وزارة التعليم العالي و بحث علمي

جامعة ميسان-كلية التمريض

دراسة الأعباء الاقتصادية التي تؤثر على أسر أطفال الثلاسيميا في المركز العام لعلاج الثلاسيميا بمدينة ميسان

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الاهداء

نهدي مجهودنا المتواضع ....

الى من بلغ الرسالة وأدى الأمانة ونصح الأمه الى نبي الرحمة ونور العالمين محمد (صل الله عليه واله وسلم) وآل بيته الأطهار (عليهم السلام)

الى من نسعى للتمهيد الى دولته بقية الله في الارض امامنا القائم المهدي المنتظر (عجل الله في ظهوره)

إلى كل من في الوجود بعد الله ورسوله الى والدتي العزيزة حبا وإكراماً إلى من لا يمكن للكلمات إن توفي حقه إلى والدي العزيز أدام الله ضله..

الى من بوجودهم نكتسب قوة ومحبة لا حدود لها (اخوتي واخواتي واصدقائي)..

واخيرا الى كل من علمني حرفاً اضاء لي الطريق الى الامام ابتداءاً من المعلمين ،المدرسين وصولا الى اساتذتنا الافاضل في كلية التمريض ..

نهدي اليكم بحثنا هذا...

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الحمد لله رب العاملين والصلاة والسلام على سيد الاوصياء

والمرسلين محمد

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الذي أنار لنا درب العلم والمعرفة وأعاننا على أداء هذا الواجب ووفقنا إلى انجاز هذا العمل...

وانطلاقًا من مبدأ أنه لا يشكر الله من لا يشكر الناس، فإننا نتوجه بالشكر الجزيل للأستاذ :

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الذي رافقنا في مسيرتنا لإنجاز هذا البحث وكانت له بصمات واضحة

من خلال توجيهاته وانتقاداته البناءة والدعم الأكاديمي.

كما نشكر عائلاتنا التي صبرت وتحملت معنا ورفدتنا بالكثير من

الدعم على جميع الأصعدة، ونشكر الأصدقاء والأحباب وكل من قدم

لنا الدعم المادي أو المعنوي...

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إقرار المشرفين

نحن الموقعين أدناه المشرفين على البحث الموسوم **(دراسة الأعباء الداخلية التي تؤثر على أسر أطفال الثلاسيميا في المركز العام لعلاج الثلاسيميا بمدينة ميسان)** وقد تم من قبل الطلاب:

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وقد تم اجراء البحث تحت إشرافنا.

المشرفان:

(م.مصطفى سالم ،م.هادي حسين ماضي)

التوقيع: التوقيع:

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الخلاصة:

مقدمة : ثالاسميا هو اضطراب الدم ينتقل عبر العائلة (وراثي) عندما يصنع الجسم شكل غير طبيعي من الهيموغلوبين. هذا الاضطراب يؤدي إلى تدمير مفرط من خلايا الدم الحمراء، وليس هناك علاج فعال. المرضى يتطلبون نقل الدم مدى الحياة ، وعادة ما تبدأ في غضون 6 إلى 12 شهرا من ولادة المريض، والذي على كفة أخرى لديه مضاعفاته الخاصة به. وهو مرض مزمن الذي يتجلى في وقت مبكر من الحياة والذي يؤدي إلى المشاكل النفسية والاجتماعية للآباء والأمهات.

الأهداف:

(1) لتحديد الأعباء الاقتصادية التي تؤثر على أسر الأطفال الثلاسيميا في المركز العام لعلاج ثالاسميا في مدينة ميسان.

(2) لدراسة العلاقات بين الأعباء الاقتصادية التي تؤثر على أسر الثلاسيميا وبياناتها الاجتماعية - الديمغرافية .

المنهجية : تم أخذ عينات ملائمه لهذه الدراسة. تم جمع 53 عينة تمثل أولياء أمور أطفال الثلاسيميا. تم إنشاء استبيان من قبل الباحثين لغرض الدراسة. وهو يتألف من جزأين: الجزء الأول من الاستبيان: البيانات الديموغرافية. يتكون من (12) فقرة ، الجزء الثاني من الاستبيان: معلومات محددة لعينة البحث. يحتوي على (26) فقرة. تم جمع البيانات خلال الفترة من 10 نوفمبر 2020 وانتهت في 20 مايو 2021.

النتائج : بينت نتائج الدراســـة أن أكثر من الأطفال في الفئة العمرية لعينة الدراســـة كانوا خلال (6-10) ســـنوات (30.2٪) ، كما بينت الدراســـة أن غالبية المشـــاركين كانوا من الذكور (62.3٪). أن هناك علاقة ذات دلالة إحصـــائية عالية بين تأثير العبء الاقتصـــادي تجاه والدي أطفال الثلاســـيميا وحالتهم الاقتصـــــادية عند (P 0.05). وفيما يتعلق بعدد أفراد الأســـــرة ، أظهرت النتائج أن أكثر من نصـــفهم في الفئة العمرية كانت عينة الدراســـة خلال (6-10) سنوات (69.8٪).

الخلاصة: أظهرت النتائج وجود علاقة ذات دلالة إحصائية عالية بين تأثير العبء الاقتصـادي على أولياء أمور أطفال الثلاسيميا وحالتهم الاقتصـادية ، وأظهرت النتائج أن أكثر من نصـفهم في الفئة العمرية لعينة الدراسـة كانت في حدود (6-10) سـنوات. كما كشـفت النتائج أن غالبية العينات تعاني من مستوى اقتصادي منخفض.

التوصـــيات: المرض هو من الأمراض الوراثية التي تنتقل عن الآباء الذين يحملون المرض لأطفالهم. لذلك، نوصـــي الاختبارات في الدم قبل الزواج لتجنب الأطفال والآثار المضـــاعفة لأنها تؤدي إلى موتهم. ضـــرورة التشـخيص المبكر للمرض لغرض استخدام أساليب العلاج المناسبة لتجنب المضـاعفات الخطيرة في المسـتقبل، مثل إزالة بعض الأعضـاء مثل الكبد، الطحال أو حتى نخاع العظام.

Ministry of Higher Education

& Scientific Research

Misan University_ College of Nursing

Study of the encomic burdens that affects the families of thalassemia children in general center for the treatment of thalassemia at misan city

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Obtain a Bachelor's Degree in Nursing Science

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Mr.Hadi Husain Madhi

Novmber/2020

سورة يوسف / أية 76

Dedication

We dedicate our humble effort ....

To the one who delivered the message, led the trust, and advised his nation to the Prophet of mercy and the light of the worlds

Muhammad (may God bless him and grant him peace) and his pure family (peace be upon them)

To whom we seek to prepare for his state, the rest of God on earth before us, the awaited Mahdi (may God hasten his appearance)

To everyone who exists after God and His Messenger, to my dear mother, out of love and honor to whom words cannot, if they fulfill their rights, to my dear father, may God continue to mislead him ..

To whom, by their presence, we gain strength and love that has no limits (my brothers, sisters and friends) ..

Finally, to everyone who taught me a letter that illuminated the way forward for me, starting with teachers, teachers, and ending with our distinguished professors in the College of Nursing ..

We dedicate this research to you ...

Researchers

Acknowledgment

Praise be to God, the Lord of workers, and prayers and peace be upon the master of the guardians and messengers, Muhammad(May God's prayers and peace be upon him and his family and companions)

Praise be to God, the number of tree leaves, praise be to God, the number of angels' and human breaths, thank God

Who enlightened us on the path of science and knowledge, helped us to perform this duty, and granted us the achievement of this work...

And based on the principle that he does not thank God who does not thank people, we extend our sincere thanks to the professor:

(Mr.Mustafa Salem Abdel Reda and Mr.Hadi Husain)

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We also thank our families who have been patient and enduring with us and provided us with a lot of support at all levels, and we thank friends and loved ones and everyone who provided us with material or moral support...

researchers

Abstract

Introduction, Thalassemia is a blood disorder passed down through families (inherited) in which the body makes an abnormal form of hemoglobin. This disorder results in excessive destruction of red blood cells, and there is no effective treatment. Patients require lifelong blood transfusion, usually started within 6 to 12 months of birth of patient, which on other hand has its own complications. It is a chronic disease that manifests so early in life that it leads to psychological and social problems for parents .

Objectives,(1)to identify encomic burdens that affects the families of thalassemia Children in general Center for the treatment of Thalassemia at Misan City.(2)to Examine relationships between economic burdens that affects the families of Thalassemia and their perceived socio-demographic related data.

Methodology,Convenient sampling was done for this study; 53 samples collected representing to the parents of children thalassemia. a questionnaire is constructed by the researchers for the purpose of the study. It is comprised of two parts:First part of questionnaire :Demographic data. consisted of (12) items,Second part of questionnaire: specific information to sample research. That contains of (26) items. The data collected during period from 10 November 2020 and ended in 20 May 2021.

Results, The results of study show that more of the children in age group to the study sample were within (6-10) years was (30.2%).The study also shows that the majority of participants were male (62.3%). that there was high significant relationship between the effect of economic burden toward parents children of

thalassemia and their economic status at (P > 0.05).in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%).

Conclusion, The findings there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status.the results show that more half of them in age group to the study sample were within (6-10) years was ,The findings also revealed The majority of the samples suffer from a low economic level.

Recommendation, The disease is among the hereditary diseases that are transmitted from parents who carry the disease to their children. Therefore, we recommend blood tests before marriage to avoid infecting children and what complications happen to them that lead to their death.The necessity of early diagnosis of the disease for the purpose of using appropriate treatment methods to avoid serious complications in the future, such as removing some organs such as the liver, spleen or even the bone marrow.

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List of Abbreviations

Items	Meaning
Hb	hemoglobin
HbH	hemoglobin H
Hb Bart's	hemoglobin Bart's
MRI	magnetic resonance imagin
BMT	Bone marrow transplantation
ROC	receiver operator char acteristic
CBC	Complete blood count
HLA	human leukocyte antigen
HCV	Hebatitis C Virus
IE	Ineffective Erythropoiesis
OFT	osmotic fragility test
HPLC	High Performance Liquid Chromatography
DCIP	Dichlorophenolindolphenol
PCR	Polymerase chain reaction
ARMS	amplification-refractory mutation system
BCB	Body Chemistry Balancing

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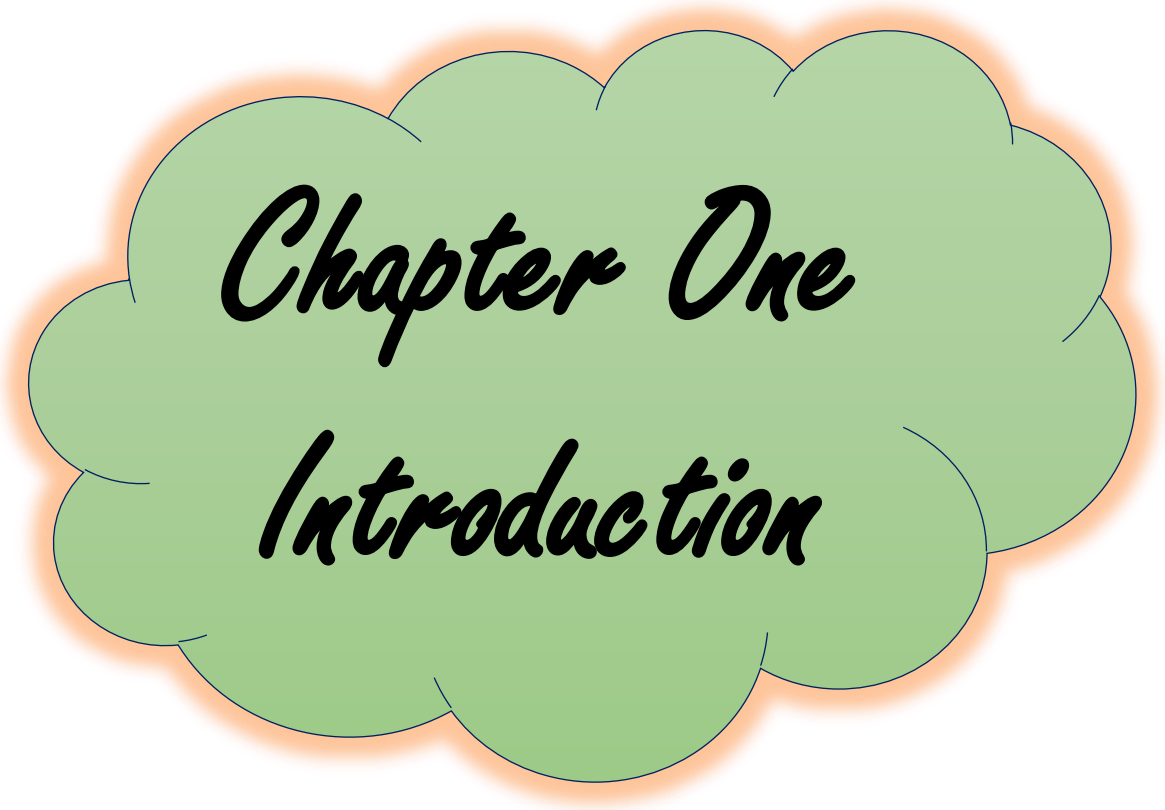

Chapter One
Introduction

1.1.Introduction

Thalassemia syndromes are among the most serious and common genetic conditions. They are indigenous in a wide but specific geographical area. However, through migration they are spreading across regions not previously affected. Thalassemias are caused by mutations in the α (HBA1/HBA2) and β globin (HBB) genes and are usually inherited in an autosomal recessive manner. The corresponding proteins form the adult hemoglobin molecule (HbA) which is a heterotetramer of two α and two β globin chains. Thalassemia-causing mutations lead to an imbalanced globin chain production and consecutively to impaired erythropoiesis. The severity of the disease is largely determined by the degree of chain imbalance. In the worst case, survival is dependent on regular blood transfusions, which in turn cause transfusional iron overload and secondary multi-organ damage due toiron toxicity. A vigorous monitoring and treatment regime is required, even for the milder syndromes. Thalassemias are a major public health issue in many populations which many health authorities fail to address. Even though comprehensive care has resulted in long-term survival and good quality of life, poor access to essential components of management results in complications which increase the cost of treatment and lead to poor outcomes. These requirements are not recognized by measures such as the Global Burden of Disease project, which ranks thalassemia very low in terms of disability-adjusted life years (DALYs), and fails to consider that it ranks highly in the one to four-year-old age group, making it an important contributor to under-5 mortality. Thalassemia does not fulfil the criteria to be accepted as a target disease for neonatal screening. Nevertheless, depending on the screening methodology, severe cases of thalassemia will be detected in most neonatal screening programs for sickle cell disease. This is very valuable because:

(1) it helps to prepare the affected families for having a sick child and (2) it is an important measure of secondary prevention (Angstiniotis and Lobitz, 2019).

Furthermore Thalassemia is a common disorder worldwide with a predominant incidence in Mediterranean countries and Southeast Asia. Approximately, 240 million people are estimated as carriers for βthalassemia throughout the world while 100,000 children with thalassemia major are born annually (Bala and sarin , 2014).

Children living with β-thalassemia major need a life-long treatment of regular blood transfusions and iron chelation therapy ,which cause major social and financial burdens on patients, families, and health care system. A higher prevalence of thalassemia is mainly seen in developing countries ranging from the Mediterranean Sea, including Turkey, Iran, and India to South East of Asia including Thailand and southern China (pillitteri, 2010).

The cost of therapy in these patients as well as any other disease does not only cover medication cost. These extra costs include the cost of medical consultation, laboratory tests, diagnostic tests, cost of preventative or treatments of side effects of therapies and many other indirect costs. Indirect costs include travel expenses, the cost attributable to the loss of productivity by the patients or their caregivers, the impairment of well-being and all other related aspects.

1.2. Importance of the study

Thalassemia is a chronic condition caused due to genetic abnormality which affects a child's normal physiological functioning. Thalassemia challenges every individual as well as their family members at physical, emotional, cognitive level and disrupts their quality of life.(Saldanha, 2013).

Today, the life expectancy of patients with thalassemia has increased along with therapeutic advances. Therefore, they need lifelong care, and caring for them would incur many costs. Being aware of the patients' costs can be effective for controlling and managing the costs and providing efficient treatments for the care of patients. Thalassemia is a disease which needs lifelong therapy. Thalassemia therapy includes regular blood transfusion, administration of several medications such as iron chelating agents and other concomitant medications .Due to the high costs of treatment and the lack of receiving adequate measures, many thalassemic children and adolescents die in poor countries. Timely blood transfusion appears to prevent early symptoms of the disease, and the patients will continues to grow up. In many cases, however, transfusion reactions such as excess iron is deposited in the body, causing heart failure. chronic liver diseases, endocrine problems, growth disorders, osteoporosis, etc., leading to mortality in these patients.Thus, health management as well as planning the required services for early diagnosis and treatment of these patients seems essential.The life expectancy of patients with major thalassemia has significantly increased along with therapeutic advances, and this has changed thalassemia from a fatal to a chronic disease. As a result, thalassemic patients need lifelong care, but it requires high costs including the costs of blood transfusion, iron chelation drugs, laboratory tests, treatment of side effects, periodic visits, and indirect costs such as the costs of lost opportunities as well as lost welfare and quality of life. Since health care funders are seeking to control the costs and effectively allocate the resources, having knowledge of the invested costs for thalassemic patients is essential for optimal allocation of resources in this sector. Due to the changes in medications and the survival of thalassemic patients, the costs in this sector have changed significantly compared to previous years. Therefore, the aim of

this study was to estimate comprehensively the costs and encomic burdens that affects the families of thalassemia children (Esmaeilzadeh et al., 2015).

If the children with thalassemia major are not treated they usually die between the age of one and eight years old. These patients have to be treated the whole time their lives. The only treatment for the patient of thalassemia major is bone-marrow transplantation. The procedure of bone-marrow transplantation is very expensive costing more than two million rupees. It is necessary that to have full compatible donor with tissues that match correct compatible donor with tissues that match the thalassemia patient exactly. Most likely the donors can be of a brother or a sister of thalassemia major patient. Health care funders including governments, social security funds, and insurance companies are struggling to meet the rising costs of medical treatments. Expenditure on drug therapy is a particular target for their attention for several reasons such as the size of the drug bill; the ease of measurement of pharmaceutical costs and evidence of wasteful prescribing (Walley, 2004).

Results of this study can be effective to control, manage the costs, and provide efficient treatments that are taking place in different sectors to care for thalassemic patients. Furthermore, being aware of the treatment costs of the patients with major thalassemia can help making decisions for screening programs.

1.3. The statement of Problem:

Study of the Encomic Burdens that affects the Families of Thalassemia Children in General Center for the Treatment of Thalassemia at Misan City.

1.4. Objectives of The Study:

The specific objectives were to:

1) Examine relationships between economic burdens that affects the families of Thalassemia and their perceived socio-demographic related data.

2)To identify the Encomic Burdens that affects the Families of Thalassemia Children in General Center for the Treatment of Thalassemia at Misan City.

3)Identify factors predicting that affects the families of Thalassemia children.

1.4. Definitions of The Term:

1.4.1 Study:

Theortical defintion: Study is the act of learning and spending time discovering information or an academic work or investigation about a particular thing or subject area (https://www.merriam-webster.com/dictionary/study).

Operational defintion: Study is the activity or process of learning about something by reading, memorizing facts, attending school, etc.

1.4.2 Encomic Burdens:

Theortical defintion: Refers to the costs required to deal with a specific situation (e.g., disease burden) (https://www.merriam-webster.com/dictionary/burden).

Operational defintion: In medicine, a term used to describe problems a patient has related to the cost of medical care.

1.4.3 Families:

Theortical defintion: family is a group of people related either by consanguinity (by recognized birth) or affinity (by marriage or other relationship). The purpose of families is to maintain the well-being of its members and of society(Donald Collins; Catheleen Jordan; and Heather Coleman (2010).

Operational defintion: The family may be considered a separated open population system composed of varying number of individuals.

1.4.4. Thalassemia:

Theortical defintion: The thalassemias are hereditary disorders characterized by a decrease in the synthesis of globin chains (alpha or beta). Impaired globin chain synthesis causes impaired production of hemoglobin and eventually results in a hypochromic microcytic anemia because of defective hemoglobinization of the red blood cells (Weatherall, 2010b).

Operational defintion: Thalassemia is an inherited blood disorder in which the body makes an abnormal form of hemoglobin.

1.4.5 Children:

Theortical defintion: child is a human being between the developmental period of infancy and puberty.(Rathus SA,2013).

Operational defintion: as anyone who has not yet reached their 18th birthday.

1.4.6 Treatment:

Theortical defintion: Treatment the action or way of treating a patient or a

condition medically or surgically.(https://www.merriam webster.com/dictionary/treatment).

Operational defintion: The application of medicines, surgery, therapy, etc., in treating a disease or disorder.

Chapter Two
Review of Literatures

Review of Literatures:

This chapter present literatures and previous studies related to Thalassemia**.**

2.1. Background:

Thalassemia is an inherited disorder of autosomal recessive gene disorder caused by impaired synthesis of one or more globin chains. The impairment alters production of hemoglobin (Hb) **(**Ridolfi et al., 2002).

These hematologic disorders range from asymptomatic to severe anemia that can cause significant morbidity and mortality. It was first recognized clinically in 1925 by Dr. Thomas Cooley, who described a syndrome of anemia with microcytic erythrocytes. Then it was called Cooley's anemia. Later Wipple and Bradford renamed this disease as "Thalassemia". Because it was found in the region of the Mediterranean Sea (thalasa is an old Greek word for sea) (Cooley, 1946).

Thalassemias can cause significant problems because these are inherited disorders, newborn screening and prenatal diagnosis are important in management of patients. This topic will review the clinical features of thalassemia while focusing on pathophysiology, clinical features, complication, management, screening and diagnosis. Depending upon the globin chain involvement, thalassaemia is categorized into alpha-thalassaemia and beta thalassaemia. Beta thalassaemia is further classified as beta-thalassaemia major, intermedia and minor, on the basis of clinical severity and inheritance pattern. (Kukreja et al., 2009).

It is a blood disorder passed down through families (inherited) in which the body makes an abnormal form of hemoglobin. This disorder results in excessive destruction of red blood cells, and there is no effective treatment. Patients require lifelong blood transfusion, usually started within 6 to 12 months of birth of patient, which on other hand has its own complications. It is a chronic disease that manifests

so early in life that it leads to psychological and social problems for parents . We focused on parents to assess the impact of their child's disease Aziz1 et al., 2012).

The types of thalassemia major is an inherited hematological disorder leading to anemia in affected children. It is an autosomal recessive disease in which chromosome 11 is involved. It affects synthesis of the B globin chain of hemoglobin, which is either decreased or absent, leading to an early turnover of Red Blood Cell (RBC). When one of the beta globin chain genes is normal and other abnormal, it is Thalassemia minor. If both the genes are involved and disorder presents later in life (older children and adults), it is called as Thalassemia intermedia. If both the genes are involved and disorder is manifested early in life (infants) it is called as Thalassemia major which is a more aggressive disease. Abnormal shaped RBCs are rapidly destroyed by the reticuloendothelial system, particularly the spleen leading to micro crystal hypo chronic anemia and iron overload.(Porecha, 2010).

It is a disease which needs lifelong therapy. Thalassemia therapy includes regular blood transfusion, administration of several medications such as iron chelating agents and other concomitant medications.(Jelvehgari and Mashayekhi, 2004).

Significant advances have been made over the years on thalassaemia leading to better understanding of genetic control of haemoglobin, the abnormalities in the different forms, the pathophysiology of the disease and hence improvement in treatment. (Weatherall and Clegg, 2001).

This marked development in the diagnosis and management has not been matched by progress in psychosocial rehabilitation of thalassaemia patients. Worldwide, thalassemia poses a serious public health problem due to the high prevalence. It extends from the Mediterranean basin and parts of Africa, throughout the Middle East, the Indian Sub-continent, South-East Asia, Melanesia and into the

Pacific Islands, with reported rates ranging from 2% to 25%. Each year, 50,000 to 100,000 children die of thalassemia major in low and middle income countries, while about 7% of the world's population is a carrier of a hemoglobin disorder (Kuo et al., 2006).

2.2. Pathophysiology:

Hemoglobin (Hb) is the molecule that carries and transports oxygen all through the body. Normal human hemoglobin is a tetramer formed by two pairs of globin chains attached to heme. The hemoglobin type is determined by the combination of tetra-globin chains (α, β, δ, and γ chains). Each globin chain is structurally different and thus has different oxygen affinity, electrical charge, and electrophoretic mobility. Normal adult hemoglobins are expressed as A_2, A and F (fetal). Ninety-five to ninety-eight percent of adult hemoglobin is A the major hemoglobin, which consists of two α- and two β-chains (α_2, β_2). Hemoglobin A_2 (α_2, δ_2), the remainder of hemoglobin in adults is a minor component (less than 3.3%), and 1% or less of F (α_2, γ_2) (Nathan & Oski, 1993).

The gamma hemoglobin (Hb-F) is the predominant hemoglobin found only during fetal development. The equal production of α and non-α (β, δ, γ) globin chains is necessary for normal red blood cell (RBC) function. The failure in hemoglobin synthesis is a main cause of microcytosis and anemia in many population groups around the world. Hb variants are characterized by the gene mutation of the globin chains form hemoglobin (i.e., the replacement of different amino acids at a certain position). Thalassemia occurs when there is decreased or absent production of one of the types of globin chains (most commonly either α or β), that cause insufficeient amount of normal structure globin chains. This results in an imbalance between α- and β-chains and causes the clinical features of thalassemia (Nathan & Gunn, 1966).

(Figure 1) In severe -thalassemia, IE results in expanded marrow cavities that impinge on normal bone and cause distortion of the cranium, and of facial and long bones. In addition, erythroid activity proliferates in extramedullary hematopoietic sites, causing extensive lymphadenopathy, hepatosplenomegaly, and, in some cases, extramedullary tumors.(giardina and foeget, 2008).

Severe IE, chronic anemia, and hypoxia also cause increased gastrointestinal (GI) tract iron absorption. Without transfusion support, 85% of patients with severe homozygous or compound heterozygous -thalassemia will die by 5 years of age because of severe anemia.(schwartz, 1989).

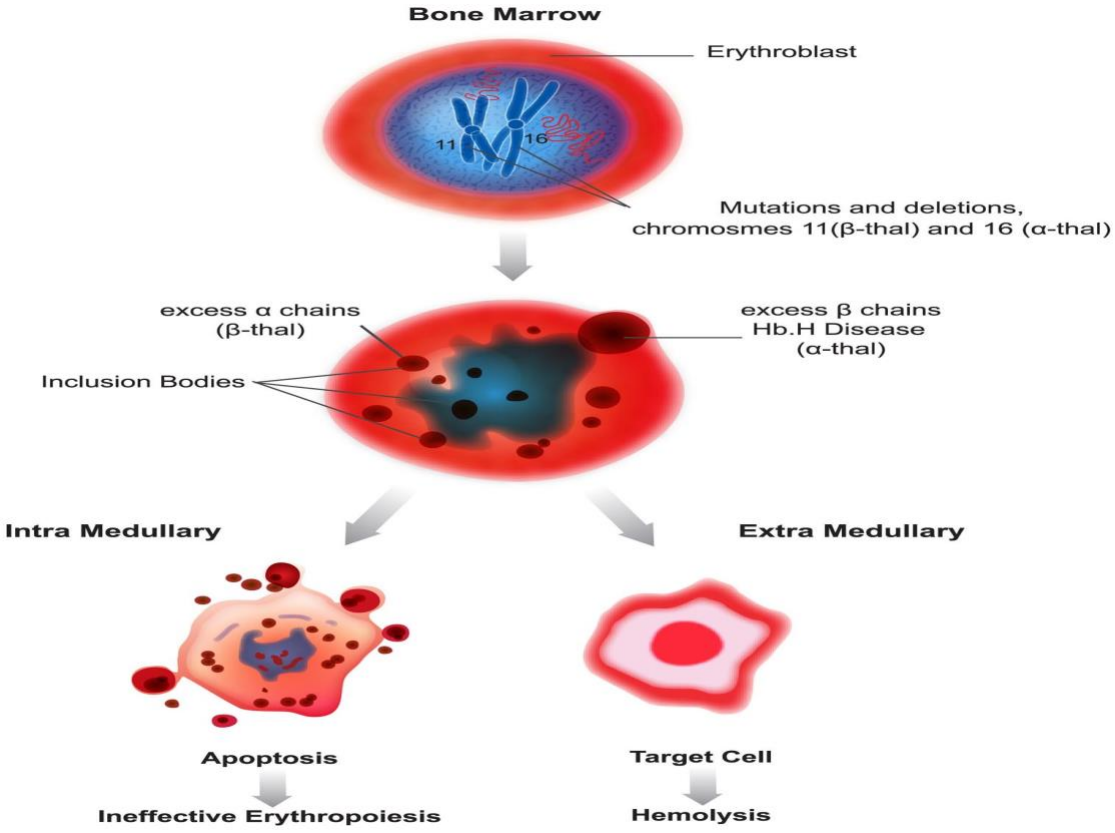


Figure 1. Mechanism of IE and hemolysis in thalassemia.

2.3. Classification:

Thalassemia is due to decreased production of one or more globin chains. The most important types are those that affect either alpha or beta chain synthesis.

2.3.1. ALPHA THALASSEMIA:

Alpha thalassemia is the result of deficient or absent synthesis of alpha globin chains, leading to excess beta globin chains. Alpha globin chain production is controlled by two genes on each chromosome 16 . Deficient production is usually caused by a deletion of one or more of these genes. A single gene deletion results in alpha thalassemia silent carrier status, which is asymptomatic with normal hematologic findings. The twogene deletion causes alpha thalassemia trait (minor) with microcytosis and usually no anemia. The three- gene deletion results in significant production of hemoglobin H (HbH), which has four beta chains (beta4). Alpha thalassemia intermedia, or HbH disease, causes microcytic anemia, hemolysis, and splenomegaly. The four-gene deletion results in significant production of hemoglobin Bart's (Hb Bart's), which has four gamma chains (gamma4). Alpha thalassemia major with Hb Bart's usually results in fatal hydrops fetalis.(Herbert et al., 2009). **2.3.2.**

BETA THALASSEMIA:

Beta thalassemia is the result of deficient or absent synthesis of beta globin chains, leading to excess alpha chains. Beta globin synthesis is controlled by one gene on each chromosome 11. Beta thalassemia occurs from any of more than 200 point mutations and (rarely) deletions of the two genes. Beta globin chain production can range from near normal to completely absent, leading to varying degrees of excess alpha globin to beta globin chain production. The one gene defect, beta thalassemia trait (minor), is asymptomatic and results in microcytosis and mild anemia. If the synthesis from both genes is severely reduced or absent, the person has beta thalassemia major, also known as Cooley anemia. Persons with beta thalassemia major are almost never symptomatic at birth because of the presence of HbF but symptoms begin to develop by six months age if the synthesis of beta chains is less severely reduced, the person has beta thalassemia intermedia. These persons experience symptoms that are less severe and do not require lifelong transfusions to survive past 20 years of age (Table 2) (Herbert et al., 2009).

Table 1. Prototypical Forms of Alpha Thalassemia (Chui DH, Fucharoen S, Chan V. 2003)

Variant	*Chromosome 16*	*Signs and symptoms*
Alpha thalassemia silent carrier	One of four gene deletions	Asymptomatic
Alpha thalassemia trait	Two of four gene deletions	Asymptomatic
Hemoglobin Constant Spring	Reduced output of alpha globin	Silent or mildly symptomatic
Alpha thalassemia intermedia with significant hemoglobin H (hemoglobin H disease)	Three of four gene deletions	Moderate to severe hemolytic anemia, modest degree of ineffective erythropoiesis, splenomegaly, variable bone changes[4]
Alpha thalassemia major with significant hemoglobin Bart's	Four of four gene deletions	Causes nonimmune hydrops fetalis, usually fatal[5]

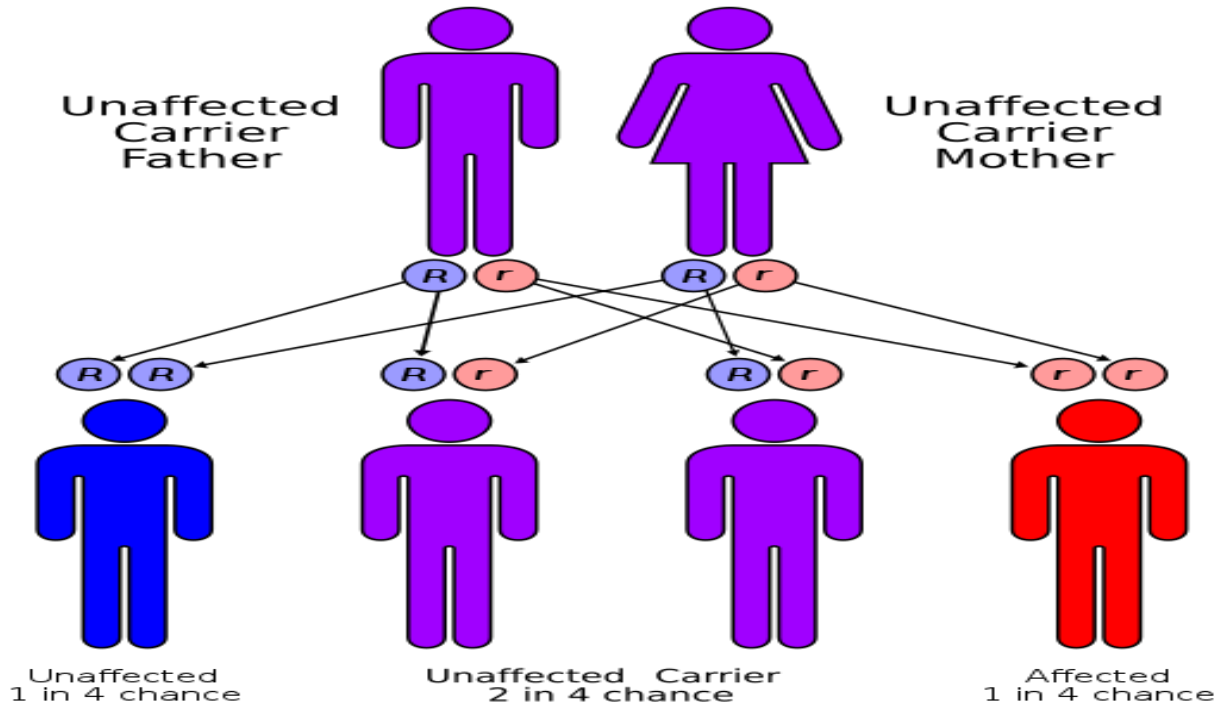
Table 2. Prototypical Forms of Beta Thalassemia (Olivieri NF.1999)

Variant	*Chromosome 11*	*Signs and Symptoms*
Beta thalassemia trait	One gene defect	Asymptomatic
Beta thalassemia intermedia	Two genes defective (mild to moderate decrease in beta globin synthesis)	Variable degrees of severity of symptoms of thalassemia major
Beta thalassemia major	Two genes defective (severe decrease in beta globin synthesis)	Abdominal swelling, growth retardation, irritability, jaundice, pallor, skeletal abnormalities, splenomegaly; requires lifelong blood transfusions[6]

2.4.Causes:

Both α- and β-thalassemias are often inherited in an autosomal recessive manner. Cases of dominantly inherited αand β-thalassemias have been reported, the first of which was in an Irish family with two deletions of 4 and 11 bp in exon 3 interrupted by an insertion of 5 bp in the βglobin gene. For the autosomal recessive forms of the disease, both parents must be carriers for a child to be affected. If both

parents carry a hemoglobinopathy trait, the risk is 25% for each pregnancy for an affected child. **figure 2.** (Thalassemia wikipedia).



Figuere 2 Thalassemia has an autosomal recessive pattern of inheritance.

2.5. Screening and diagnosis

2.5.1. Screening and diagnosis for hemoglobin variants and thalassemia

There are many techniques that have been used to screen and diagnose for hemoglobin variants and thalassemia, mostly done in combinations. These techniques were ranging from screening to extensive analysis, including a few indirect studies. Screening techniques can indicate a defect in hemoglobin synthesis. Positive results from these tests need confirmation by a more extensive analysis technique. Negative results normally help in cutting down the number of subjects that need to be further diagnosed by a more advanced and complicated testing. Extensive analysis techniques can give more precise information in types of thalassemia or types of Hb variants. They normally perform with higher instruments

and technologies, and therefore are more expensive than screening techniques. The flow chart shown in Fig 2 summarizes the techniques for diagnosis of thalassemia and hemoglobinopathies that are commonly used in most laboratories.

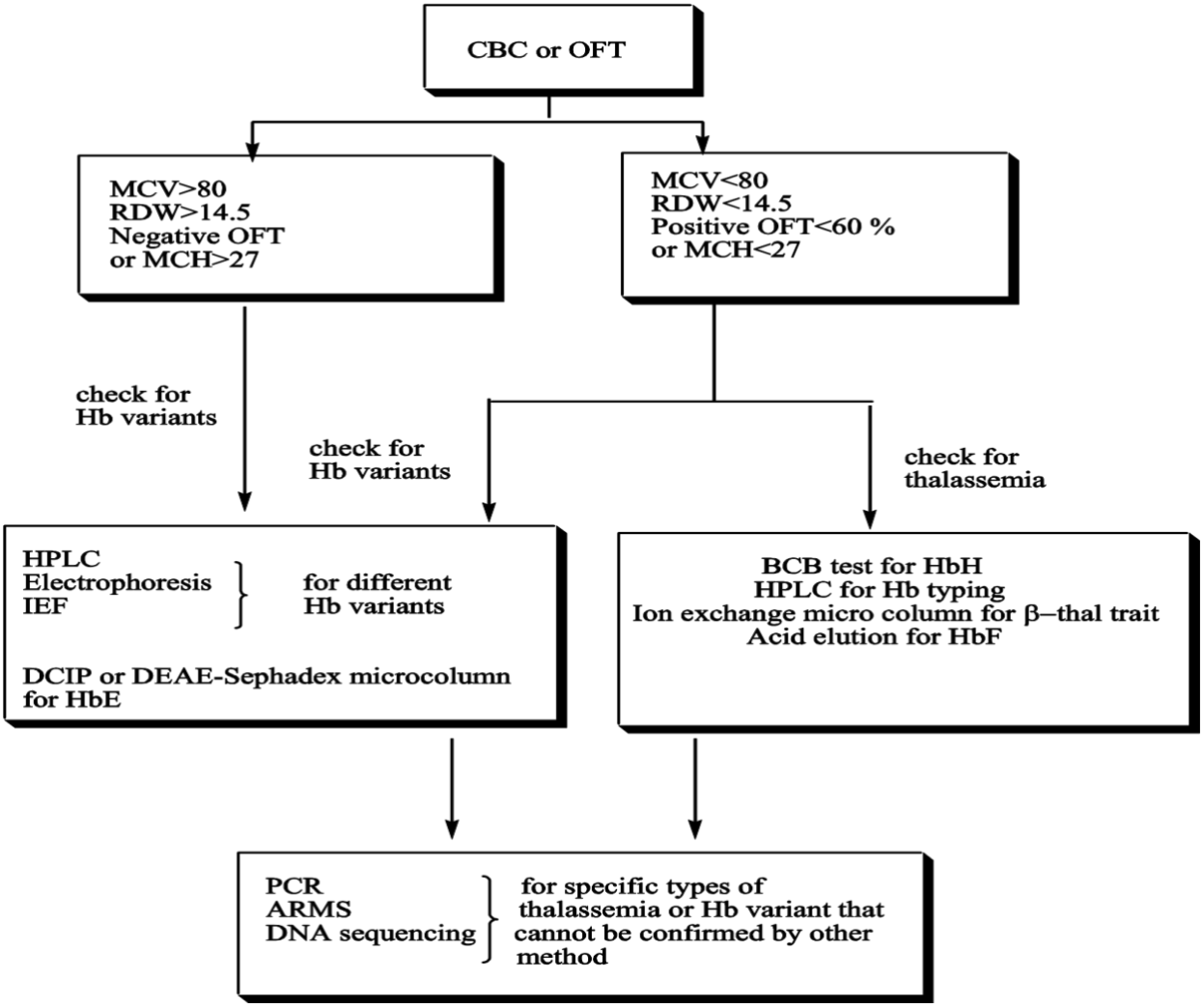


Fig. 2.The summerised chart of normal process of hemoglobin variants and thalassemia

2.5.2. Complete blood count (CBC):

Complete blood count, a primary screening for thalassemia used an electronic blood-cell counter to provide accurate erythrocyte indices as the characteristics of the blood (Hillman & Ault, 1980). The main features of the blood

tested in the CBC are the total white blood cell count (WBC), red blood cell count (RBC), hematocrit (Hct), hemoglobin (Hb), red cell distribution width (RDW), peripheral blood smear and other important erythrocyte indices (EI), included mean corpuscular volume (MCV), mean corpuscular hemoglobin (MCH), and mean corpuscular hemoglobin concentration (MCHC) (Klee et al., 2000).

Among these parameters, MCV and MCH are the most important indicies that can indicate the existence of thalassemia trait, i.e., when individuals who have hypochromic microcytosis with MCV< 80 fL and MCH< 27 pg should be investigated further. Many laboratories use a CBC autoanalyzer which can provide many blood parameters (such as MCH, MCV, RDW) also be added along with osmotic fragility test an alternative screening test for specific thalassemia testing.

2.6.Management of β-thalassemia major:

2.6.1.Transfusions:

Goals of transfusion therapy are the primary means of treatment for patients with severe βthalassemia for correction of anemia, suppression of erythropoiesis and inhibition of gastrointestinal iron absorption, which occurs in non transfused patients as a consequence of an increased ineffective erythropoiesis. The decision to start transfusion in patients with confirmed diagnosis of thalassemia should be based on the presence of severe anemia (Hb < 7 g/dl for more than two weeks, excluding other contributory causes such as infections). However, also in patients with Hb > 7 g/dl, other factors should be considered, including facial changes, poor growth, evidence of bony expansion and increasing splenomegaly. Post-transfusion Hb level of 9 to 10 g/dl - 13 to 14 g/dl prevents growth impairment, organ damage and bone deformities, allowing normal activity and quality of life The frequency of transfusion is usually every two to four weeks. Shorter intervals might further reduce the overall blood requirement, but are incompatible with an acceptable quality of

life. The amount of blood to be transfused depends on several factors including weight of the patient, target increase in Hb level and hematocrit of blood unit. Appropriate graphs and formulae to calculate the amount of blood to be transfused are available (Thalassemia International Federation: Guidelines for the clinical management of thalassemia 2nd edition. 2008 [http://www.thalassemia.org.cy], BorgnaPignatti & Galanello, 2004).

In general, the amount of transfused RBC should not exceed 15 to 20 ml/kg/day, infused at a maximum rate of 5 ml/kg/hour, to avoid a fast increase in blood volume. To monitor the effectiveness of transfusion therapy, some indices should be recorded at each transfusion, such as pre- and posttransfusion Hb, amount and hematocrit of the blood unit, daily Hb fall and transfusional interval. These measurements enable two important parameters to be calculated: red cell requirement and iron intake. Hypertransfusion and iron chelation is the standard therapy for thalassemia major. These transfusion regimens will provide a marked improvement in survival, growth and sexual development, prevent disfiguring bony abnormalities, decrease cardiac effort, and limit the development of hepatosplenomegaly.

2.6.2. Assessment of iron overload:

Patients maintained on a regular transfusion regimen progressively develop clinical manifestations of iron overload: hypogonadism (35-55% of the patients), hypothyroidism (911%), hypoparathyroidism (4%), diabetes (6-10%), liver fibrosis, and heart dysfunction (33%) (Cunningham et al., 2004, Borgna-Pignatti et al., 2004). Iron status should be accurately assessed in order to evaluate its clinical relevance, the need for treatment, and the timing and monitoring of chelation therapy. The iron status of multitransfused patients can be assessed by several methods. Serum ferritin has in general been found to correlate with body iron stores (Brittenham et al., 1993).

However, as a single value it is not always reliable because, being an acute phase reactant, it is influenced by other factors such as inflammatory disorders, liver disease, malignant. Despite this, serial measurements of serum ferritin remain a reliable and the easiest method to evaluate iron overload and efficacy of chelation therapy. Determination of liver iron concentration in a liver biopsy specimen shows a high correlation with total body iron accumulation and is considered the gold standard for the evaluation of iron overload (Angelucci et al., 2000).

However, liver biopsy is an invasive technique with the possibility (though low) of complications. Moreover, we should consider that the presence of hepatic fibrosis, which commonly occurs in individuals with iron overload and HCV infection, and heterogeneous liver iron distribution can lead to possible false negative results (Villeneuve et al., 1996).

2.6.3.Bone marrow and cord blood transplantation:

Bone marrow transplantation (BMT) from HLA-identical donors has been successfully performed worldwide. BMT remains the only definitive cure currently available for patients with thalassemia. The outcome of BMT is related to the pretransplantation clinical conditions, specifically the presence of hepatomegaly, extent of liver fibrosis, history of regular chelation and hence severity of iron accumulation. In patients without the above risk factors, stem cell transplantation from an HLA identical sibling has a disease free survival rate over 90% (Gaziev & Lucarelli, 2003).

The major limitation of allogenic BMT is the lack of an HLAidentical sibling donor for the majority of affected patients. In fact, approximately 25-30% of thalassemic patients could have a matched sibling donor. BMT from unrelated donors has been carried out on a limited number of individuals with β-thalassemia. Provided that selection of the donor is based on stringent criteria of HLA

compatibility and that individuals have limited iron overload, results are comparable to those obtained when the donor is a compatible sib (La Nasa et al., 2005).

2.7.Complications:

2.7.1. Complications of Transfusion:

In developed countries, patients are now given routine transfusion therapy, which has lengthened survival and altered the clinical course of the disease. Assessment and treatment of iron overload patients maintained on a regular transfusion regimen progressively develop clinical manifestations of iron overload. Iron overload of tissue is fatal with or without transfusion if not prevented or adequately treated. It is the most important complication of β-thalassemia and is a major focus of management (Olivieri & Brittenham, 1997).

Iron status should be accurately assessed in order to evaluate its clinical relevance, the need for treatment, and the timing and monitoring of chelation therapy. After approximately one year of transfusions, iron begins to be deposited in parenchymal tissues (Risdon et al., 1973), where it may cause substantial toxicity as compared with that within reticuloendothelial cells (Hershko &Weatherall 1988, Hershko et al., 1998).

2.7.2. Iron overload-related complications:

Iron overload of tissue with or without transfusion is fatal, which is the most important complication of β-thalassemia if not prevented or adequately treated, which is a major focus of management (Olivieri & Brittenham, 1997). In patients who are not receiving transfusions, abnormally regulated iron absorption results in increases in body iron burden, depending on the severity of erythroid expansion (Pippard et al., 1979, Pootrakul et al., 1988).

Regular transfusions may double this rate of iron accumulation. Most clinical manifestations of iron loading do not appear until the second decade of life in patients with inadequate chelation. After approximately one year of transfusions, iron begins to be deposited in parenchymal tissues, (Risdon et al., 1973). Endocrine abnormalities related to iron overload include diabetes mellitus and impaired glucose tolerance, adrenal insufficiency, hypothyroidism, osteoporosis, hypoparathyroidism and hypogonadism (Fosburg & Nathan, 1990).

2.8. Splenectomy:

If the annual red cell requirement exceeds 180-200 ml/Kg of RBC (assuming that the Hct of the unit of red cells is about 75%), splenectomy should be considered, provided that other reasons for increased consumption, such as hemolytic reactions, have been excluded. Other indications for splenectomy are symptoms of splenic enlargement, leukopenia and/or thrombocytopenia and increasing iron overload despite good chelation (Weatherall & Clegg, 2001).

2.9.The impact of thalassemia:

2.9.1.Psychological impact of thalassemia

Having thalassemia is a burden for the patient and his family. Lifelong treatment with increasing risk of morbidity and complications over time affects patient's mental health. An observational study has showed higher rate of psychiatric disorder in thalassemia patients as compared to the general population . (Mednick et al.,2010). Patients with thalassemia major have higher prevalence of psychiatric disorders, and therefore, are likely to exhibit lower treatment adherence. Psychological disorders range from anxiety, depression, attention-deficit hyperactivity disorder, to bipolar mood disorder. Ghanizadeh found more than 43% of the patients with thalassemia had recurrent thoughts of suicide and 27.3% had considered suicide in the last year .(Ghanizadeh, 2006).

2.9.2.The Financial and Social Impact of Thalassemia and Its Treatment

Thalassemia treatment costs are very high and much of the costs are related to the drugs received by the patients. Most of the costs of drugs are related to iron chelation and Deferoxamine drugs. The insurance coverage of the services received by thalassemia patients is relatively low. Patients with thalassemia major pay a lot of money to receive the services and this can lead to catastrophic expenditures for them.

2.10. Previous studies:

Several studies that similar to our study have been showed different result;

First study was made by Mohammadreza Sattari, Dorna Sheykhi, Alireza Nikanfar, Abasali Hosseyn Pourfeizi, Maryam Nazari, Roya Dolatkhah, Simin Mashayekhi and their study aimed to examine the economic burden of thalassemia treatment in Iran, They use All thalassemic patients, registered at two hematology clinics of Tabriz in 2009 were invited to the study. Those who consented (100 patients) completed a simple questionnaire. The Results of their study found The total cost of treating thalassemia was €1,730.52 per patient/year. Total annual direct cost was €146,621.49 and indirect cost was €26430.22 for 100 patients. Blood transfusion and nursing charges were the most costly expenditures. It is estimated that up to €26 million/year is spent for treatment of all registered thalassemic patients in Iran.

Conclusion of This study showed that a large amount of money is paid for thalassemia treatment by the government and patients. When the income of an average Iranian is considered, the magnitude of problem emerges.

Second study made by ,Kamran Ishfaq, Salman Bin Naeem and Johar Ali about socio-economic factors of thalassemia major on patientś families a case study of the childrenś hospital and the institute of child health multan'pakistan. The objectives of the study were to identify the awareness among the parents regarding thalassemia

major, to describe the cost on treatment of thalassemia major children and the sufferings it brings to the families. A total of 200 subjects were interviewed to obtain the data with the help of convenient sampling. The participants of the study were parents of the thalassemia major children. Results showed that the majority of the respondents were illiterate and study summarized that without proper health education it is difficult for parents to know the exact nature of this deadly disease. So the parents of major thalassemia patients and general public should be sensitized in this regard.

Third study was about economic burden of beta-thalassemia/Hb E and beta-thalassemia major in Thai children was done by Arthorn Riewpaiboon, Issarang Nuchprayoon, Kitti Torcharus, Kaemthong Indaratna,Montarat Thavorncharoensap, Bang-on Ubol. The aim of this study was to analyze the societal cost of caring for children with b-thalassemias in Thailand. The study was designed as a prevalence-based cost-of-illness analysis in a societal perspective. Medical records from three public hospitals of children aged 2-18 years with b-thalassemia/Hb E and homozygous b-thalassemia were reviewed for direct medical cost determination. For direct non-medical cost and indirect cost, a family member was interviewed.

Findings of their study was found that 201 patients with b-thalassemia/Hb E (91%) and homozygous b-thalassemia (9%) were recruited for this study. Ninety-two (46%) were severe thalassemia and 109 (54%) were mild to moderate severity. The annual average cost of treatment was US$950; 59% was direct medical cost, 17% direct non-medical cost, and 24% indirect cost. The costs were differentiated by some potential predictors. Significant predictor variables were: hospital, health insurance scheme, blood transfusion pattern, and iron chelation drug use.

The Conclusions of study showed The average annual cost per patient was calculated, and the cost model was estimated. These would be applied for national

planning, economic evaluation of treatment and prevention interventions, and budget impact analysis.

Chapter Three
Methodology

Chapter three

Methodology

This chapter contains research approach, study design, the sampling technique, development and description of the tool, data collection and plan of analysis.

3.1 Research approach

Descriptive survey approach was used in this study

3.2 Setting of the study

The study was conducted in Department of Pediatrics, General center of Thalassemia , Maysan.

3.3 Study population

Populations of the study were the parents of children thalassemia.

3.4 Sample and sampling techniques

Convenient sampling was done for this study; 53 samples collected representing to the parents of children thalassemia. The total period of study lasted five months started from 2020/ 11/10 and ended in 2021 / 5/10.

3.5-Description of the tools

The tools used in this study contains : appendix A

First part of questionnaire :Demographic data.

consisted of (12) items, which include, age, gender, number of family members, ordinal of the child, educational level of mother, educational level of father, occupation status of mother, occupation status of father, economic status, social status of the family, type of family and type of house.

Second part of questionnaire: **specific information to sample research.** That contains of (26) items, which included question regarded related to the parents of children thalassemia and questions about the introduction, causes, signs and symptom , nursing care and treatment of thalassemia.

3.6-Data collection

Formal permission obtained from the authorities for the collection of data. conducted at the Department of Pediatrics, General center of Thalassemia , Maysan, on the registered cases of patients. Before the conduction of the interviews, informed consent was obtained from the parents or attendants of all participants and explained the need and purpose of the study.

3.7-Data Analyses

Data was analyzed statistically by means of Portable IBM SPSS Statistics (Statistical Package for the Social Sciences) version 20. The researcher used descriptive statistics, which include frequency, percent, mean and chi X.

Chapter Four
Results of the Study

4- Results and Findings:

This chapter presents the findings of the data analysis systematically in tables and these correspond with the objectives of the study as follows:

Table (1): Distribution of the Study Sample by their Demographic characteristics the parents of children thalassemia. (n= 53 child)

No.	Variables	Characteristics	Frequency	Percent
1-	Age (year)	1-5	10	18.9
		6-10	16	30.2
		11-15	15	28.3
		16-20	12	22.6
		Total	**53**	**100.0**
2-	Gender	**Male**	33	62.3
		Female	20	37.7
		Total	**53**	**100.0**
3-	Number of family members	1-5 yrs	13	24.5
		6-10 yrs	37	69.8
		11-15 yrs	3	5.7
		Total	**30**	**100.0**
4-	Ordinal of the child	1 rank	28	52.8
		2 rank	20	37.7
		3 rank	2	3.8
		4 rank	3	5.7
		Total	**30**	**100.0**
5-	Educational level of mother	**Do not read or write**	16	30.2
		Read and write	2	3.8
		Primary	20	37.7
		Secondary	15	28.3
		Total	**30**	**100.0**
6-	Educational level of father	**Do not read or write**	7	13.2
		Read and write	2	3.8
		Primary	26	49.1
		Secondary	11	20.7
		Institute or college	7	13.2
		Total	**53**	**100.0**
7-	Occupation status of mother	**Employment**	2	3.8
		Unemployment	51	96.2
		Total	**53**	**100.0**

8-	**Occupation status of father**	**Employment**	30	56.6
		Unemployment	**23**	**43.4**
		Total	**53**	**100.0**
9-	**Economic status**	**Good**	3	5.7
		Moderate	39	73.6
		Poor	11	20.8
		Total	**53**	**100.0**
10-	**Social status of the family**	**One of them died**	3	5.7
		Death of parents	1	1.9
		Parents are together	49	92.5
		Total	**30**	**100.0**
11-	**Type of family**	**Nucleus**	41	77.4
		Extended	12	22.6
		Total	**30**	**100.0**
12-	**Type of house**	**owned**	24	45.3
		rent	21	39.6
		other	8	15.1
		Total	**30**	**100.0**

No. = number of Variable , n = number of sample, ≥ = more than and equal .

The results of this table show that more of the children in age group to the study sample were within (6-10) years was (30.2%). The above table also shows that the majority of participants were male (62.3%). %). Also in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%), and most of the children involved in this study are ranked first in the family (52.8%). Also in regarding to the subjects level of education of mother, the results show that more level of them has primary graduates (37.7%), As well as for the educational level of the father will be among the graduates of the primary (49.1%). In addition, the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%). majority of teachers for occupational status in the study sample were employment (73.3%), while the

economic status presented that the majority in the study sample were moderate (73.6). In regarding to the social status shows that the majority of participants were parents are together (92.5%). Also, with regard to the results of this table, most of the children participating in this study are from single families (77.4%). Finally, in the table above, the results showed that the majority of participants live in homes owned by them (45.3).

Table (2): Distribution of the participants' level of economic status through the Mean of questions related to the parents of children thalassemia.

Level of economic status	Frequency	Percent
Poor	18	34.0%
Moderate	26	49.1%
Good	9	17.0%
Total	**53**	**100.0 %**

Assessment Level : 1-1.66 = Low; 1.67-2.33 = Moderate; 2.34-3.00 = High

This table reveals that the majority of participants have moderate level of parents' economic status (n=26; 49.1%).

Table (3): Cross-tabulation and Correlation between the effect of economic burden toward parents' children of thalassemia and their occupational status of father.

Occupation status of father		Economic			Total
		Never	sometimes	Always	
Employment	F	14	13	3	30
	%	26.4%	24.5%	5.7%	56.6%
Unemployment	F	4	13	6	23
	%	7.6%	24.5%	11.3%	43.4%
Total	F	18	26	9	53
	%	34.0%	49.0%	17.0%	100.0%
χ^2obs.= 14.860	χ^2crit. =9.958	df=4	p value=0.04	P < 0.05	

The results of data analysis, as presented in table (6) revealed that there was high significant relationship between the parents' economic status toward children of thalasemia and their Occupation status of father at (P < 0.05) ,when analyzed by chi-square test.

Table (4): Cross-tabulation and Correlation between the economic burden toward parents' children of thalassemia and their economic status.

Economic Status		Economic burden			Total
		Never	sometimes	Always	
Good	F	0	3	0	3
	%	0.0%	5.7%	0.0%	5.7%
Moderate	F	14	21	4	39
	%	26.4%	39.6%	7.5%	73.6%
Poor	F	4	2	5	11
	%	7.5%	3.8%	9.4%	20.8%

Total	**F**	18	26	9	53
	%	34.0%	49.1%	17.0%	100.0%
χ^2obs.= 11.787	**χ^2crit. =9.944**	**df=4**	**p value=0.01**	**P < 0.05**	

The results of data analysis, as presented in table (7) revealed that there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status at (P > 0.05) ,when analyzed by chi-square test.

Table (5): Association between the effect of economic burden toward parents children of thalassemia and their type of housing.

Type of housing		**Economic burden**			**Total**
		Never	**sometimes**	**Always**	
owned	**F**	3	18	3	24
	%	5.7%	34.0%	5.7%	45.3%
rent	**F**	12	5	4	21
	%	22.6%	9.4%	7.5%	39.6%
other	**F**	3	3	2	8
	%	5.7%	5.7%	3.8%	15.1%
Total	**F**	18	26	9	53
	%	34.0%	49.1%	17.0%	100.0%
χ^2obs.= 13.486	**χ^2crit. =9.488**	**df=4**	**p-value=0. 000**	**P < 0.05**	

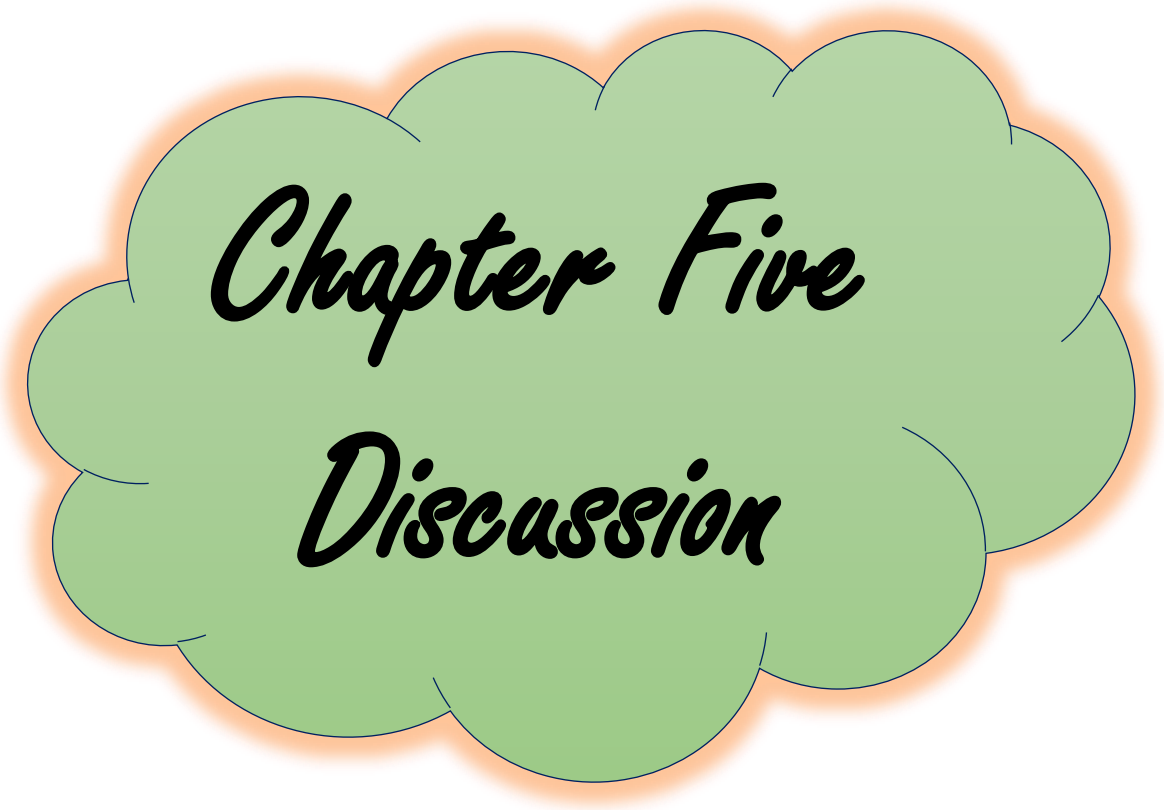
The results of data analysis, as presented in this table, indicates that there was a high significant relationship between the effect of economic burden toward parents children of thalassemia and their type of housing at (P < 0.05) ,when analyzed by chi-square test.

Table (6): Association between the effect of economic burden toward parents children of thalassemia and their type of family.

Type of family		Economic burden			Total
		Never	sometimes	Always	
Nucleus	F	17	20	4	41
	%	32.1%	37.7%	7.5%	77.4%
Extended	F	1	6	5	12
	%	1.9%	11.3%	9.4%	22.6%
Total	F	18	26	9	53
	%	34.0%	49.1%	17.0%	100.0%

χ^2obs.= 8.570 χ^2crit. =5.991 df=2 P value=0. 01 P > 0.05

The results of data analysis, as presented in this table, indicates that there was a significant relationship between the effect of economic burden toward parents children of thalassemia and their type of family at ($P < 0.05$) ,when analyzed by chi-square test.


Chapter Five
Discussion

Chapter Five

Discussion of the Study Results

This chapter presents a systematically designed interpretation and reasonably derived discussion of the results reported in chapter four. The interpretation of the results in this chapter are supported by available related studies .

5.1. The Demographic characteristics the parents of children thalassemia:

The results of table 1 show that more of the teachers in age group to the study sample were within (6-10) years was (30.2%). The above table also shows that the majority of participants were male (62.3%). %). Also in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%), and most of the children involved in this study are ranked first in the family (52.8%). Also in regarding to the subjects level of education of mother, the results show that more level of them has primary graduates (37.7%), As well as for the educational level of the father will be among the graduates of the primary (49.1%). In addition, the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%). majority of teachers for occupational status in the study sample were employment (73.3%), while the economic status presented that the majority in the study sample were moderate (73.6). In regarding to the social status shows that the majority of participants were parents are together (92.5%). Also, with regard to the results of this table, most of the children participating in this study are from single families (77.4%). Finally, in the table above, the results showed that the majority of participants live in homes owned by them (45.3). this study is agree with Tafash, Saad Ahmed Younis2006 (

Study of the characteristic features of patients with Thalassemia and their relationship to some variables) where the number of males exceeds the number of females and their average age is 8 years.

5.2. The Distribution of the participants' level of economic status to the parents of children thalassemia:

The table 3 reveals that the majority of participants have moderate level of parents' economic status. This study does not apply with its findings from the Mosby Incorporated 1900 study in the care of nursing children with thalassemia. As the majority of patients' families, 53%, have a low monthly income.

5.3. The. Correlation between the effect of economic burden toward parents' children of thalassemia and their occupational status of father :

The results of the **(Table 6 & 7)** revealed that there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status at ($P > 0.05$) ,when analyzed by chi-square test. this study agree with Tafesh, Asaad Ahmad Younis, 2006 (Study the characteristic features of children with thalassemia and their relationship to some variables) There are statistically significant differences in personality traits between children with Thalassemia attributable to the economic level of the family. The MSA test in the fifth and eighth questions. As for the results of the study, they came as follows: The personal traits intended in this study tend to be somewhat positive, with slight differences in the level of availability of these traits in the same gender on the one hand, and between males and females on the other hand.

5.4. Association between the effect of economic burden toward parents children of thalassemia and their type of housing.

The results of data analysis, as presented in table(10 &11), indicates that there was a significant relationship between the effect of economic burden toward parents children of thalassemia and their type of family at ($P < 0.05$) ,when analyzed by chi-square test.in study of Ammar Sidqi Abdul-Ghani Jayyousi, 2008 (Thalassemia disease and related provisions in Islamic jurisprudence) Where he discussed in his study the psychological and economic burdens that affect me. Families and parents of children with thalassemia. As the effects and problems multiply for them then. There were more than one injured child in the family, and this undoubtedly poses more pressure on the family and makes the matter more difficult as the patient needs a long period of treatment that is not limited to only. Blood transfusion and disposal of excess iron in the body can lead to behavioral and social problems in the patient.

Chapter Six Conclusion and Recommendation

Chapter Six
Conclusion and Recommendation

6.1:Conclusions: Regarding to the present study findings, the researcher concludes the following:

- The results of our study show that more of the children in age group to the study sample were within (6-10) years was (30.2%).
- The study also shows that the majority of participants were male (62.3%).
- in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%), and
- The results shows that most of the children involved in this study are ranked first in the family (52.8%).
- Also in regarding to the subjects level of education of mother, the results show that more level of them has primary graduates (37.7%), The findings revealed that the educational level of the father will be among the graduates of the primary (49.1%).
- the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%).
- majority of parents for occupational status in the study sample were employment (73.3%), while the economic status presented that the majority in the study sample were moderate (73.6).
- In regarding to the social status shows that the majority of participants were parents are together (92.5%).

- The study revealed most of the children participating in this study are from single families (77.4%).
- The results showed that the majority of participants live in homes owned by them (45.3).
- In our study the results revealed high significant association between the the parents' economic status toward children of thalasemia and their Occupation status of father.
- The findings in our study revealed The majority of the samples suffer from a low economic level.
- The findings there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status.

6.2. Recommendations :

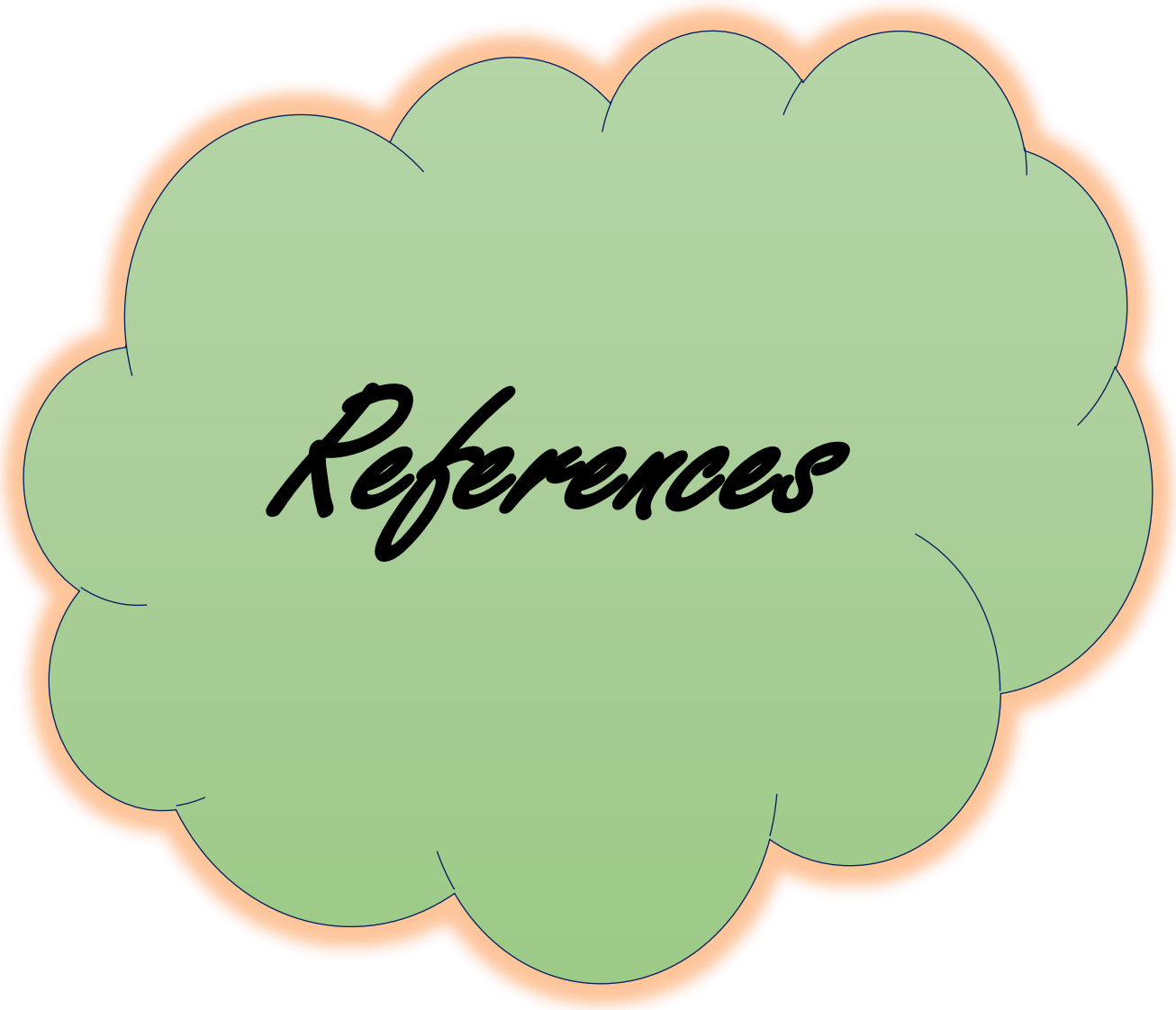
6.2.1. The disease is among the hereditary diseases that are transmitted from parents who carry the disease to their children. Therefore, we recommend blood tests before marriage to avoid infecting children and what complications happen to them that lead to their death.

6.2.2.The necessity of early diagnosis of the disease for the purpose of using appropriate treatment methods to avoid serious complications in the future, such as removing some organs such as the liver, spleen or even the bone marrow.

6.2.3.Helping patients and their families with complete psychological support does not cause them problems that affect them. Their social life

6.2.4. If a person is infected with or is a carrier of thalassemia and you can get married and his offspring do not suffer from this disease, God willing, then he must marry a person who is not infected and also does not transmit the disease.

6.2.5. The Expanding the study of the disease, especially the related economic burdens for poor families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