 2: تقييم الفجوات المعرفية عن المرض بين مرضى التلاسيميا.

* ٠ (للإجابات بلا أو لا أعرف) و ١ (للإجابات الصحيحة) * لكل فرع إجابة واحدة فقط.		لا (٠)	نعم (١)	لا اعرف (2)
٢١.	هل لديك المعلومات الكافية عن مرض التلاسيميا			
٢٢.	التلاسيميا مرض وراثي.			
٢٣.	عندما يكون لدى الزوجين طفل مصاب بالتلاسيميا فإن كلا الوالدين يحملان الصفة الوراثية للتلاسيميا			
٢٤.	يلعب زواج الأقارب دوراً مهماً في انتقال مرض التلاسيميا الى الجيل القادم			
٢٥.	تلاسيميا تؤثر على النمو والنشاط البدني			
٢٦.	تظهر أعراض مرض التلاسيميا بعد عدة أشهر من الولادة			
٢٧.	يؤدي تراكم الحديد في الدم إلى اعتلال عضلة القلب			
٢٨.	تلاسيميا تؤدي إلى انخفاض في عدد خلايا الدم الحمراء			
٢٩.	يجب أن يحتوي النظام الغذائي لمرضى التلاسيميا على نسبة منخفضة من الحديد.			
٣٠.	إن زرع نخاع العظام / الخلايا الجذعية المتطابق هو الطريقة الوحيدة المعروفة لعلاج التلاسيميا في الوقت الحاضر.			
٣١.	يمكن أن يسبب الحمل الزائد للحديد اضطرابات في الغدد			
٣٢.	يمكن أن يسبب الحمل الزائد للحديد تأثيرًا على النمو			
٣٣.	للوقاية من تلاسيميا يجب إجراء الاستشارة والتحقيقات الوراثية قبل الزواج			
٣٤.	للحفاظ على صحة مرضى التلاسيميا الرئيسيين، يجب إعطاء العلاج باستخلاب الحديد			
٣٥.	علاجك بـ Iron Chelation Therapy من شأنه أن يوقف الحمل الزائد للحديد من التفاقم			

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Table ٣: Questionnaire on adherence patient to iron chelation therapy

الجدول ٣: استبيان حول التزام المريض بالعلاج باستخلاب الحديد

	* ٠ (للإجابات لا) و ١ (للإجابات الصحيحة) * لكل فرع إجابة واحدة فقط.	لا (٠)	نعم (١)
مدى رضا المريض عند تلقيه العلاج في المستشفى			
٣٦.	هل انت راضي عن تكلفه المواصلات من والى المستشفى		
٣٧.	هل انت راضي عن عملية التسجيل في القسم لتلقي العلاج		
٣٨.	هل يساعدك علاجك بـــIron Chelation Therapy - الحالي على العيش لفترة أطول		
٣٩.	كان علاجك بـ Iron Chelation Therapy فعال يستحق المتابعة		
٤٠.	هل انت راضي عن النتائج الصحية الناتجة عن التزامك في العلاج بـ Iron Chelation Therapy		
٤١.	هل كان العلاج بـ Iron Chelation Therapy سهلاً كما توقعت		
٤٢.	هل انت راضي عن الوقت الذي تستغرقه في العلاج بـ Iron Chelation Therapy		
٤٣.	هل انتا راضي عن شكل عملية إزالة معدن ثقيل العلاج (حبوب عن طريق الفم / أو عن طريق الوريد)		
مدى رضا المريض عند تلقيه الخدمات الطبية في المستشفى			
٤٤.	تلتزم إدارة المستشفى بتوفير الادوية الضرورية والمستلزمات الطبية بشكل دائم دون انقطاع داخل صيدلية المستشفى		
٤٥.	توفر الدواء بشكل منتظم يؤثر على التزامك في العلاج		
٤٦.	هل انت راضي عن توفر العلاجات التكميلية (الفيتامينات والمكملات الغذائية) بشكل دائم ومستمر		
٤٧.	العلاج بـIron Chelation Therapy عن طريق الفم زاد من التزامك في الدواء		
٤٨.	تعمل إدارة المستشفى على توفير وحدات الدم اللازمة مفلتره وامنه وذات جودة عالية داخل المستشفى		
٤٩.	تعمل إدارة المستشفى على توفير الفحوصات المخبرية اللازمة بشكل دوري داخل المستشفى (الحديد، الهرمونات، هشاشه العظام وغيرها)		
٥٠.	تلتزم إدارة المستشفى بتوفير العلاج والعناية اللازمة والسماح بالدخول المبيت بالمستشفى عند الحاجة		
٥١.	تلتزم إدارة المستشفى بتقديم الخدمات الطبية في الوقت المحدد المتفق عليه والالتزام بالمواعيد		
مدى رضا المريض عند تلقيه العلاج مع المجتمع			
٥٢.	علاجك بـ Iron Chelation Therapy قلل من اعتمادك على الأخرين		
٥٣.	ساعدك نظام العلاج بـ Iron Chelation Therapy من ممارسة أنشطتك النهارية		
٥٤.	تشعر بسهوله ممارسة حياتك الطبيعية عند أخذ العلاج بـ Iron Chelation Therapy		
٥٥.	بنظرك العلاج بـ Iron Chelation Therapy ناجح في تلبية احتياجاتك		
٥٦.	انتظامك في العلاج بـ Iron Chelation Therapy أثر إيجابي على مظهر جسمك أو جلدك		
٥٧.	التزامك في العلاج قلل من ظاهره الوصمة الاجتماعية والتمييز		
مدى رضا المريض على الطاقم الطبي			
٥٨.	هل انت راضي عن إدارة المستشفى في توفير عدد كافي من: الأطباء- العاملين- الاسرة - المعدات		
٥٩.	هل انت راضي عن إدارة المستشفى في توفير طاقم طبي متعدد التخصصات مؤلف من: اخصائي دم، ممرضات، اخصائي نفسي، اخصائي اجتماعي		
٦٠.	هل انت راضي عن إدارة المستشفى على تسهيل حصولك على العلاج الطبي في الطوارئ عند الحاجه		
٦١.	تعمل إدارة المستشفى على ساعات دوام كافية من قبل الطاقم الطبي حيث تتلاءم مع احتياجات المرضى		

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	* ٠ (للإجابات لا) و ١ (للإجابات الصحيحة) * لكل فرع إجابة واحدة فقط.	لا (٠)	نعم (١)
٦٢.	هل انت راضي عن المتابعة والاشراف من قبل الطاقم الطبي (الفحوصات الروتينية، متابعة حاله المريض في حال وجود مضاعفات او شكوى)		
٦٣.	يلتزم الطاقم الطبي في فحص المريض وإعطاء الوقت الكافي لفحصه واعطائه التعليمات الطبية وشرح واضح عن حالته		
٦٤.	يقوم الطاقم الطبي بالاستجابة السريعة لطلبات المرضى واتخاذ إجراءات مباشرة في أي حاله طارئة ناتجه من مضاعفات المرض		
٦٥.	يضع الطاقم الطبي مصلحه المرضى في صلب اهتمامهم قلباً وقالباً		
مدى ثقة المريض في الطاقم الطبي عند تلقيه العلاج			
٦٦.	تعمل إدارة المستشفى على غرس الثقة والطمأنينة في نفس المريض من قبل الأطباء والعاملين		
٦٧.	هل تلتزم إدارة المستشفى بتأمين السلامة والشعور بالأمان في تلقي الرعاية الصحية		
٦٨.	تحرص إدارة المستشفى على ان يتم علاج المريض باحترام وكرامه		
٦٩.	هل تحرص إدارة المستشفى على خلق جو من المرح وبذل جهد لجعل المريض يتلقى العلاج بشكل مريح		
٧٠.	هل يهتم الطاقم الطبي بتقديم الدعم النفسي والاجتماعي		
٧١.	هل يتم تشجيعك من قبل الطاقم الطبي في الرعاية الذاتية والالتزام بالعلاج		
٧٢.	هل يتم عمل تقييم من قبل الطاقم الإداري في المستشفى يعبر عن رضاكم عن الخدمة الطبية بعد تلقيها		
٧٣.	هل انت راضي عن إدارة المستشفى في تلبيه وفهم احتياجاتك عند تلقي العلاج		
مدى رضا المريض على الجوانب المادية الملموسة			
٧٤.	تحرص إدارة المستشفى على السرية والمحافظة على الخصوصية اثناء العلاج		
٧٥.	تهتم إدارة المستشفى بتوفير نظام معلومات وقاعدة بيانات شامله عن المريض وحالته الصحية		
٧٦.	تقوم إدارة المستشفى بالمحافظة على بيئة المركز نظيفة ومريحة (تعقيم المعدات، نظافة الاسرة، والشراشف والممرات)		
٧٧.	تقوم ادارة المستشفى بتوفير الاجهزة والمستلزمات الطبية حديثة ومتطورة		
٧٨.	تحرص ادارة المستشفى على استعداد العاملين دوما لمساعدة المرضى		
٧٩.	تعمل ادارة المستشفى على استخدام المعدات الطبية بأمان وسرعة ومهاره		
٨٠.	تهتم ادارة المستشفى بطريقة وهيئه ملابس العمل للأطباء والطاقم الطبي		
٨١.	هل يوجد لديك مقترحات تساعد في التزامك بطريقة أفضل في اخذ الدواء باستمرار ____________________ ____________________ ____________________		
٨٢.	ماهي المعوقات التي تمنعك من الالتزام في أخذ الدواء بانتظام لم يتم ذكره سابقاً ____________________ ____________________ ____________________		

شكراً لتعاونكم

جامعة النجاح الوطنية

كليَّة الدّراسات العليا

تقييم الالتزام بالعلاج بالاستخلاب بالحديد بين الفلسطينيين المصابين بالثلاسيميا في مستشفى الوطني الحكومي، نابلس، فلسطين

إعداد

زين توفيق عيران

إشراف

أ. د. حمزة الزبدي

قدمت هذه الرسالة استكمالا لمتطلبات الحصول على درجه الماجستير في إدارة الصحة العامة، من كلية الدراسات العليا، في جامعة النجاح الوطنية، نابلس– فلسطين.

2024

تقييم الالتزام بالعلاج بالاستخلاب بالحديد بين الفلسطينيين المصابين بالثلاسيميا في مستشفى الوطني الحكومي، نابلس، فلسطين

إعداد

زين توفيق عيران

إشراف

أ. د. حمزة الزبدي

الملخص

مقدمة: يعد الالتزام بالعلاج باستخلاب الحديد خطوة حاسمة في تقليل مستويات الحديد الزائدة في الجسم، حيث يهدف جميع المرضى إلى خفض مستويات الحديد إلى ما هو أبعد من المعدل الطبيعي. من المرجح أن يتم التحقيق في عوامل مثل العمر، ووجود أخ مصاب بالثلاسيميا، ونقص الإشراف الأبوي، وانخفاض دخل الأسرة، وندرة عمليات نقل الدم، والقضايا النفسية كمنبئات مهمة لعدم الالتزام. سيتم فحص العلاقة بين المعرفة بالمرض وحالة الالتزام.

الهدف: تقييم العوائق المختلفة التي تحول دون التزام المرضى المصابين بثلاسيميا بيتا بما في ذلك العوامل المرتبطة بالمريض، والعوامل المرتبطة بالأدوية، والعوامل الاجتماعية والثقافية، والسياق البيئي والموارد، وعوامل العلاقة بين المريض ومقدم الرعاية الصحية.

الطريقة: تم اعتماد التصميم الوصفي المقطعي لتقييم التزام مرضى الثلاسيميا بمركز الثلاسيميا الوطني في المستشفى الوطني نابلس. بلغ حجم العينة 120 مريض ثلاسيميا. تم جمع البيانات باستخدام المقابلة المباشرة أو عن طريق الهاتف والتي تتكون من استبيان من ثلاثة أجزاء. الجزء الأول من الاستبيان الخصائص الاجتماعية والديموغرافية والسريرية للعينات في مركز الثلاسيميا الجزء الثاني من الاستبيان تضمن تقييم فجوات المعرفة بالمرض بين مرضى الثلاسيميا والجزء الثالث من الاستبيان حول التزام المريض بالعلاج بالاستخلاب بالحديد.

النتائج: قامت الدراسة، التي أجريت في المستشفى الوطني الحكومي في نابلس، بتقييم 120 مريضاً بالثلاسيميا، وكشفت عن توزيع متساوٍ تقريباً بين الجنسين (63% ذكور، 57% إناث) وفئة عمرية سائدة تتراوح بين 18 إلى 26 سنة. يرتبط الالتزام بالعلاج بالحديد بمستويات منخفضة من الفيريتين، مما يشير إلى فعالية العلاج. المرضى الملتزمين وغير الملتزمين أظهروا فهمًا جيدًا لمرض الثلاسيميا، مما يشير إلى معرفة كافية بالمرض بين المشاركين. ومع ذلك، فإن الالتزام أثر بشكل إيجابي على رضا المرضى عن العلاج في المستشفى والخدمات الطبية، مما يسلط الضوء على أهمية تثقيف المرضى وأنظمة الدعم في تعزيز الالتزام بالعلاج وتجربة الرعاية الصحية الشاملة.

الخلاصة: خلصت الدراسة إلى أن العديد من المرضى في المستشفى الوطني الحكومي في نابلس يظهرون التزامهم بالعلاج باستخلاب الحديد. لا تزال هناك تحديات، بما في ذلك الصعوبات في الحصول على الدواء والمؤثرات الخارجية التي تؤثر على الالتزام على الرغم من المعرفة الكافية. دور مقدمي الرعاية الصحية مهم في تعزيز العلاقات بين المريض ومقدم الخدمة، وتوفير رعاية متعددة التخصصات، وإبراز أهمية التثقيف والدعم المستمر للمرضى، بالإضافة إلى معالجة المعوقات التي تؤدي إلى عدم امتثال المرضى للعلاج.

الكلمات المفتاحية: الثلاسيميا؛ الالتزام؛ العلاج باستخلاب الحديد؛ المعتقدات؛ ديفيراسيروكس (إكسجيد).