University of Kerbala/Collage of Nursing

Effectiveness of an Instructional Program on Parents' Knowledge toward Prevention of Iron Overload Complications among Children with Thalassemia

Thesis submitted

To the Council College of Nursing/University of Kerbala, in Partial Fulfillment of the Requirements for the Master Degree in Nursing Sciences

By

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Supervised by

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Safer - 1444 A.H **September - 2022 A.D**

﴿ يَرْفَعِ اللَّهُ الَّذِينَ آمَنُوا مِنْكُمْ وَالَّذِينَ
أُوتُوا الْعِلْمَ دَرَجَاتٍ وَاللَّهُ بِمَا تَعْمَلُونَ
خَبِيرٌ ﴾

"صدق الله العلي العظيم"

Supervisor Certification

I certify that this thesis, which entitled (Effectiveness of an Instructional Program on Parents' Knowledge toward Prevention of Iron Overload Complications among Children with Thalassemia) was prepared under my supervision at the College of Nursing, the University of Kerbala in partial fulfillment of the requirements for the degree of master in nursing sciences.

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Dedication

To my mother with love and respect forever….

To my father with love and respect forever….

To my brothers with love and respect forever….

To my friends and to all who support me to pursue my study thank you so much….

Meaid
2022

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Abstract

Background: Iron overload is disorders associated with excess bodily iron storage and ensuing end-organ damage called iron overload disorders.

Objective: The aim of the study to find out the effectiveness of an instructional program on parents' knowledge toward prevention of iron overload complications in children with thalassemia.

Methodology: The study from October 2021 to July 2022, a quasi-experimental study, non-probability, convenience sample of parent's children with thalassemia was conducted at the Thalassemic Center in Kerbala City.

Results: The results of a study showed that there was most of parents involved were within the age group of (≥25). And the female more than (50.0%) in the study respectively. A high percentage of parents were literate represented (32%). most participant were work represented 60% and most parents living in city represented 60%. Also the results showed the majority of parents 96% had one to two children. The instructional program is effective in the improvement of parent's knowledge regarding prevention of iron overload complications, and significant impact by using post-tests one and posttest two to increase of parents' knowledge in the study group at $p>0.05$. There is not a statistically correlation between knowledge of the parents and their age, gender, and number of children but the correlation with education levels at $P > 0.05$.

Conclusion: The study found that an instructional program improve parents' knowledge on how to prevent iron overload complications in children with thalassemia.

Recommendation: The instructional guidelines, posters and booklets, about complication of iron overload thalassemia all parents in the wards should have access to them, and parents should be urged to use them. The motivate parents to attend complication of iron overload thalassemia-related training courses and conferences to keep their knowledge up to date.

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Meaning	Symbols
Adult hemoglobin stabilize protein	AHSP
Analysis of variance	ANOVA
And	&
chi-square	χ^2
Deferasirax	DFX
Degree of Freedom	d.f.
Element	ELT
Equal to	=
Food and drug administration	FDA
Frequency	F
Gram \ decliter	G \ DL
Gram \ Gram	G \ G
Hemoglobin adult	HB A
Hemoglobin h	HBH
High	H.
Highly Significant	H.S
Iron overload	IOL
Less than	<
Low	L.
Magnetic resonance imaging	MRI
Mailgram \ kilogram	MG\KG
Mailgram \ mall	MG \ ML
Mean Of Score	M.S
Mitermidiates	MDS
More than	>

Non transfusion dependent	NTD
Not significant	N.S
Number	No
Osteoclasts	OCS
Osteoporosis	OP
Probability	P.
Reed blood cells	RBCS
Rumah sakit cipto mangunkusumo	RSCM
Sick cell disease	SCD
Significant	S or Sig.
Standard deviation	SD
statistical package of social sciences	SPSS
Tartrate resistant acid phosphates	TRAP
Thalassemia action group	TAG
Thalassemia intermedia	TI
Thalassemia major	TM
Transfusion dependent thalassemia	TDT
t-statistics	t.S
United states	US
Percentage	%

Chapter One

Introductio

Chapter one

1.1 Introduction:

Iron overload are defined by iron buildup in tissues, organs, or even just a single cell or a group of cells. Mutations in the genes responsible for hepcidin control, cellular iron intake, management, and export, as well as iron transport and storage, define their existence. Increased serum ferritin with or without high transferrin saturation and with or without functional iron deficiency anemia define systemic variants (Piperno et al., 2020). The illness is autosomal recessive in inheritance pattern. It is characterized by a lack or reduction in the synthesis of globin chains, producing in faulty adult hemoglobin (HB A1 - A2) production and hemolytic anemia (Basu et al ., 2021).Thalassemia can make patients pale, tired, and irritable, as well as cause tachycardia (an abnormally fast pulse), enlarged spleen, sluggish physical growth, difficulty doing physical activity, weakness, lethargic, and irritable. There have been 13 beta-Thalassemia mutations discovered. Thalassemia is inherited in an autosomal recessive manner (Basu et al., 2021).When both parents are carriers, the child has a one in four or 25% risk of being affected by thalassemia major, one in two (50%) chance of being afflicted as a carrier of thalassemia, and a one in four (25%) chance of not being affected (Wahidiyat et al., 2018).

Clinical signs of iron excess normally occur between the ages of ten and twenty, however signs of iron toxicity have been observed in considerably younger children. Within two years of initiating packed red cell infusion, hepatic fibrosis frequently develops. In the absence of chelation therapy, cirrhosis of the liver can develop before the age of ten , especially if hepatitis B and/or C is present (Piperno et al ., 2020).

There is a one in four chance (25%) of being impacted in every pregnancy. The number of people affected by this serious, life-shortening condition is rising at an alarming rate. The prevalence of being a carrier is considered to be anywhere between 6% and 10%. Serum indicators of iron overload, such as serum Ferritin and transferring saturation, are low-cost methods for predicting iron levels in the blood (Wahidiyat et al., 2018).

Cardiac problems from iron excess normally develop after fifteen years or more, but have been documented as early as ten years after transfusion therapy began .Endocrine organs are not spared when iron is consumed. In fifty percent of both male and female thalassemia patients, it is a major cause of delayed puberty. Twenty-five percent of women are unable to conceive a child. It can also cause damage to the pancreas, leading to diabetes mellitus. Thyroid and parathyroid glands can be harmed by too much iron (Piperno et al., 2020).An estimated 16 million Americans, either by inheritance or acquisition, have some degree of Iron overload because of thalassemia. The white population with a European ancestry is more likely to have hereditary hemochromatosis. According to estimates, one in every 200 white US patients has iron excess, and ten to fourteen percent of them carry a hereditary mutation. Due to the absence of menstruation, men with primary hemochromatosis are more prone than women to have symptoms (Mcdowell et al., 2018).The number of cases in Karbala for the year 2022 is estimated at 490 people with thalassemia, as shown in Table (1-1).

Table (1-1): Number of thalassemia cases in the city of Karbala during (2017-2022).

The years	The number
2017	448
2018	454
2019	466
2020	470
2021	485
2022	490

(Kerbala Teaching Hospital for Children Center Thalassemia.,2022)

Thalassemia can be readily avoided with the help of awareness campaigns, genetic counseling before marriage, screening, and prenatal diagnosis. There aren't many articles on how much the general public or parents of children with thalassemia know and understand about the disease. The purpose of this study was to assess the level of thalassemia awareness, knowledge, and attitudes among medical students. It also aimed to examine any differences between first- and second-year MBBS students and their associations with key socio-demographic factors (Pujani et al., 2017) .

1.2 Importance of the Study:

Mediterranean Sea anemia (thalassemia) is a hereditary disorder that is prevalent in most parts of the Middle East (particularly Iraq) and it is a growing problem. In 2010, there were approximately 500 patients in Iraq's Najaf province. According to data from the Al-Zahra Teaching Hospital in Najaf province, the number of cases grew to 1500 in 2018. The condition is treated with blood transfusions to compensate for a lack of globin. Continued transfusion results in higher iron levels in the body, increasing the risk of damage as well as oxidation and deposition of iron in the endocrine, liver, and kidney systems. The study is significant in Iraq and in health,

especially for thalassemia patients, because that reduces the complications of iron overload in patients, many of which are deadly, decreasing patients mortality risk (Elalfy et al., 2018).

Indonesia has one of the highest rates of thalassemia in the world. Occurrence rates for beta thalassemia carriers be believed to be between 3-10 % (Garber et al., 2018).

This group's most common subtype is beta -thalassemia, which is found in nations the Mediterranean, Central Asia, the Middle East, Africa, India, Southern Chinaies and South Africa. It is believed that about 1.5 % population of the world is infected with this disease, which also affects over 60,000 newborn babies each year (Basu et al., 2021).

The most common genetic blood condition in the world is known to be Thalassemia. However, thalassemia is the most prevalent autosomal single-gene condition in the world, with a carrier population of up to 150 million people (Wetherall and Clegg, 2001).The incidence of major and intermediate -thalassemia was 78.97% and 21.03%,in Iraq (Abdul-Karim et al.2005) , 64% and 36% in Lebanon (Inati et al., 2006), and 93% and 7% in Pakistan (Ain et al., 2011).

Thalassemia major is frequently prevented by preventing marriage between two carrier parents or by doing prenatal diagnosis in high risk mothers. Thalassemia major is more common than thalassemia intermedia. When two carriers marry, there is a 25% risk that the offspring will be thalassemic, a 50% probability that the offspring will become a carrier who can pass the disease on, and a 25% chance that the offspring will be normal (i.e., neither thalassemic nor a carrier) (Wahidiyat, 2010).

1.3 Problem Statement:

This study was conducted through the indicative program for parents to know the complications of iron deposition in thalassemia children. It was found that the complications of iron overload are caused by the parents' lack of knowledge about iron overload and the causes of complications. There is an urgent need to increase parents' knowledge of the direction of preventing the complications of iron overload in thalassemia children, and this study attempts to identify the lack of knowledge of the complications of iron overload in thalassemia children**.** The important to the increase parent's knowledge toward the prevention complication iron overload cause to the complication increase cause the iron overload and cause the decrease in the parent's knowledge, there for to give the parents instructional program to improve the knowledge parents.

1.4 Objectives of Study:

1. To assess the parents' knowledge concerning of iron overload complications among children with thalassemia.
2. To assess the effectiveness of program on parent's knowledge toward prevention of iron overload complications among children with thalassemia.
3. To find out the relationship between the effectiveness of an instructional program and parents socio demographic characteristics (age, gender, number of children, levels of education).

1.5 Definition of the Terms

1.5.1. Instructional Program:

Theoretical definition:

A key improvement method is instructional program coherence, which refers to the consistency and stability of programs (Park et al., 2021).

Operational definition:

It is education parents regarding information and knowledge about the complications of iron overload in children with thalassemia.

1.5.2. Parents Knowledge

Theoretical definition:

understanding of "developmental norms and milestones, processes of child development, and familiarity with caregiving skills (Sanders et al., 2005).

Operational definition:

It refers to data gathered by parents following the implementation of a special program aimed at improving about prevention of iron overload complications among children with thalassemia .

1.5.3. Iron overload

Theoretical definition:

The leading cause of morbidity and mortality, In individuals with transfusion-dependent thalassemia (Elalfy et al., 2018) .

Operational definition:

An accumulation of iron from the frequent blood transfusion to the children with thalassemia.

Research Question:

Does the application of an instructional program effect on the parent's knowledge toward reduce the complications of iron overload in children with Thalassemia?

Chapter Two Review of Literature

Chapter Two
Review of Literature

2.1. Historical Review of Thalassemia:

Thalassemia was first recognized by Cooley and Lee in 1925 , when cases were diagnosed for patients suffering from severe anemia, a group of symptoms of bone deformities and the eventual death of the patient. The term thalassemia is derived from the Greek thalassa (Qάlassa), which mean "sea" and "blood," since many of the early cases came from the Mediterranean region. However, denoting the high prevalence of this hematologic disorder in people of Greek, Italian, Cypriot, Turkish, or Sicilian ancestrydall of whom originate around the Mediterranean and Black Seas (Siddiqui et al., 2017).

In 1925 in Detroit, the pediatrician (Cooley Thomas) Thalassemia as an inherited blood disease the dangerous type of anemia in Italian children, originally named Cooley anemia (Weatherall & Clegg, 2001).

In 1940, The genetic nature of the disease was first investigated by Mintrobem and colleagues , when atypical hemolytic anemias were reported in a group of Italians patients, and in 1949 it became clear that Cooley's anemia is homozygous state of a partially dominant Mendelian gene (Wolf & Ingator, 1963; Old, 2003).

In 1959, Stretton and Ingram found that there are two main types of thalassemia, which are alpha and beta. Later, research in cytopathology focused on studying cases of β-thalassemia using techniques to measure the synthesis of the thalassemia globulin chain (Thalassemia disorders) (Weatherall,2004). In addition, molecular biotechnology is now able to help

patients when genetic errors and the nature of mutations and their distribution in the world community are recognized (Kayisli et al., 2005).

2.2. Concept of Thalassemia:

Thalassemia is hereditary disorders with a complex pathophysiology and serious multi-organ involvement.It affects the body's ability to produce hemoglobin, which is responsible for carrying oxygen in red blood cells. This disorder leads to a decrease in the number of red blood cells, which causes the patient to suffer from anemia. The disease is caused bymutations 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 transfusion iron overload and secondary multi-organ damage due to iron toxicity. The most common treatments for thalassemia, which is considered as ways to maintain the stability of the disease without its development (Angastiniotis & Lobitz, 2019; Nualkaew et al., 2021).

Hemoglobin disorders affect roughly 300 million people worldwide, with the majority of them living in Southeast Asia. The majority of thalassemia births occur in Asia, India, and the Middle East ninety five percent .The compound heterozygous condition is widespread across much of Southeast Asia, from Indonesia to Sri Lanka, Northeast India, and Bangladesh, with a frequency rate of 30-40%. The frequency of thalassemia in Thailand is as high as (25%) in diverse sections of Thailand, Laos, and

Cambodia, three Southeast Asian countries. In these areas, Hb Constant Spring is found in 1–10% of the population. About 5% of persons in Southern China, which has a population of about 350 million people, have a-thalassemia (Shah et al., 2021).

There are two types of thalassemia, depending on which type of globin is mutated: alpha-thalassemia and beta-thalassemia, α-thalassemia occurs when one or more of the four α-globin genes are damaged or altered, while β-thalassemia occurs when both β-globin genes are damaged or mutated. Furthermore, thalassemia major occurs when a child inherits two defective globin genes, one from each parent, and thalassemia minor occurs when the child inherits one defective globin gene from only one parent (Galanello & Origa, 2010; Kim & Tridane, 2017).

2.3. Risk Factors of Thalassemia :

The risk factors for thalassemia are family history thalassemia is transmitted from parents to children through mutated hemoglobin genes (Farashi & Harteveld, 2018).And ethnicity thalassemia occurs most often in African Americans and in people of Mediterranean and Southeast Asian descent (Rafi et al., 2018). The risk factors can also be divided into three similar trends, the first being the disease allied risk factors of thalassemia. The second trend is socioeconomic risk factors of thalassemia, while the third trend is cultural risk factors of thalassemia.

2.3.1 Disease Allied Risk Factors of Thalassemia

Negligence and lack of professional support from hospital staff, doctors and blood donation are all factors for which thalassemia is propagating worldwide, during clinical practices doctors face numerous

breaches to manage the negligence of supporting staff, basic health units and specifically the parents, who don't care about the premarital and prenatal measures of thalassemia's diagnosis(Surapon, 2011).

There are a number of challenges in thalassemia:

One major: challenge is to decide about the patient's care and management of disease because like other sickle cell diseases, thalassemia also required a strenuous management (Benz & Angelucci, 2018).

The second: highlighted challenge is the availability of technologies, medicines and therapeutic apparatuses because most of these elements are out of the reach of families of developing countries (Sultana et al., 2016).

The third: challenge is very chronic because its negligence leads to serious troubles for patients and their families and that is the knowledge of doctors , nurses and health practitioners (Heidari et al., 2018).

There is an unplumbed need to educate caregivers and provide them enough support, because it is directly related to patient's health. This support includes technical knowledge and information as well social, financial, psychological and moral support to the patients and their families (Hisam et al., 2018). Thalassemia engrains because it requires an effective and expensive management mechanism, in the form of blood transfusion and bone marrow transplantation (Faulkner, 2018), while these methods a very expensive and required a reflective procedural knowledge and skills. Other than social and psychological therapies and interventions in the form of counselling, guidance and awareness, these epidemiological measures are obligatory to cure and manage thalassemia (Tanveer et al., 2018).

2.3.2 Socioeconomic Risk Factors of Thalassemia

Major risk factors of thalassemia propagation are low socio-economic status and socio-economic constraints for the treatment and prevention of thalassemia (Alkinani et al., 2017). Children belong to the poor economic status are more vulnerable to thalassemia and families tie with traditional values and norms where consanguinity is an imperative, are at high risk to have thalassemia (Gul et al., 2017; Singh & Negi, 2019). Due to regular blood transfusion, medicines and precautionary diet, families suffer rigorous economic burden and the families having low socio-economic status suffer a lot because, expenditures of hospitals and medicines are not affordable.

A study was conducted by Sattari et al., (2012) in Iran on financial and social impact of thalassemia and the entire beta-thalassemia patents were involved in the study to know the impact (financial and social) on patients and their families. The information was drawn to find the direct and indirect expenditure of the thalassemia's treatment and researchers found that patients have a very enormous economic burden for the treatment of disease. Studies conducted by (Al Sabbah et al., 2017; Grewal, Sodhi, & Sobti, 2017) identified that propagation of thalassemia is mainly allied with lower socio-economic status, lack of awareness among families.

Parental education plays a vital role in normalizing their behavior and to avoid the stigmatization due to illness of a thalassemic child (Punaglom et al.,2019 ; Suzanah et al., 2011), because adequate education and knowledge enables them to be acquainted with the causes of disease and don't blame their fate, while contradictory insinuations are seen in traditional societies and among the illiterate couples because their low level

of education detain them to go against their cultural values, believes and practices (Ebrahim et al., 2019). Parental knowledge and awareness about thalassemia and its preventive measures has a significant importance for the propagation of thalassemia. Parents with little knowledge about the preventive measures and causes of thalassemia make their children to be exposed to the disease (Tahura et al., 2016). Understanding of thalassemia can be enhanced by increasing health literacy of families and caregivers, because understanding of basic knowledge of health practices and precautions of thalassemia are the result of increased health literacy of families (Sananreangsak et al.,2012).

Like many other genetic abnormalities, thalassemia also required a strong decision-making ability of couples and families, especially for genetic screening, counseling and in many cases the termination of pregnancy also (Stevens et al., 2019; Mustafa et al., 2018). It has been found in many studies that low level of health literacy, outcomes a poor health and is considered a major barrier for self-management, active participation in communal activates and low self-esteem of any individual (Nair & Ibrahim, 2015).

Family is believed to be the primary and most important source of social support for patients and their parents to mitigate the psychological and social burden caused by thalassemia. Patients of thalassemia are required medical as well as social support from their families, medical professionals and other community members for their social adjustment and confrontation against thalassemia. The effective management and social support also required general knowledge about the disease, so the general population of any area required to gain at least the basic (Kelsey, 2015). Found Radke et al.,(2019) that lack of knowledge about disease, manifestation of disorder,

rate of survival, availability of treatment and health facilities (medicalization and counseling), psychological and cultural issues may cause barriers to ideal health care including thalassemia. For all hemoglobin disorders generally and thalassemia particularly, awareness, attitude, perception and adaptation of screening towards the disease is very important to reduce the vulnerability and susceptibility of the couples towards thalassemia.30 It has been found by (Pouraboli et al.,2017).

2.3.3 Cultural Risk Factors of Thalassemia

Thalassemia Due to many cultural risk factors, propagation of thalassemia is found to be projecting across the world and especially in those countries where family values are constricted with culture. Marriages within the families are prominent and termination of pregnancy and prenatal screening is considered as unethical and religiously excluded. An effervescent sway of cultural and religious factors has also been patent for the treatment and management of beta thalassemia major among parents (Maheen et al., 2015). That family attitude, role and understanding is mainly determined by social, cultural and religious factors, especially in rural and traditional societies. These factors determine the patterns of living and life styles of residents of practicing communities, where individuals are bound to follow traditional ways for disease management and coping strategies. However, if individuals follow humanitarian practices, then religion could be the main source of social support for parents and families to manage sickle cell disease like thalassemia (Tokur-Kesgin et al., 2019;Chong et al., 2019).

Considering consanguinity, a major factor of thalassemia propagation across the world and especially in those countries where cultural dominancy and family preferences are apex phenomenon (Waheed et al.,

2016). It has been found Abdulhadi, (2018) that close family linkages and traditional family ties destined individuals to fuse with their familial customs and consanguinity is one of those traditional factors . As a result among other genetic disorders, thalassemia is also very common in these vicinities where cousin marriages are preferred (Nadkarni et al., 2008).

Birth incidences of many genetic disorders, including thalassemia occur due to consanguineous marriages. The growing rate of these cases is difficult to end because cousin marriages are encouraged by local cultural and traditional patterns. Substantial persuasion of endogamy, caste system, sectarian preferences and aboriginal customs impel peoples to prefer consanguine marriages; that result in many chronic genetic abnormalities like thalassemia (Premawardhena et al., 2019).

Genetic disorders due to consanguineous marriages are not new, these have been studied and sought for many decades and were found momentous for inherited disease like thalassemia, mental abnormalities, down syndrome and intellectual disabilities (Al-Gazali et al., 2006). Studies conducted by Abu-Libdeh & Teebi, (2010) in West Bank and Gaza included 130 families to find out the genetic aspects of beta thalassemia and it was found that 77.3 % of the couples having cousin marriages are found to be the carrier of same mutation. Another study conducted by Ashfaq et al., (2013), focusing the effects of cousin marriages on genetic disorders among Qatari inhabitants, found a very significant relationship between adult genetic disorders and the cousin marriages.

Numerous studies Cremonini et al., (2009); Katz et al.,(2017); Nutini & Bell, (2019) included cultural and religious aspects as major variables to reckon their influence on individual's choices and decisions about his life. Families handling dexterities, disease management and adaptation

approaches are shaped by social, cultural and religious practices (Ishfaq, 2015). As found by Chong et al., (2019), support provided by religion, society and community members, including family, relatives and friends is the main factor, that helps parents to assuage the problems of sickle cell disease or thalassemia. The perceived importance of social, cultural and religious factors altering people's opinion regarding treatment of thalassemia in not universal and it varies for countries and families based on indigenous practices and acquaintance. The importance of cultural and religious factors cannot be ignored in diagnosis and treatment of thalassemia especially in traditional societies, where families and couples are more ardent toward their religious beliefs (Hossain et al., 2017).

Distinctive studies have been conducted by Moudi et al., (2018) and Renani et al.,(2016) on socio-cultural and moral aspects of beta thalassemia major, and it has been found that these aspects are vital to ensure the universal standards of genetic services and women health reproduction, but they become leading snags when followed traditional and strict norms. Albeit, these factors are evident to explore the chronic impact of thalassemia over the lives of patients and their families but there are rare evidences to explore the effect of beta thalassemia major on decision making, gender roles and health literacy at the time of marriages, pregnancies and prenatal screening (Seven et al., 2019). Fear of stigmatization and social exclusion are significant associated factors and results of beta thalassemia and require rigorous attention to be overpowered (Kyriakides, 2016).

2.4. Types of Thalassemia

2.4.1.Beta thalassemia

The type in which there is a deficiency in the production of Beta-globin, most prevalent in people of Mediterranean and Middle Eastern descent. It

can lead to ineffective production of red blood cells, chronic anemia and accumulation of excess iron in the blood and organs. Beta thalassemia is further classified by the severity of the disease into three main forms (Borgna-Pignatti & Gamberini, 2011):

1. Beta thalassemia major is characterized by profound anemia, often requiring medical attention in the first two years of life and leading to a dependency on blood transfusions.
2. Beta thalassemia intermedia is a type of thalassemia that affects people of all ages. It's a type of chronic hemolytic anemia in which the body can't produce alpha or beta chains. This disorder's clinical manifestations These patients may have chronic liver malfunction, osteoporosis, mild hepatomegaly, and chronic anemia.
3. Beta thalassemia minor is usually clinically asymptomatic but may lead to mild anemia in some carriers (Tari et al., 2018).

2.4.2. Another type is Hemoglobin E (HbE)

Beta thalassemia, which is one of the most common mutations. The severity can vary significantly ,Patients with hemoglobin H disease are underweight and appear gaunt despite eating properly. When all four globin genes are missing, the condition is known as hydrops fetalis (Farashi & Harteveld,2018).

2.4.3. Alpha thalassemia

The type in which there is a deficiency in the production of Alpha-globin, most occurs in people of Southeast Asian, Middle Eastern and Mediterranean descent, The type of mutation influences severity, A moderate-to-severe form called hemoglobin H (Harteveld & Higgs, 2010).

2.5. Complications of Thalassemia:

In the Borgna-Pignatti et al., (2011) study, common complications of thalassemia include: heart disease (heart failure and arrhythmias), chronic liver hepatitis, which can evolve in cirrhosis and, rarely, in hepatocellular carcinoma, endocrineproblems (hypogonadism, hypothyroidism, diabetes, hypopa rathyroidism), stunted growth, osteoporosis, thrombophilia and pseudoxanthoma elasticum. The incidence of complications is decreasing in younger cohorts of patients who have been transfused with blood that has been screened for viruses and thanks to the introduction of new oral iron chelators and imaging methods.

In the Cunningham et al.,(2004) study, showed that the complications of thalassemia in North America include: transfusion-transmitted infections, transfusional iron overload, toxicities of iron chelation therapy, bacterial infections. Age is directly related to the prevalence of most of these complications.

Face anomalies in the bones, loss of growth, difficulty breathing, yellow skin (jaundice) and fatigue are some of the other symptoms, Heart failure caused by severe thalassemia can lead to early death (between the ages of 20 and 30 years) (Elewa et al ., 2017).

Through the table (2-1) we have clarified the most important complications of thalassemia (Gul et al., 2017).

Table (2-1). Thalassemia complications and management options.

N	Complication	Management
1	Extramedullary Haematopoietic Pseudotumors	-Radiotherapy - Hydroxyurea - Tranfusion - Surgery
2	Thromboembolic events and Silent Brain Infarcts	-Tranfusion therapy - Aspirin therapy - Anticoagulants or antiaggregants - Iron chelation or hydroxyurea therapy - Brain or cerebrovascular imaging
3	Pulmonary Hypertension	-Transfusion therapy - Hydroxyurea - Sildenafil citrate - Control of iron overload - Anticoagulant therapy
4	Hepatocellular Carcinoma	-Surgical resection - Chemoembolization - Simultaneous percutaneous radiofrequency thermoablation - Ethanol injection
5	Leg ulcers	-Transfusion as first treatment option -If persistent : Hydroxyurea, Dialzep (vasodilators), Oxygen chamber, Skin grafts, Platelet derived wound healing factors and granulocyte macrophage, Anticoagulation, Topical antibiotics, Sodium nitrite cream

6	Endocrinopathies	-Iron chelation therapy - Hormonal therapy
7	Bone Disease	-Hypertransfusion - Iron chelation therapy -Nutritional supplementation, and Bisphosphonates
8	Pregnancy-related complications	-Splenectomy in cases of hypersplenism or splenomegaly - Transfusion therapy (depending on Hb level, fetal growth status and maternal general and cardiac status)

2.6. Clinical Manifestations of Thalassemia:

Three main factors are responsible for the clinical sequelae of β-thalassemia ineffective erythropoiesis, chronic anemia, and iron overload (Figure 2-1) .Though thalassemia major children first appear normal, they experience severe anemia in the first year of life (Gul et al., 2017).

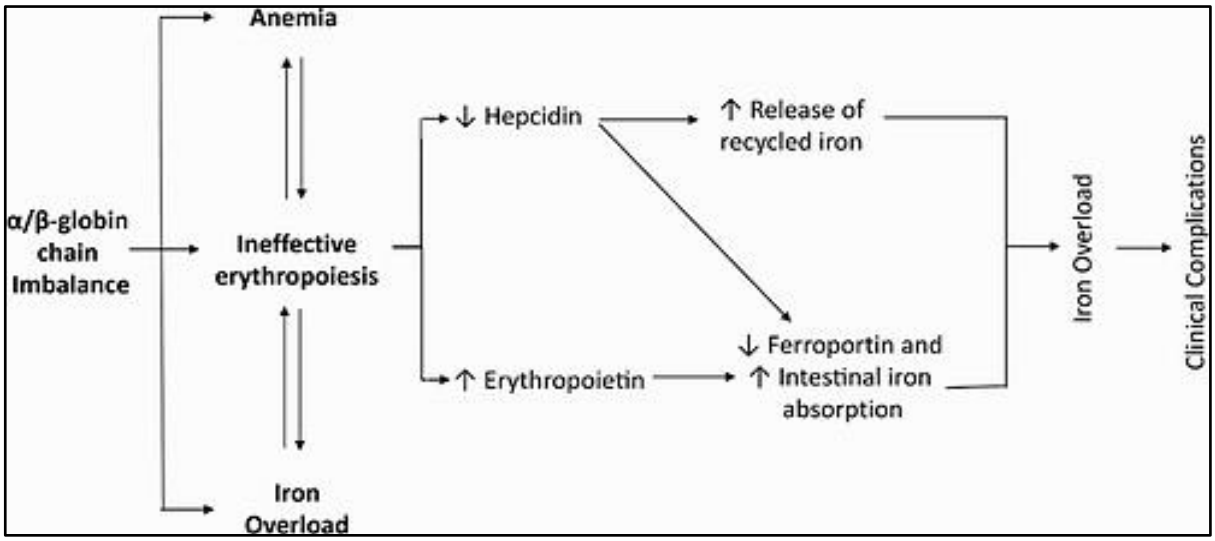

Figure (2-1). Mechanism of iron overload development due to ineffective erythropoiesis in β- thalassemia(Ben Salah et al.,2017).

The children with homozygous thalassemia are not treated, they will develop substantial in the second six years of life, there is weakening and cardiac decompensation. Months since birth transfusions are necessary in beta thalassemia major depending on the gene and level of fetal production of hemoglobin from the second month to the second year of life (Kowdley et al., 2019).

Children with severe illness of the face, including brow ridge hypertrophy, flat nasal bridge, forehead bossing, structural bone fractures, substantial hepatosplenomegaly, and cachexia are now most commonly seen in nations without long-term transfusion therapy (Chatterjee et al., 2019).

Without blood-transfused may experience the patient's severe anemia, significant splenomegaly and stomach ache. Increased medullary spaces, more ventricular hematopoiesis, and greater metabolic needs are all indicators of inefficient erythropoiesis. Extensive growth of the face and skull's marrow leads to the characteristic thalassemic facies (Praveen et al ., 2019).

Without a blood transfusion, chronic anemia increases iron absorption from the gastrointestinal system. As a result of secondary iron overload-related organ damage .Chronic blood transfusions increase the life of quality while lowering sever thalassemia of the risk consequences (Racine-Brzostek et al., 2020).

There is also no natural mechanism in place to rid the body of excess iron. The liver is the first place where iron is accumulated. After a year of extended transfusion therapy, the liver develops iron overload, and iron accumulates in the endocrine system. Common side effects include hypothyroidism, images gonadism, growth hormone deficit,

hyperparathyroidism, and diabetes. Iron overload leads in cardiac dysfunction after ten years of transfusion (Pate et al.,2020).

2.7. Overview of iron overload:

Iron overload is a multifactor and genetically diverse disorder in which the body accumulates excessive amounts of iron. Hemochromatosis can be classified into two parts. The first is primary hemochromatosis caused by genetic mutations and secondary hemochromatosis that develops as a result of another disease or group of diseases, Iron accumulates in the body in primary hemochromatosis due to mutations in five distinct genes (Punzo et al., 2018).

Several illnesses defined as hereditary iron overload are characterized by iron buildup in tissues, organs, or even individual cells or subcellular sections. Mutations in the genes responsible for hepcidin management, cellular iron intake, management, and export, as well as iron transport and storage, higher serum ferritin with or without high transferrin saturation and with or without functional iron - deficiency anemia define systemic variants. There are five main genetic types of hemochromatosis, each having a high ferritin saturate and serum ferritin but varying levels of penetrance and presentation (Piperno et al., 2020) .

The most prevalent monogenic genetic hemoglobin condition, beta thalassemia, has a serious impact on Sri Lanka's health. These patients must get regular erythrocyte transfusions to survive, which inevitably results in iron overload, which is seen by high serum ferritin levels. Major organ dysfunction and failure are caused by iron deposition over time (Karunaratna et al., 2017).

The many types of inherited iron overload illnesses are diagnosed sequentially using clinical, imaging, biochemical, and genetic information. Iron removal and iron chelators are the two main treatments used to manage iron overload (Piperno et al., 2020) .

Iron overload disorders lead to excess iron deposition in the body, a potentially serious condition, is often overlooked as the symptoms are non-specific and often develop gradually making iron overload a complex condition .Excess body iron is stored in organs and tissues where it may cause injuries resulting in a variety of disorders, including heart disease, diabetes, arthritis, cancer, cirrhosis, impotence and sterility. Screening both symptomatic patients and certain asymptomatic persons can make a positive impact on long-term outcomes. Further study is needed to define the risks associated with Iron overload to look for treatment plans work better (Palmer et al., 2018).

2.8. Factors that Influence Iron Overload:

Factors that influence iron overload are genetic factors. One of the factors that influence iron overload. gene mutations of the HFE gene were discovered and linked to primary iron overload. The most common is C282Y.Hereditary hemochromatosis is the leading case of iron overload disease. Other factors that Influence iron overload include are transfusion, hemolysis, or excessive parenteral and/or dietary consumption of iron (Radford-Smith et al., 2018).

2.9. Complication of Iron Overload:

Iron overload is the most common symptom of regular blood transfusions. The liver and pancreas are two organs that store a lot of iron. These two organs are necessary for metabolism. By producing insulin and its counter-regulatory hormone glucagon, the liver regulates cholesterol

metabolism while the pancreas regulates blood glucose levels (Hendarto et al., 2019).

The Children with severe beta-thalassemia die from the following cause cardiac failure caused by iron overload. Myocardial fibrosis and iron overload cardiomyopathy impact the majority of the children who are affected (Mishra, 2019).

Excessive iron deposition occurs in a range of tissues, including the heart, liver, and endocrine glands. Cardiac problems are the most common, accounting for more than half of all fatalities in this population, making it the most important survival factor in thalassemic patients (El-Haggar., 2018).

Iron overload is a condition that occurs as a result of excessive iron absorption or chronic blood transfusions. Anemia caused by a reduction in (RBC) production, increased cell death, or prolonged blood loss may necessitate red blood cell transfusion therapy. Chronic diseases such as Sickle Cell Anemia SCD and Beta-Thalassemia Major (TM) need long-term blood transfusions therapy to extend life (Punzo et al., 2018).

Iron needs, iron storage, erythropoiesis, hypoxia, and inflammation all influence the main iron regulator, hepcidin. It's mostly made in the liver and then secreted into the bloodstream. Hepcidin identifies ferroportin, a membrane-bound molecule that becomes the body's main iron exporter after it leaves the cell (Rivella , 2019).

This typically results in secondary iron overload, which may severely damage a range of organs, including the liver, heart, and endocrine system, through the formation of free radicals, Osteoporosis (OP) is caused by a buildup of iron in bone tissue. Because it is vital to reduce excess iron using

a medicinal strategy and prevent the catastrophic clinical effects of its overload because there are no physiological processes to do so and stop it from collecting in end organs. 40–50% of adult TM individuals have osteoporosis and OP, which impair patient quality of life by causing severe back pain, bone fractures, skeletal deformities, and nerve compression (Punzo et al., 2018).

The primary factor causing disease and death is iron overload patient's blood transfusion dependent thalassemia (TDT). Thus, lifelong iron chelation therapy is required for morbidity prevention and long-term survival (Elalfy et al., 2018).

The molecular and cellular processes underlying thalassemia major (TM) bone resorption pathophysiology are still unknown. We showed that iron overload indicates that oral chelation may be important in alleviating symptoms associated with TM by causing osteoclasts (OCS) in the TM to overexpress due to up-regulation of expression. Normal functional levels can be restored with chelation therapy (Punzo et al., 2018).

2.10. Treatment iron overload:

Supportive therapy's goal is to keep hemoglobin levels stable enough to avoid bone marrow enlargement and abnormalities, as well as to give enough red blood cells (RBCs) for normal growth and physical activity. The purpose of medical treatment is to maintain hemoglobin levels above a certain threshold. 9.5 g/dl, which may necessitate three-weekly blood transfusions. The ability to engage in common activities improves one's physical and mental health (Mcgann et al., 2017).

Iron overload is one of the probable side effects of frequent blood transfusions (iron overload). Because the body has no effective mechanism of eliminating excess iron, it accumulates in human tissues. To assist prevent iron overload and hemochromatosis, deferoxamine, an iron chelating medication, is used with oral vitamin C supplements. Only patients who are lacking in ascorbate and who are taking deferoxamine should take vitamin C. In patients with vitamin C deficiency, vitamin C supplementation increases iron excretion in response to deferoxamine. Vitamin C may inhibit the conversion of Ferritin to hemosiderin, allowing more iron to remain in chelatable form (Angastiniotis & Lobitz, 2019).

Cardiomegaly and hepatosplenomegaly are reduced, there are fewer bone abnormalities, growth and development are normal or near normal until adolescence, and this treatment offers a lot of benefits, including fewer infections (Mcgann et al., 2017).

Deferoxamine is administered intravenously or subcutaneously at home using a pump for infusions lasting 8–10 hours (typically while sleeping) five to seven days a week. If chelation therapy is administered properly during childhood, significant liver fibrosis, heart dysfunction, and growth limitation can be avoided. As a result, sticking to a strict regimen is essential. Significant chelation therapy necessitates a regimen. Oral chelators (deferiprone and deferasirox) represent a significant advancement in the treatment of patients receiving long-term transfusion therapy. In 2004, the Food and Drug Administration (FDA) approved deferasirox for the treatment of recurrent blood transfusion-induced chronic iron overload in patients aged two and above (Crisponi et al., 2019).

Deferirox is generally well tolerated at a daily dose of 20 to 40 mg/kg, with the most common adverse effects being moderate gastrointestinal

difficulties and redness. Agranulocytosis, which occurs in 1.1 percent of patients and neutropenia in 4.9 percent, is the most serious adverse effect of deferiprone, necessitating blood count monitoring. Deferiprone is not yet approved in North America since long-term controlled trials have shown no reduction in organ iron concentration, though it is available on a compassionate-use basis. Magnetic resonance imaging (MRI) is a method of imaging that uses radio waves to produce images. Has become the gold standard for determining the iron levels in the liver, heart, and other organs, as well as for guiding iron chelating therapy. In conjunction with blood Ferritin levels being measured in the lab and, in some cases, liver biopsy (Zeidan et al., 2018).

The treatment of iron overload, various pharmaceutical and non-pharmacological approaches are available; however, they must be employed in accordance with the etiology and patient compliance. The foundation for treating hereditary hemochromatosis is therapeutic phlebotomy. Iron chelators are required for individuals with transfusion excess and those who cannot undergo phlebotomy. Modern therapeutics and new pharmacological targets have greatly improved as a result of breakthroughs in our understanding of iron overload (Jeesh et al., 2018)

A splenectomy may be recommended for children with severe splenomegaly who require regular blood transfusions to alleviate the devastating effects of abdominal pressure and to increase the lifetime of supplemented RBCs. The spleen may hasten the destruction of RBCs. Increasing the requirement for blood transfusions over time. Despite the fact that the underlying defect in hemoglobin synthesis remains unaffected, children who have their spleen removed require fewer blood transfusions. A major post-splenectomy complication is severe and overwhelming infection.

As a result, young children are frequently on prophylactic antibiotics for many years while being closely monitored by their doctors, and they should also receive pneumococcal and meningococcal vaccines in addition to their usual immunizations (Bonnet et al., 2017).

Point mutations, minor deletions, and insertions involving regions influencing gene expression are significantly more prevalent than deletions that remove one or both genes. Greater reductions in globin synthesis may result from thalassemia non-deletion mutations than from single-gene losses (Farashi & Harteveld, 2018).

Patients with TM were discriminated from the first day of culture until they were entirely distinct in the absence of elevated level thalassemia ELT Ammonium three iron was used to treat them beginning on seven days (second medium change) until they could fully discriminate from healthy individuals (Punzo et al., 2018).

There are a large variety of globin gene variants that impact expression, globin chain stability, and associations between chain variant and the adult hemoglobin stabilizing protein Alpha hemoglobin-stabilizing protein (AHSP) Other globin changes may affect the formation of heme pockets, the connection between the globin chains, the stability of the variable hemoglobin, or the variation's oxygen sensitivity. Lists of mutations that are more thorough (Farashi & Harteveld , 2018). Children having beta thalassemia major require regular blood transfusions every 3-4 weeks for the rest of their lives, and iron chelation therapy, which removes iron from the body, can help improve the prognosis. Because thalassemia requires lifelong blood transfusions and chelating drugs, it is a concern for individuals, their families, and the healthcare system (Shang et al., 2017).

Iron chelation therapy aims to prevent the accumulation of toxic iron and eliminate the excess iron in thalassemia patients. Effective chelation and good management of the patients have been correlated with a decline in early deaths and complications (Porter, 2009).At present, three standard iron chelators including desferrioxamine (DFO), deferiprone (DFP), and deferasirox (DFX) are widely used for the treatment of β-thalassemia patients with iron overload to prevent oxidative stress-induced organ dysfunctions and such complications (Figure 2-2). Combined DFO/DFP and DFP/DFX treatments can reverse endocrine complications by improving glucose intolerance and gonadal dysfunction in TDT patients (Farmaki et al., 2011).

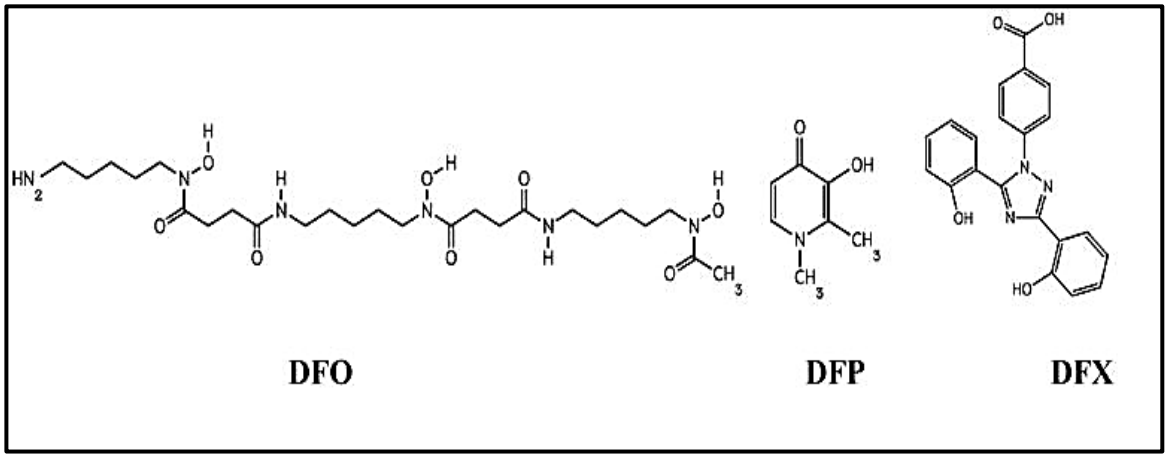

Figure (2-2).Chemical structures of desferrioxamine (DFO), deferiprone (DFP), and deferasirox (DFX)(Srichairatanakool et al., 2020)

Iron supplies are depleted, chelation toxicity rises. The most thoroughly researched iron chelator, deferroxamine (Desferal), has a very good safety and effectiveness profile. It must be given subcutaneously or intravenously for at least 8 hours throughout the day, five to seven days per week, because it has a half-life of less than 30 minutes (Brittenham et al ., 2020) .

Three iron chelators available are deferroxamine, deferasirox, and deferiprone; each has its own manner of administration, pharmacokinetics, side effects, and efficacy. A lot of patients need combined chelation therapy at various stages of their illness. The main objective is to avoid chelation toxicity and tissue damage caused by iron overload. This needs the patients' continual observation (Holman et al., 2017) .

Deferoxamine is started at 20 mg/kg in severely iron-overloaded children and gradually increased to 60 mg/kg. The biggest problem with deferoxamine is noncompliance owing to the method of administration. Some of the negative side effects include ototoxicity, abnormalities of the retina, and bone dysplasia with truncal shortening (Stoffel et al., 2020) .

Desferal, the most current oral iron chelator is Deferasirox (DFX). Because of its capacity to offer consistent chelation coverage and considerably improve patient compliance, it is efficacious and very well once daily, preventing iron overload from transfusion. We recently demonstrated that tartrate-resistant acid nitrogen and phosphorus (TRAP) are responsible for the development of (OCS) in the TM, and that iron chelation therapy can restore normal levels of activity. In vitro results have supported the lowering in (OP) and elevation in bone mineral density shown in a cohort of TM patients treated with (DFX) have been corroborated by vitro data (Punzo et al.,2018) .

The most frequent clinical consequence of blood transfusion-dependent thalassemia is iron overload. One milligram of iron can be found in one milliliter of packed red blood cells (Lokeshwar et al., 2020) .

The majority of people who did not receive enough Iron reduction deliver medical passed away from iron overload related cardiac arrest and/or heart arrhythmias. Sufficient iron chelation therapy can reduce iron

overload-related morbidity(Pilo et al., 2021). Despite several options for treatment, there is no clear guideline for its management. Therefore, there is a need for further study of the disease to better understand its causes and options to cure it. For the present time the two main issues have been the managing of thalassemia in adults and developments of complication in the youth. For adults, with thalassemia following recommendations have been put forward.

- Transfusion at early stage and iron chelation therapy
- Regular follow up
- Regular follow up of liver iron concentration
- Avoid smoking, and use of oral contraceptives (Taher et al.,2006).

2.11.Nutrition for child with iron overload

Depressed circulating levels of essential micronutrients such as zinc, copper, vitamin C, vitamin D, and folate have been observed previously in transfusion dependent adults with thalassemia who consume an American diet (Claster et al.,2009). Deficiencies may be caused by decreased dietary intake, elevated losses, or an increased endogenous requirement for key micronutrients. An increased urinary excretion of multiple minerals and transport proteins has been observed in thalassemia including calcium, zinc and albumin (Fung , 2010; Quinn et al., 2011). The increased renal losses of key nutrients, up to 400% above subjects without thalassemia, is thought to be one of the strongest predictors of mineral deficiencies (Aydinok et al., 1999; Uysal et al.,1993).

Reduced total caloric intake is also frequently observed in individuals with thalassemia, purportedly related to small stature and reduced physical activity (Fung et al., 2015). Decreased caloric consumption may increase the risk of nutritional deficits if an individual

consumes a significant amount of empty calories or foods with little nutritional value. When the nutritional and physiological status of 30 patients with thalassemia was compared to healthy controls, thalassemia patients presented with poor growth, lower body fat, and decreased albumin (Soliman et al.,2004). When these patients were subsequently provided a high calorie diet, after eight weeks all parameters (growth, body fat, albumin) significantly increased. Authors concluded that dietary intake in patients with thalassemia was not adequate to support endogenous needs for growth and immune function.

A study Srichairatanakool et al., (2020) showed on the treatment of regular iron chelation therapy with high dietary intake of antioxidants effectively lowers the harmfulness of iron overload-mediated oxidative tissue damage and organ dysfunctions in thalassemia patients. The supplementation with single nutrients, like antioxidants, is generally not effective in ameliorating such iron overload conditions or in slowing the progression of the disease. It is recommended that these nutrients should be consumed as part of a healthy diet/functional fruits in daily meals. Nutritional and herbal strategies for modifying the pathological and clinical courses of thalassemia disease should consider the major active ingredients, nutraceuticals, biological activities, and hematological efficacy.

2.12. Prevention of iron overload:

The immersion of social and cultural restrictions for the diagnosis and treatment of thalassemia is making this disease chronic and required a serious attention of parents, families, government, policy makers and enforcement agencies to adopt the effective mechanism for the prevention of thalassemia across the world (Cappellini et al.,2018). Thalassemia patients

are victims of hemoglobin deficiency, so they need constant blood transfusions in order to survive, but continuous blood transfusions require many healthy donors as well as preventing iron overload (Farugia & Dale, 2015).

The inability of the human organism to remove excess iron exposes transfusion-dependent thalassemia patients to its toxic effects. Consequently, patients no longer die from anemia, but die in the second decade of life from iron-induced cardiomyopathy. The availability of iron chelators has dramatically improved survival by preventing and reversing heart failure (Borgna-Pignatti et al.,2006).

Magnetic resonance imaging (MRI) , which can accurately monitor multiorgan iron overload (IOL), has enabled iron chelation therapy to be tailored to the individual patient's needs. Regular transfusion therapy to maintain values of pre-transfusion hemoglobin (Hb) over 9 mg/dL reduces ineffective erythropoiesis (Wood, 2015; Wood, 2014; Cazzola et al.,1995), related bone dysmorphism, and splenomegaly, decreasing the need for splenectomy (Piga et al.,2011). The improved quality and safety of transfused blood components have reduced the risk of blood-borne viral infections. thalassemia patients can now survive into their 50 s and 60 s and enjoy a full life , and pregnancies are common (Origa et al.,2010).

Iron toxicity in thalassemia patients can affect all stages of development (erythropoiesis, growth, sexual maturation, endocrine homeostasis, cardiac, liver, and renal function, bone metabolism, aging) (Pinto et al., 2019) and exposes them to an increased risk of malignant transformation (Borgna-Pignatti et al., 2014). In non-transfusion-dependent thalassemia, even in the absence of regular red blood cell (RBC) transfusions, IOL occurs due to the enhanced intestinal absorption that is

secondary to ineffective erythropoiesis and hepcidin suppression and at slower rate than in transfusion-dependent thalassemia, making IOL a cumulative process with advancing age (Ginzburg & Rivella, 2011).

Due to differences in organ-specific iron transport, the rate of iron loading and unloading is much faster in the liver than in the heart and endocrine organs (Taher & Saliba, 2017). The aim of chelation is to consistently neutralize the toxic effects of iron and prevent or eradicate iron overload (Coates & Wood, 2017; Kolnagou & Kontoghiorghes, 2010).

Antenatal screening via amniocentesis, chorionic villous sampling, or fetoscopy during the first trimester of pregnancy can assist detect thalassemia in the fetal life. Among the 2.2% of Caucasians who are C282Y homozygous or C282Y/H63D compound heterozygous, only a quarter develop the disease. This means the risk genotypes predispose the disease , Simple blood tests or the identification of the thalassemia gene can both detect carriers before marriage is one of the ways to protect against thalassemia, which causes iron overload. patients overload should be advised to avoid iron-rich food (e.g., red meat, beans, spinach) and also avoid excess vitamin C contribute to the development of the disease (Brittenham, 2011; Hanson et al., 2001).

Calcium channel blockers are a prevention method for cardiomyopathy due to iron overload in people with blood transfusion dependent beta thalassemia. To evaluate the effects of calcium channel blockers combined with conventional iron chelation therapy on the amount of iron deposited in the myocardium, on heart function parameters, and on the incidence of severe heart failure or arrhythmias and related morbidity and mortality in people with transfusion-dependent beta thalassemia(Sadaf et al., 2018).

2.12. Parent role in prevention iron overload :

Thalassemia causes significant disruption in the family number as well as impediments to normal development. Early use of child life services reduces treatment-related psychological stress by anticipating culturally appropriate therapy. Early social service counseling is critical for addressing financial and social difficulties (Hockenberry & Wilke, 2021).

Supportive management is critical for addressing linked issues and treating complications like hepatic failure. Along with other normal immunizations, hepatitis 'B' vaccination will be administered to avoid transfusion-related illness. The importance of emotional support for both parents and children cannot be overstated. Basic supportive nursing care is critical for avoiding a variety of problems (Mammas et al., 2017).

2.13. Family education toward iron overload :

Providing information toward children with iron overload and their families about the most effective alternatives therapy. Assist families in capacity the significance of adhering to the child's blood transfusion and chelation therapy schedules. Chelation therapy must be continued at home to keep the body's iron levels low. Teach family members how to use a tiny battery-powered infusion pump to deliver deferoxamine subcutaneously over a several-hour period each night (usually while the child is sleeping). If the doctor has ordered oral deferasirox, tell the family that they should dissolve the tablet in juice or water and take it once a day (Nettis et al.,2021).

Children having beta thalassemia major require regular blood transfusions every 3-4 weeks for the rest of their lives, and iron chelation therapy, which removes iron from the body, can help improve the prognosis.

The need for continuous blood transfusions and chelating treatment makes thalassemia problematic for individuals, their families, and the healthcare system medications.

Individuals with thalassemia major and many with intermediate require blood transfusions as a mainstay of treatment. Transfusions have two purposes , to improve anemia and to decrease inefficient erythropoiesis (Shang et al.,2017).

As needed, refer the family to genetic counseling and family support. The Cooley's anemia foundation, which includes a link on, is a beneficial resource for families of children with thalassemia. The Thalassemia Action Group (TAG), a subset of the Cooley's Anemia Foundation, was created by a group of young adults with Cooley anemia to provide a platform for discussion and information, as well as to encourage a positive approach on living with the disease. Raise awareness of the need of completing the disease's treatment TAG is a part of the Cooley anemia website, where you may get more information (Morse & Pence ,2021).Chronic blood transfusions avoid the majority of thalassemia major's significant growth, skeletal, and neurological issues . Despite its critical role in preserving and improving the lives of patients. The fact that the correct things are being done right is reflected in the quality of care provided to patients, their families, and their communities (Shang et al .,2017).

2. 14. Previous Study: -

The study was conducted by Ahmed et al.,(2022) under the title early detection of iron overload cardiomyopathy in transfusion dependent thalassemia patients in Sulaimaniyah city in Iraq, That aim to evaluate the reliability of a variety of electrocardiographic (ECG) data in patients at high risk of arrhythmia, early detection of structural and functional changes in the left atrium and ventricle using ECG and echocardiography (two dimensional, M-mode echocardiography along with Doppler studies), and to track the relationships between plasma B-type atrial natriuretic peptide (BNP)/serum ferritin and electrocardiogram with Doppler as well as echocardic. After applying exclusion criteria, 75 thalassemia cases with a mean age of 9.55 ± 3.83 and 74 age and sex-matched control subjects with a mean age of 9.93 ± 3.66. There were no significant differences ($p>0.05$) in the gender between cases and controls. Among the patients, 18.7% had major thalassemia, while 81.3% had intermedia. On the other hand, 90.7% of cases had facial disfigurement, and the percentage of splenomegaly, hepatomegaly, and jaundice were 88%, 26.7%, and 96%, respectively, with none of these findings in control subjects ($p<0.05$). Splenectomy was present in 5.3% of thalassemia patients. Neither basal crepitation nor cardiac murmur was present in cases and the controls.

Second study was conducted by Alenezi et al .,(2020) under the title Association between hyperuricemia, serum iron level and possibility of gout among Saudi patients: a retrospective study. The goal of the current study is to assess the correlation between blood uric acid levels and iron excess in Saudis. King Fahad Medical City conducted a retrospective cohort analysis in the Saudi Arabia's center region around Riyadh, there is a positive link between serum uric acid and serum iron level, according to the Pearson

correlation (r=0.52). The blood uric acid and ferritin level have a positive link, according to the Pearson correlation (r=0.46). There is a positive link between serum uric acid and transferrin level, according to the Pearson correlation (r=0.23). Serum uric acid and transferrin saturation have a positive connection, according to the Pearson correlation (r=0.56). This study shows that in Saudi patients, serum ferritin, serum transferrin, and serum hemoglobin all have a positive connection with serum uric acid. Even in the absence of associated symptoms, undiagnosed hemochromatosis or iron overload should be taken into account when there are excessive uric acid values.

Third study was conducted by Wang et al.,(2022) under the title Research Progress on Relationship Between Iron Overload and Lower Limb Arterial Disease in Type 2 Diabetes Mellitus, one of the most crucial trace elements for life processes is iron. Through the oxidation-reduction reaction, it takes part in a variety of significant physiological processes in the body. Numerous studies have demonstrated a strong correlation between iron overload (IO) and the development of diabetes and its many long-term consequences. The association between iron overload and diabetic lower extremity arterial disease (LEAD) is still unknown, as is the mechanism of iron overload in the pathogenesis of diabetes and the mechanism of iron overload in atherosclerosis (AS) , In type 2 diabetes mellitus, lower limb artery disease and iron excess are tightly connected. Through a number of pathways, including lipid peroxidation, inflammation, and altering arterial endothelial function, iron excess contributes to type 2 diabetes and its consequences, causes atherosclerosis, and fosters lower limb arteriopathy. However, further research is required to confirm the link between lower extremities artery disease and iron excess in type 2 diabetes.

The study was conducted by Pepe et al.,(2020) under the title The close link of pancreatic iron with glucose metabolism and with cardiac complications in thalassemia major: A large, multicenter observational study. In a cohort of 1,079 thalassemia major (TM) patients involved in the Extension-Myocardial Iron Overload in Thalassemia (E-MIOT) research, we thoroughly investigated the relationship between pancreatic iron and glucose metabolism and cardiac problems. Results are shown patients with normal glucose metabolism showed significantly higher global pancreas T2* values than patients with impaired fasting glucose, impaired glucose tolerance, and diabetes. A pancreas T2* <13.07 ms predicted an abnormal OGTT. A normal pancreas T2* value showed a 100% negative predictive value for disturbances of glucose metabolism and for cardiac iron. Patients with myocardial fibrosis showed significantly lower pancreas T2* values. Patients with cardiac complications had significantly lower pancreas T2* values. No patient with arrhythmias/heart failure had a normal global pancreas T2*.The study concluded pancreatic iron is a powerful predictor not only for glucose metabolism but also for cardiac iron and complications, supporting the close link between pancreatic iron and heart disease and the need to intensify iron chelation therapy to prevent both alterations of glucose metabolism and cardiac iron accumulation.

study showed Biswas et al.,(2018) under the title knowledge, attitude and practice in parents of chronically transfused thalassemic patients regarding thalassemia in thalassemia day care unit in government medical college, Amritsar, Punjab, India. 50 caregivers (either mother or father) of chronically transfused thalassemic children were questioned regarding their knowledge, attitude and practice towards this disease, using a self-

constructed questionnaire. It was found that despite adequate knowledge regarding every aspect of this disease, there is a lack of attitude of practice towards prevention of this disease in their subsequent child or in their near and dear ones. Study recommended need to promote an attitude of practice in prevention of the birth of thalassemic children as mere knowledge regarding the disease is not enough in the present scenario where the disease burden is increasing as is the financial and emotional burden on the families. Role of Government sponsorship, a social worker and a child psychologist in the Thalassemia day care unit cannot be minimized

study showed Biswas et al.,(2018) under the title knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India. Knowledge level of caregivers of thalassemic children and its socio-demographic determinants. included 328 caregivers of thalassemic children attending thalassemia day care unit during. The results indicated out of 328 caregivers only 47.6% knew about genetic etiology of the disease, while only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively. Regarding treatment of the disease, 75.9% knew that both blood transfusion and iron chelation are the treatment of thalassemia, while only 19.2% and 2.7% of them had knowledge regarding splenectomy and bone marrow transplantation, respectively. Only 52.7% had satisfactory knowledge regarding the disease. In multivariable model, caregivers educational level (adjusted odds ratio, AOR-3.13 [1.87–5.25]), working status (AOR-2.18 [1.23–3.86]), place of residence (AOR-2.05 [1.19–3.52]), and socioeconomic class (AOR-2.11 [1.25–3.58]) were significant predictors of their knowledge. The study explained Caregivers' knowledge

regarding thalassemia was not at all satisfactory. Regular counseling of caregivers should be done addressing the knowledge lacunae's among them.

Study Elewa & Elkattan,(2017) under the title effect of an educational program on improving quality of nursing care of patients with thalassemia major as regards blood transfusion, aimed to evaluate the effect of an educational program on improving quality of nursing care for patients with thalassemia major as regards blood transfusion. Was conducted at both in- and out-patient pediatric and adult medicine hematology departments affiliated to Ain Shams University Hospital. A purposive sample consisted of two groups: The first group included all nurses (n=30) working in the above mentioned settings; and the second group included adolescent and adult patients with thalassemia major (n=50), who were attending the above mentioned settings over a period of six months, they were chosen randomly. Data were collected through: (I) An interviewing questionnaire which include: sociodemographic data sheet for nurses and patients, nurse's knowledge sheet and routine blood transfusion knowledge questionnaire (RBTKQ) (II) An observational checklist to assess nurse's practice related to blood transfusion, assessment of the body system, measuring of vital signs and administration of intravenous iron chelation therapy. (III) Patient satisfaction scale. Based upon the actual need assessment of the study subjects an intervention program was designed and implemented. Findings revealed that, the educational program had a positive effect on nurses' knowledge and practice related to thalassemia and blood transfusion, which improved quality of nursing care as well as increased patients' satisfaction. The study recommended that, a specialized orientation program should be developed for newly appointed nurses to prepare them before working at the

hematology departments further studies should be conducted to improve nurses' knowledge and practice regarding to blood transfusion care of patients with thalassemia.

The study also examined by Pan et al., (2007) under the title Current status of thalassemia in minority populations in Guangxi, China in order to develop a community-based prevention program, study included 12,900 individuals for α- and β-thalassemia in Baise City with hematological methods and molecular assays. We found that the frequency of carriers in this area for α-thalassemia is 15%. β-thalassemia carriers comprise 4.8% of the populations .Five mutations account for 98% of α-thalassemia [−−SEA 46.7%; −α/4.2, 23.9%; −α/3.7, 21.7%; hemoglobin (Hb) Constant Spring, 6.5%; Hb Quong Sze, 1.1%]. Seven mutations in the β-globin gene account for 99% of the mutations .Most individuals with α-thalassemia major die in the uterus or shortly after birth. Among 106 patients with β-thalassemia major followed by our clinic, the majority died before 5 years of age .This study shows that thalassemia is a very severe public health issue in minority populations in Baise City, China. Identification of the common mutations will allow us to design cost-effective molecular tests. There is an urgent need to educate the general population and the medical community for a successful community-based prevention program.

In a study Abu Samra et al.,(2015) under the title Impact of educational programme regarding chelation therapy on the quality of life for B-thalassemia major children. The study was carried out at the Mansoura University Children's Hospital in the period between March 2010 and May 2011. It included 173 B-thalassemia children (84 boys and 89 girls) with age ranging between 8–18 years.The research findings showed that a significant statistical difference of the studied children's knowledge regarding chelation

therapy and their quality of life.Where the study explained that was a positive effect of the educational programme in improving children's knowledge score and their quality of life. Application of educational programmes for thalassemic children and their nurses regarding chelation therapy and its importance in preventing thalassemia complications is established.

At the thalassemia welfare organization Apollo Specialty Hospital in Chennai, India, a cross-sectional observational study Was conducted Kesavan & Devaskar, (2019). To assess knowledge of the condition, screening, prevention, and medical interventions for thalassemia major, a questionnaire was used. The purpose of this study was to determine how well parents of children, also, Getting regular transfusions for thalassemia major understood the situation. There were 40 parents questioned in total, with 25 (62.5%) of them being Mothers. 25 parents thought an inherited thalassemia , while ninety two percent believed it was a blood disorder that could be Diagnosed with a blood test. Thirty-four parents (85%) believed that if their Children were not treated, they would die. 35 parents (32.5%) feel that consanguineous marriage raises their children's chance of serious thalassemia. Other than chelation and blood transfusions, 28 people (70 %) believed thalassemia major can be cured permanently. Thirty-three parent (82.5 %) believed that if adequate testing is done During pregnancy, thalassemia can be avoided in subsequent births. Conclusion, In a cohort of parents whose children were getting transfusions As part of a thalassemia society, more than (80%) were aware of prenatal Diagnosis for preventing future births, and more than (70%) were aware That a therapeutic alternative is available. Forming groups support parent And widening they

understanding welfare through thalassemia Organizations is to thalassemia free Indian a critical to achieving (Kesavan & Devaskar ,2019) .

In a study Hassan et al.,(2016) under the title Study of the Health Instructions Effect on Quality of Life and Psychological Problems among Children with Thalassemia. Pre and post evaluation done to identify the effect of health instructions sessions which provided by the researchers for thalassemic children and their parents on children heath related quality of life and psychological problems using Pediatric quality of life inventory PedsQL 4.0 generic core scale which was used to measure health-related quality of life in children and adolescent. In addition, Depression, Anxiety and Stress Scale (DASS) used to evaluate psychological problems among children. The total children included in this study were 23 children of either sex, aged (7-18y). The results of this study showed that more than two third of studied children scored medium level in physical and school function. As well as, there was no significant differences in thalassemic children health related quality of life domains post health instructions sessions where $p > 0.05$. Also these study findings demonstrated that 60% of children had extremely sever anxiety and 43.5% of them had severe depression. However, post health instruction sessions these findings showed statistical significant decline where p value = .001 and .000 respectively. An important finding to emerge in this study is studied children with thalthemia had psychological problems with poorer health related quality of life. However, the results set out to the provision of health instructions for children with thalthemia and their parents had significant effect in improvement of children psychological problems.

Study Qader & Hussein, (2013) under the title effectiveness of an educational health programme on mothers' knowledge of thalassaemic

children who receiving desferal therapy in hawler thalassemia center/ erbil city. One hundred mothers were selected and divided into two groups, (50) mothers as control group and another (50) mothers as study group. Educational Health Program was concentrated on several major topics and it was implemented through two sessions, a pretest was done for both groups before implementing the health education program and the post-test was done after one month for both groups .Data were collected through the use of a questionnaire tool by direct interview techniques which was used as a mean of data collection. The results revealed that the mothers' knowledge in the study group was improved their knowledge after implementation health education program at p –value 0.000 comparing in control group. The study recommended to health education programmes apply in mass media (TV , radio journal) . As well as screening should be apply for the risk groups(Carrier population screening detection at population level, Pre-marital, Prenatal and suspected family and their children).

Chapter Three Methodology

Chapter Three

Methodology

3.1. Design of the Study:

Quantitative research with a quasi-experimental study sample divided to two groups (study and control) which gave information about the complication of iron excess in thalassemia children.

3.2. Administrative Arrangements:

The study was approval by Kerbala Governorate's Health Department, the Training and Development Center, and Kerbala Teaching Hospital for Children, also the data was collected after parental agreement (Appendix A – II).

3.3. Ethical considerations:

In order to participate in the study, the participate were fully informed of the current study and its goals and the voluntary verbal consent was received. in addition, the confidentiality of information gained has been taken into account by parents. Ethical approval was also received form the ethical research committee at the faculty of Nursing University of Kerbala regarding confidentiality and anonymity of participants (Appendix A).

3.4 Setting of the study:

Samples were taken from the Thalassemia Center Department of the Kerbala Teaching Hospital for Children, as well as from the parents of children with thalassemia. This hospital provides free healthcare to children with thalassemia. As this hospital included several departments, including the Thalassemia Department, where this department is only specialized in genetic blood cases. This section is integrated in terms of laboratory,

management and registration to preserve patients' information at the time of review, doctors specializing in hematology and specialized nursing staff.

3.5. Sample of the Study:

A non-probability (convenience) sample selected from parents of children with thalassemia in thalassemia center in Kerbala Teaching Hospital for Children. The sample divided to two groups (25) parents as control group and (25) parents as a study group. the study group participates were exposed to an instructional program.

3.6. Steps of the Study:

A preliminary assessment is an initial study aimed at exploring parent's knowledge about complications iron overload in thalassemia center department Kerbala Teaching Hospital for Children. The preliminary study conducted in 7th of December 2021 on 10 participants. The assessment questionnaire of knowledge is composed 28 question; each parents was given a time period between 15 -30 minute to answer the questions, the results of assessment indicate that the parents have poor knowledge in thalassemia center toward complications iron overload, therefore, the assessment revealed that it is essential to create a training program to those parents to progress their information toward complication iron overload.

3.7. Construction of an instructional program:

The instructional program is built based on the findings of the parent needs assessment, as well as a review of relevant scientific literature, previous studies, and program content evaluated by experts in various fields, in order to achieve the following goals:

- The health instructional program was created to give parents knowledge about iron overload complications.
- Causes of iron excess in thalassemic children.

- The indicators of iron overload in thalassemia affected children.
- The crucial method of protecting thalassemia-affected youngsters from iron overload.
- Parents' understanding the iron overload complications among children with thalassemia.
- The crucial method of protecting thalassemia-affected youngsters from iron overload.
- The essential method of treating iron overload in young children with thalassemia.

3.8. Construction of the Instrument:

The questionnaire is created as a method of data gathering after reviewing relevant literature and studies. to assess the impact of the health instructional program on parents about iron overload complications among children with thalassemia.

It was consisted of two major parts:

Part one: Parents socio demographic characteristics that include (age, gender, level of education, residency, occupation, number of children in family).

Part two: is concerned with parent's knowledge towards iron overload That includes:

- The most important results of iron analyze for children with thalassemia (3) item.
- Causes of iron overload among children with thalassemia (5) item.
- The most important signs and symptoms of iron overload among children with thalassemia (5) item.
- The most important complications of iron overload among children with thalassemia (5) item.
- The most important preventive measures of iron overload complication among children with thalassemia (5) item.

- The most important treatment for iron excess in thalassemic children (5) item.

The total number of questionnaire items were (28) items. It is designed on the base of two-level of Likert Scale for knowledge and (5) items for demographic information. Constructs questioner of the items of parent's knowledge are rated on two-level; I know=2 and I don't know=1. The level of knowledge is calculated by estimation of range score for total score and divided into four levels: P= poor (1–1.25), UN= Unacceptable (1.26–1.50), M= Moderate (1.51-1.75), H= High (1.76 - 2). The parents in the study group are provided information about the preventions of iron overload complications before it is knowledge exam, and they are retested when the program is completed. For all tests, the content of the questionnaire remains the same (study & control groups).

3.9 Validity of the questionnaire and the program:

The ability of an instrument's contents to capture the desired data is what establishes the validity of the instrument. An expert panel assesses the clarity, applicability, and usefulness of the questionnaire in measuring the concept of interest before determining the content validity of the early created instrument. The design was presented to (11) Appendix D specialists as a draft of the questionnaire. They are faculty member from the College of Nursing at the University of Babylon, and eight faculity member from Kerbala University, and two specialized physicians in pediatric working in Kerbala Teaching Hospital for Children .

They are requested to study the designed instruments and express their thoughts regarding the program substance, clarity, relevance, and appropriateness; certain Items are omitted and others are added.

3.10. Pilot study

A pilot study was carried out at Kerbala Teaching Hospital for Children, throughout the period from, 21th December to 25th December 2021. The researcher carried out a study of 10 samples.

3.10.1. The purpose of the pilot study to:

- Establish the reliability of the research tools (questionnaire)
- Estimate the time required to fill the questionnaire
- Identify the clarity of the questionnaire
- Identify the barriers that may be encountered during the data collection process.

3.10.2. The result of pilot study

The study instrument was reliable at an excellent level. the questionnaires were acceptable. The questionnaire required to be completed in 30 to 15 minutes.

3.11. Reliability of the study instruments

Reliability of the questionnaire was used to determine the accuracy of the questionnaire, since the results showed very high level of stability and internal consistency of principle parts concerning items responses of the questionnaire, all those were calculated but using the major statistical parameter, Alpha Cronbach, as shown in table (3-2) through calculated the result that the questionnaire is successful, as well as design questionnaire were valid to study phenomenon effective of an instructional program on parents knowledge toward prevention of iron overload complications among children with thalassemia on the same population at any time in the future under assumption of stability of conditions on the studied population and that are accounted on measuring improvements due to applying the suggested of instructional program .

Table 3-1. Appear of the reliability to pilot study to questionnaire

Cronbachs Alpha	N of Items
.976	28

3.12. Implementation of the instructional program:

The study began on the 21th December 2021 and ended on the 3ed April of 2022 with the implementation of the education program. The study's criteria, the parents in the study group requirements were notified and asked to accept to participate in the study. The instructional program's design was addressed, and the study group was exposed.

Program's implementation, which included the following:

Each parents in the study and control groups fills out demographic data, with the exception of one who is interviewed at the Thalassemia Center in Kerbala Teaching Hospital for children. The parents knowledge test have 28 questions. there are two main domains in this section, implementation of instructional two sessions are used to design and present the program. Each information lasts roughly two hours from 10 to 12 in the morning (five days). (including pre-test and post- test 1) and the number of parents attended are (25) parents (study group) and post-test 2 applied after one month.

3.13. Sessions of the Program:

First session time two hours during two days

- Introduction about the blood & the blood component.
- Definition of thalassemia.
- Type of thalassemia.
- Risk factors.
- Signs & symptoms.
- Time of lecture tow hour

Second session time two hours during three days:

- Complication of beta thalassemia major.
- Treatment of beta thalassemia major.
- Prevention complication of iron overload
- Blood transfusion.
- Iron overload.
- Treatment of iron overload.
- Nutritional of decrease of iron overload.

3.14. Teaching Methods:

- Presented by (power point) display screen.
- Discussion.
- Lectures.
- Picture
- Video

3.15. Place of Lectures:

Lectures have been done in patient ward in Thalassemia Center in Kerbala Teaching Hospital for Children.

3.16. Data Collecting:

Before beginning the data collection process, the researcher has made the necessary arrangements to gather the study samples from Thalassemia center in Kerbala Teaching Hospital for Children. The information was gathered between the 2^{end} January 2021 to the 4th of April 2022.

3.17. Date Analysis:

The statistical package for social sciences (SPSS) 2021 edition 22 includes the mean, standard deviation, frequency, and percentage as well as paired sample T-test, pearson correlation, one-Way ANOVA, and linear regression, descriptive statistic method for parents' knowledge toward the prevention of iron overload complications among Children with Thalassemia. The Significance level is at $p<0.05$.

Chapter Four

Results of the Study

Chapter Four

Results of the Study

This part presents the statistical result and findings of the current study in tables and their correspondence with the objectives of the study as shown in the tables:

Table (4-1): Distribution of the participants including study and control groups according to their demographic characteristics

Demographic Characteristics	Variables	Control Group (n=25)		Study Group (n=25)		C. S P. value
		f.	**%**	**f.**	**%**	
Age	< 25 years	1	4.0	0	0	**.265 N.S**
	≥ 25 years	24	96.0	25	100.0	
	Total	25	100.0	25	100.0	
	Mean ± SD	**39.04 ± 8.858**		**38.24 ± 7.120**		
Gender	Male	15	60.0	9	36.0	**.234 N.S**
	Female	10	40.0	16	64.0	
	Total	25	100.0	25	100.0	
Level of Education	Illiterate	6	24.0	6	24.0	**.368 N.S**
	Literate	6	24.0	8	32.0	
	Secondary school	8	32.0	6	24.0	
	High school	4	16.0	2	8.0	
	College and above	1	4.0	3	12.0	
	Total	25	100.0	25	100.0	
Occupation	Work	18	72.0	15	60.0	**.856 N.S**
	Not work	7	28.0	10	40.0	
	Total	25	100.0	25	100.0	
Residence	Rural area	10	40.0	10	40.0	**1.00 N.S**
	City	15	60.0	15	60.0	
	Total	25	100.0	25	100.0	
Number of children	1-2	24	96.0	15	60.0	**.233 N.S**
	3-4	1	4.0	10	40.0	
	Total	25	100.0	25	100.0	
	Mean ± SD	**1.36 ± .569**		**2.08 ± .954**		

f.: Frequency, No.: Number, %Percentage, M = Mean of score, S. D=Standard Deviation, C. S= chi –square, N.S = Non significant at p > 0.05.

Table (4-1) reveals that age of the parents (n= 50 for two groups) was less than forty years old as accounted for study and control groups respectively with Mean ± SD 39.04 ± 8.858 in control group and 38.24 ± 7.120 in study group. According to gender, the male was a more than 50 % in the control group while the female more than 50 % in the study respectively. 32% of parents were completed secondary school in the control group while in the study group the 32% of parents were literate. According to the occupation the majority of parents were represented 72% in control group and also in study group the most participant were work represented 60%. Regarding the residence, the most parents living in city in control and study groups represented 60%. Also the results showed the majority of parents had one to two children with Mean ± SD 1.36 ± .569 in control group represented 96% and also the most participants in study group had one to two children with Mean ± SD 2.08 ±.954 represented 60%.

Based on the analyzed result by the chi-square there is no statistically significant homogeneity with demographics two groups ($p>0.05$).

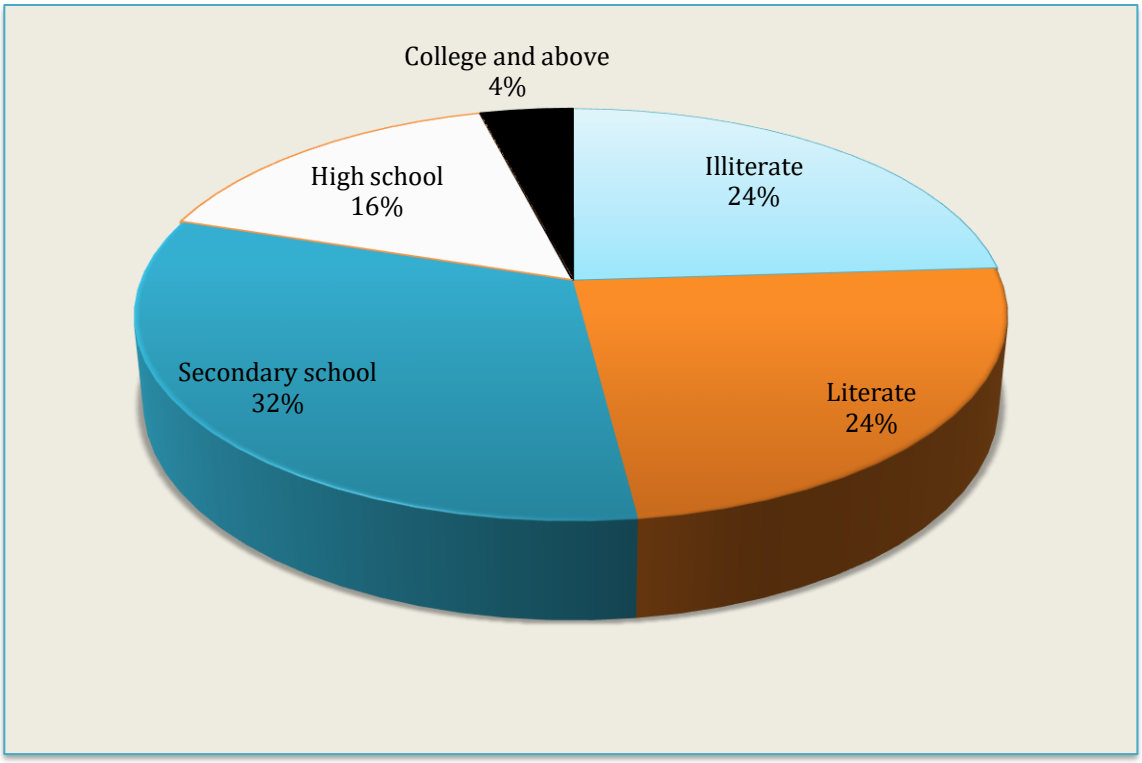

Figure (4-1): Distribution levels of education in control group

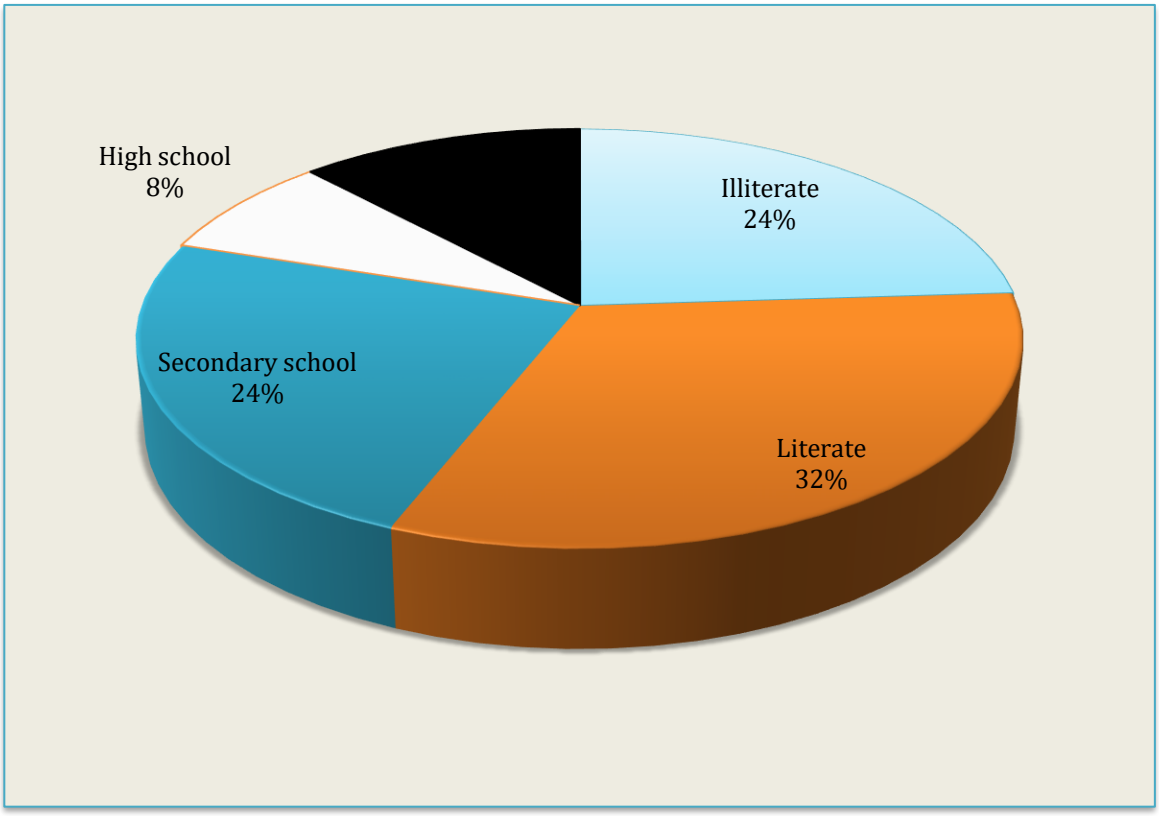

Figure (4-2): Distribution levels of education in study group

Table (4-2):The parents' knowledge concerning children with iron overload in pre, first and second post - test for the study and control groups

Domains		Control group			Study group		
		M	SD	Eva.	M	SD	Eva.
1. The most important results of iron analyzes for children with Thalassemia	Pre test	1.13	.272	P	1.14	.297	P
	Post test	1.15	.273	P	1.59	.374	M
	Post2 test	1.18	.274	P	1.76	.246	H
2. Causes of iron overload in children with thalassemia	Pre test	1.21	.192	P	1.24	.270	P
	Post test	1.26	.233	UN	1.63	.287	M
	Post2 test	1.29	.216	UN	1.83	.299	H
3. The most important symptoms and signs of iron overload in children with thalassemia	Pre test	1.44	.330	UN	1.46	.300	UN
	Post test	1.45	.323	UN	1.81	.353	H
	Post2 test	1.59	.296	M	2.00	.000	H
4. The most important complications of iron overload in children with thalassemia	Pre test	1.58	.275	M	1.62	.289	M
	Post test	1.59	.261	M	1.83	.293	H
	Post2 test	1.61	.261	M	1.98	.088	H
5. The most important prevention of iron overload in children with thalassemia	Pre test	1.35	.296	UN	1.41	.313	UN
	Post test	1.36	.275	UN	1.86	.262	H
	Post2 test	1.39	.275	UN	1.90	.263	H
6. The most important treatment for iron overload in children with thalassemia	Pre test	1.24	.325	P	1.24	.352	P
	Post test	1.26	.342	UN	1.67	.243	M
	Post2 test	1.28	.342	UN	1.80	.284	H
Total knowledge	Pre test	1.32	.195	UN	1.35	.223	UN
	Post test	1.34	.205	UN	1.73	.213	M
	Post2 test	1.39	.176	UN	.87	.113	H

M = Mean of score, S.D=Standard Deviation, Eva=evaluation level, P = poor (1 – 1.25), UN= Unacceptable (1.26 – 1.50), M= Moderate (1.51- 1.75), G = Good (1.76 - 2).

Table (4-2) showed evaluation the parents' knowledge concerning children with iron overload in pre, posts first and second posts test in control group were un acceptable knowledge level, also in pre study group were un

acceptable knowledge level, while in first post instructional program in study group the evaluation were moderate and in second post instructional program in study group the evaluation were good.

Table (4-3): Comparison for domains between pre, first and second post - test for the study and control groups for Parents' knowledge concerning children with iron overload.

Domains		Control Group		Study Group		t- test statistics
		M	**SD**	**M**	**SD**	**Sig.**
1. The most important results of iron analyzes for children with Thalassemia	Pre test	1.13	.272	1.14	.297	**.161 NS**
	Post test	1.15	.273	1.59	.374	**.034 S**
	Post2 test	1.18	.274	1.76	.246	**.000 HS**
2. Causes of iron overload in children with thalassemia	Pre test	1.21	.192	1.24	.270	**.238 NS**
	Post test	1.26	.233	1.63	.287	**.049 S**
	Post2 test	1.29	.216	1.83	.299	**.000 HS**
3.The most important symptoms and signs of iron overload in children with thalassemia	Pre test	1.44	.330	1.46	.300	**.825 NS**
	Post test	1.45	.323	1.81	.353	**.044 S**
	Post2 test	1.59	.296	2.00	.000	**.001 S**
4.The most important complications of iron overload in children with thalassemia	Pre test	1.58	.275	1.62	.289	**.368 NS**
	Post test	1.59	.261	1.83	.293	**.048 S**
	Post2 test	1.61	.261	1.98	.088	**.003 S**
5.The most important prevention of iron overload in children with thalassemia	Pre test	1.35	.296	1.41	.313	**.457 NS**
	Post test	1.36	.275	1.86	.262	**.043 S**
	Post2 test	1.39	.275	1.90	.263	**.001 S**
6. The most important treatment for iron overload in children with thalassemia	Pre test	1.24	.325	1.24	.352	**.822 NS**
	Post test	1.26	.342	1.67	.243	**.020 S**
	Post2 test	1.28	.342	1.80	.284	**.000 HS**
Total knowledge	Pre test	1.32	.195	1.35	.223	**.754 NS**
	Post test	1.34	.205	1.73	.213	**.035 S**
	Post2 test	1.39	.176	1.87	.113	**.000 HS**

M = Mean of score, S.D=Standard Deviation, Sig.= Significance, N.S=Non Significant at p>0.05, S= Significant at p<0.05, H.S: High Significant at p<0.001. d.f=degree freedom

Table (4-3) showed there were highly significant statistical differences between second posttest of control and study groups at p< 0.001 for parent's knowledge toward iron overload and significant statistical differences between first posttest of control and study groups at p<0.05, while the results showed there were non-significant statistical differences between pretest of control and study groups at p>0.05.

Table (4-4): The effect of program for parent's knowledge by comparison between Pre with first and second Post- test for the study and control groups for Parents' knowledge concerning children with iron overload.

Group	Pre		First Post		Paired t Test statistics			Second Post		Paired t Test statistics		
	M.	SD	M.	SD	t-test	df	Sig.	M.	SD	t-test	df	Sig.
Control	1.32	.195	1.34	.205	1.107-	24	.279	1.39	.176	.744-	24	.464
Study	1.35	.223	1.73	.213	2.718-	24	.012	1.87	.113	2.833-	24	.000

M = mean of score, S.D=Standard Deviation, d.f=degree freedom, Sig. = Significance, N.S =Non Significant at p > 0.05, S= Significant at p < 0.05, H.S: High Significant at p < 0.001.

Table (4-4) showed there were significant statistical differences between pre and first posttest of study group at p < 0.05 for parent's knowledge toward iron overload and highly significant statistical differences between pre and second posttest of study group at p < 0.001, while the results showed there were non-significant statistical differences between pre with first and second posttest of control group at p>0.05.

Table (4-5): Effect of program to parent's knowledge by comparison the level between Pre with first and second Post- test for the study and control Groups for parents' knowledge concerning children with iron overload

Group	Pre	First Post	Paired t Test statistics			Pre	Second Post	Paired t Test statistics		
	M.	M.	t-test	df	Sig.	M.	M.	t-test	Df	Sig.
Control	UN	UN	-1.107-	24	.279	UN	UN	-.744-	24	.464
Study	UN	M	-2.718-	24	.012	UN	G	-2.833-	24	.000

M = mean of score, S.D=Standard Deviation, d.f=degree freedom, Sig. = Significance, N.S =Non Significant at p > 0.05, S= Significant at p < 0.05, H.S: High Significant at p < 0.001.

Table (4-5) showed there were significant statistical differences between pre and first posttest of study group at $p < 0.05$ for parent's knowledge toward iron overload and highly significant statistical differences between pre and second posttest of study group at $p < 0.001$, while the results showed there were non-significant statistical differences between pre with first and second posttest of control group at $p>0.05$.

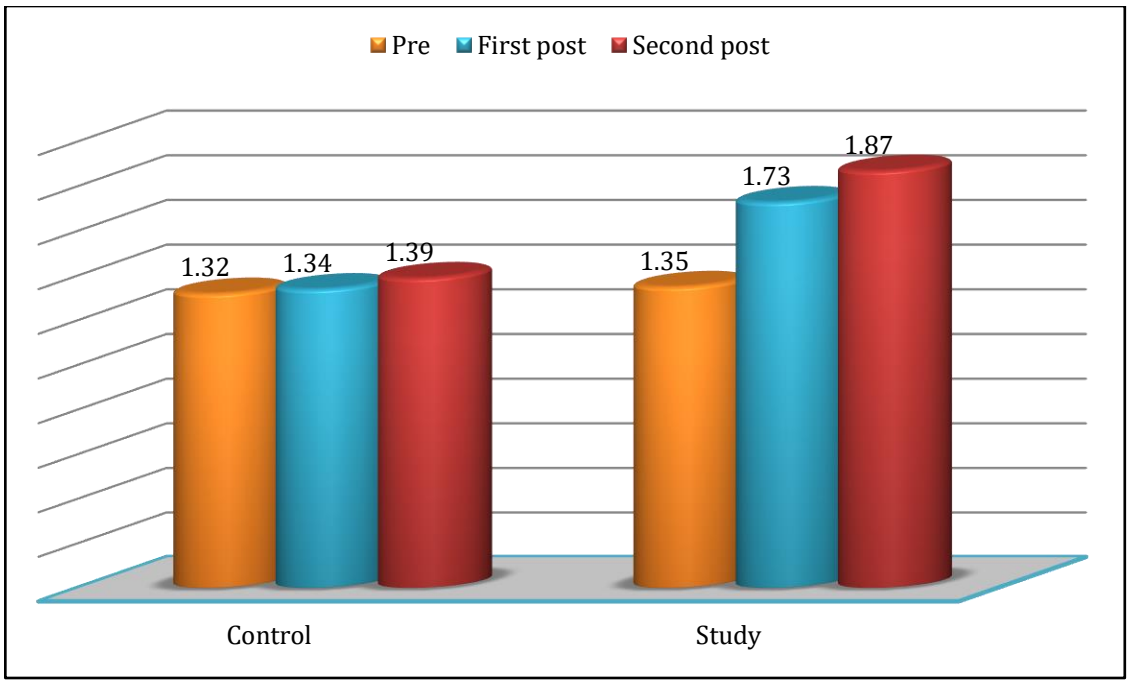

Figure (4-3): The differences between Pre, first and second post - test for study and control groups of the instructional program on parents' knowledge toward the prevention of iron overload complications among child with thalassemia.

Table (4-6):The relationship between effectiveness of an instruction program with the age of the participants

Demographic	Mean	SD	Analysis	P. value
Age	1.87 ± .113		Cc = .060	.776

P=probability value, NS: Non-Significant at P > 0.05, S: Significant at P < 0.05, HS: Highly Significant at P < 0.01

In table (4-6) the results showed there was non-significant statistical correlation between parent's age with their knowledge toward the prevention of iron overload complications among children with thalassemia at P > 0.05.

Table (4-7):The relationship between effectiveness of an instruction program with the gender of the participants

Demographic	Variables	Mean	SD	Analysis	P. value
Gender	Male	1.70	.106	F = .046	.832
	Female	1.69	.120		

P=probability value, NS: Non-Significant at P > 0.05, S: Significant at P < 0.05, HS: Highly Significant at P < 0.01

In table (4-7) the results showed there were no significant statistical differences between parents knowledge and there gender at P > 0.05.

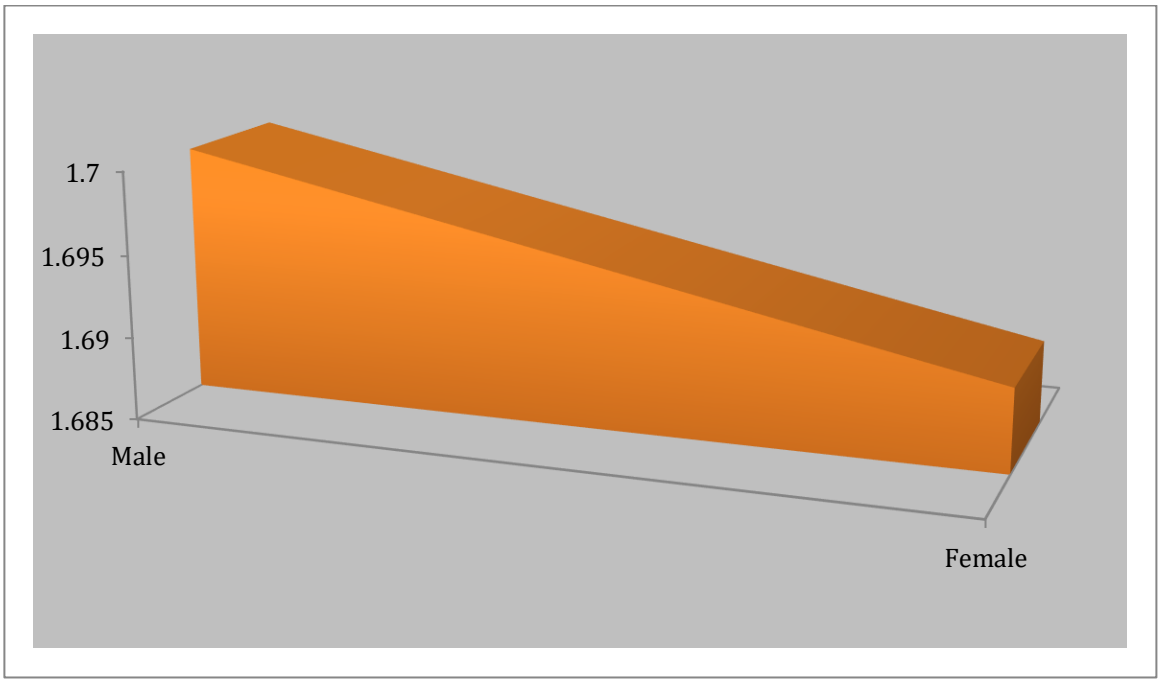

Figure (4-4): The differences between gender values

Table (4-8): The relationship between effectiveness of an instruction program with the educational level of the participants.

Demographic	Variables	Mean	SD	Analysis	P. Value
Levels of Education	Illiterate	1.59	.054	F =3.236	.034
	Literate	1.65	.189		
	Secondary school	1.69	.061		
	High school	1.74	.096		
	College and above	1.81	.178		

P=probability value, NS: Non-Significant at P > 0.05, S: Significant at P < 0.05, HS: Highly Significant at P < 0.01.

In table (4-8) the results showed there were significant statistical differences between parents knowledge and there level of education at P < 0.05.

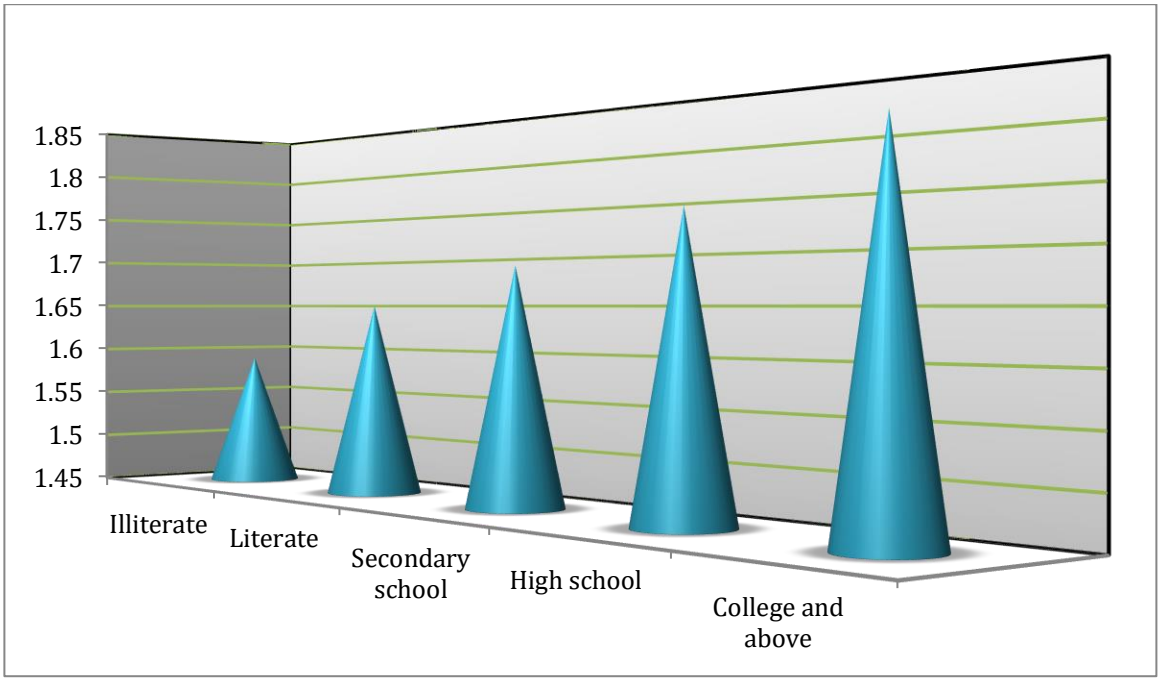

Figure (4-5): The differences between level of educational values

Table (4-9):The relationship between effectiveness of an instruction program with the number of children of the participants

Demographic	Variables	Mean	SD	Analysis	P. value
Number of children	1-2 children	1.72	.122	F = .237-	.254
	3-4 children	1.65	.084		

P=probability value, NS: Non-Significant at P > 0.05, S: Significant at P < 0.05, HS: Highly Significant at P < 0.01.

In table (4-9) the results showed there was non-significant statistical correlation between parent's number of children with their knowledge toward the Prevention of iron overload complications among child with thalassemia at P > 0.05.

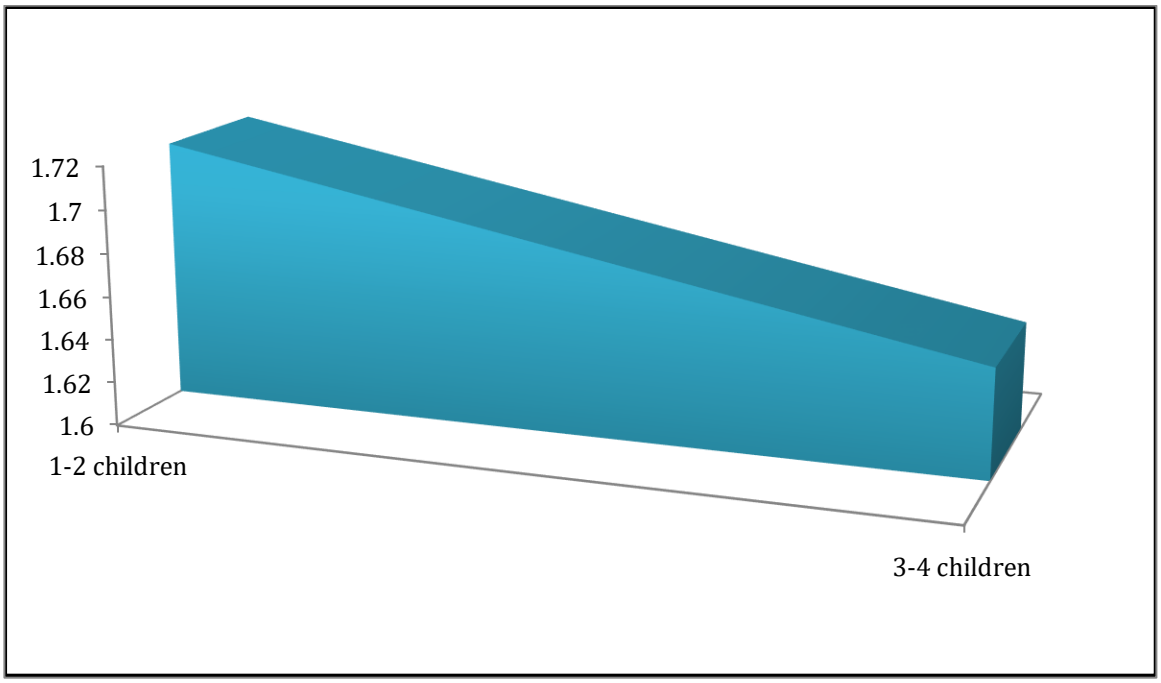

Figure (4-6): The differences between number of children values

Chapter Five Discussion

Chapter Five

Discussion of the Findings

5.1. Distribution of the participants including study and control groups according to demographic characteristics.

The analysis of findings in table (4-1) shows the distribution of parents participating in the study according to their socio-demographic data, as it showed that age of the parents (n= 50 for two groups) was less than forty years old as accounted for study and control group respectively with Mean ± SD 39.04 ± 8.858 in control group and 38.24 ± 7.120 in study group. According to gender, the male was a more than 50% in the control group while the female more than 50% in the study respectively. A high percentage (n=8; 32%) of parents were completed secondary school in the control group while in the study group the high percentage of parents were literate. According to represented 72% the occupation the majority of parents were work in control group represented 32% and also in study group the most participant were work represented 60%. Regarding the residence, the most parents 60% living in city in control and study groups. Also represented 96% the results showed the majority of parents had one to two children with Mean ± SD 1.36 ± .569 in control group and also the 60% participants in study group had one to two children with Mean ± SD 2.08 ±.954.Based on the analyzed result by the chi-square there is no statistically significant difference with demographics two groups ($p>0.05$).

The current findings are backed up by studies Pouraboli et al., 2017 which found that the bulk of the samples was between the ages of 37 and 46.In proportion to the level of education in study the high percentage of parents were literate, also present study agree with study conducted by Meah

et al.,2021which indicated that the level of education of parents secondary level 29.77%, According to the occupation the majority of parents were work 59.54%. It also agrees with the study Jeesh et al., 2018 which indicated that educational level 53% of parents got their school education and higher education respectively. Also the results showed the majority of parents had one to two children .These findings disagree with study conducted by Hossain et al.,2021 revealed additional evidence in her study, stating that 42 % families had more than two children. Indicated Coifman et al., 2014 that higher literacy rate, poses a stronger impact on parental behavior to cope and manage thalassemia. Increased literacy rate has also been found to have a positive impact on prenatal diagnosis and premarital screening, which enables the couple to effectively manage thalassemia and to opt the preventive methods, such as termination of pregnancy.

The current study are disagreed with the study conducted by Goyal et al.,2015 which found that of male 69% outnumbered female, the level of education was low among study subjects and almost 20% parents of children with thalassemia were found to be illiterate. It also differed with the study El-Said Zaghamir et al., 2019 which found that most of mother age ranged between 27 and 50 years , median 35.5 years ,while fathers ' age ranged between 33 and 55 years, median 41 years . Most mothers and fathers had basic / intermediate level of education 50% and 60% respectively. The majority of the mothers were housewives 86% and of the fathers were employees 82%. Regarding the residence the most parents 58% living in rural residences.

5.2. The parents' knowledge concerning children with iron overload in pre, first and second post-test for the study and control groups:

Table (4-2): shows the parents' knowledge concerning children with iron overload in pre, first and second post in control group were un acceptable knowledge level, also in pre study group were un acceptable knowledge level, while in first post instructional program in study group the evaluation were moderate and in second post instructional program in study group the evaluation were good.

The lack of knowledge and awareness about iron overload and their side effects and the means of managing these side effects is an important problem that interferes with compliance with decrease side effects that occurs because of the lack of knowledge problem, was mirrored in the results of the present study where almost all the studied parents had unsatisfactory total knowledge score about iron overload and side effects before implementation of instructional program. Where Khanna et al.,2015 indicated that thalassemia has a negative impact on sexual and physical growth of sick children because of abnormal hormonal growth and lack of healthy diet, along with iron overload due to excessive blood transfusion

The present study agree with study by El Sayed & Hussein, 2002 understanding the disease and factors the resultant iron overload compromises the chances of child's survival are crucial to proper parents management and leads to decrease side effects that occurs because of the poor the knowledge, it contributed educational intervention to lower incidence of painful lump and abscess formation that mothers reported as the most common side effect of the chelation therapy .

5.3. Comparison for domains between pre, first and second post - test for the study and control groups for parents' knowledge concerning children with iron overload: -

Tables (4-3) (4-4) and (4-5) :shows there are highly significant statistical differences between second posttest of control and study groups at p< 0.001 for parent's knowledge toward iron overload and significant statistical differences between first posttest of control and study groups at p<0.05, while the results showed there were non-significant statistical differences between pretest of control and study groups at p>0.05.

The present study agree with study done by El-Said Zaghamir et al., 2019, which carried out a research to determine the impact of an educational program about iron chelation therapy in Egypt. Demonstrates that the area of lowest percentage of satisfactory knowledge between the studied parents prior to the program was that of management 12%. Statistically significant improvements were revealed at the post-intervention phase in all knowledge domains (p 0.001). In the follow - up, nearby was slight decrease, especially into the area of management 54.0%. However, the percentages of satisfactory knowledge remained significantly higher compared to pretest.

lationship between effectiveness of an instruction program with the age and gender and level of education and number of children of the participants: -

Table (4-6) (4-7) (4-8) and (4-9): the results showed there was no significant statistical correlation between knowledge of the parents and

their age, gender, and number of children but the correlation with education levels at $P > 0.05$.

The present study agree with study done by Dehkordi & Heydarnejad, 2008 which indicated that the non-significant differences were found between the groups tested in terms of the mean parent's age, gender, level of education, job, number of affected children about knowledge of parents about toward the prevention of complications thalassemia ,Where the study indicated that efficient educational programs initiated for the parents can help reduce ß-thalassemia major disorder. In study Basu, 2015, non-significant relationship between thalassemia knowledge and age group, whereas in study Ishaq et al.,(2012), respondents aged 60 years and above and those falling in the 40-49 years age group gave more correct answers compared to the rest of age groups.

The present study agree with study done by Hossain et al., 2021 which indicated that the non-significant relationship between parents knowledge and gender and number of children. It also agrees with study done by Atshan et al., 2022 which indicated that is high statistical significant relationship between parents' knowledge and educational level. Knowledge, education, awareness about causes and information about the preventive measures of thalassemia play a significant role for the propagation and control of the disease ,measured a connotation between the level of education of parents and caregivers and the prevalence of thalassemia and it had been found that educated parents and caregivers tend to worry more about career screening and keen to learn about genetic counselling as compared to the respondents with low level of education (Zaman & Salahuddin, 2006).

Shawkat et al., 2019 indicated that educational programs and counseling sessions should be developed with couples and families, to build

a family-centered empowerment model for thalassemia control and prevention, enrich parenting knowledge, feel in control of illness, emotional disorders, and modify psychological dysfunction. Furthermore, these strategies develop the ability among the couples to make decisions about the lives of the sick children and families and to provide care.

Researches have proven that family functioning and family empowerment are the two major blocks, that enable couples, parents and families to build social, psychological and emotional fortes to effectively allay thalassemia (Borimnejad et al.,2018). Also study by Basu, 2015 conducted in Srinagarind Hospital showed that the factors contributing to the assessment of knowledge of thalassemia are the level of education and family income.

Chapter Six

Conclusions and Recommendations

Chapter Six

Conclusions and Recommendations

6.1. Conclusions:

According to the findings of the present study, the researcher concluded the following:

1- The most of parents involved in this study are within the age group of (≥25) ,And the female more than (50.0%).A high percentage (32%) of parents have educational level (literate). most participant were work 60% and most parents 60% living in city . Also the results showed the majority of parents 96% had one to two children.
2- The instructional program is effective in the improvement of parent's knowledge regarding prevention of iron overload complications.
3- The instructional program had a significant impact by using post-tests one and posttest two to increase of parents' knowledge in the study group at $p>0.05$.
4- There is no significant statistical correlation between parents knowledge and their age, gender, and number of children but statistically significant relationship with education levels at $P > 0.05$.
5- The study concluded that, during the pre-test period and before to the development of the instructional program, the parents in the study group demonstrated a lack of understanding regarding complication of iron overload for children with thalassemia.

6.2. Recommendations:

The researcher recommends the following issues:

1- The Instructional guidelines, posters and booklets, about complication of iron overload among children with thalassemia.
2- The motivate parents to attend complication of iron overload of children with thalassemia-related training courses and conferences to keep their knowledge up to date.
3- The instructional program for parents can be devised and constructed, with an emphasis complication of iron overload with children thalassemia.
4- The Iraqi health ministry should develop policies targeted at assisting, understanding, and then supporting parents and unwell children with iron overload in the near future, and lastly, instructional programs for parents must be recognized to improve the parents' skills, knowledge, skills, and practice, In order to be more representative and gain more results, new studies can be undertaken in other contexts and locations with a larger range of sample characteristics.

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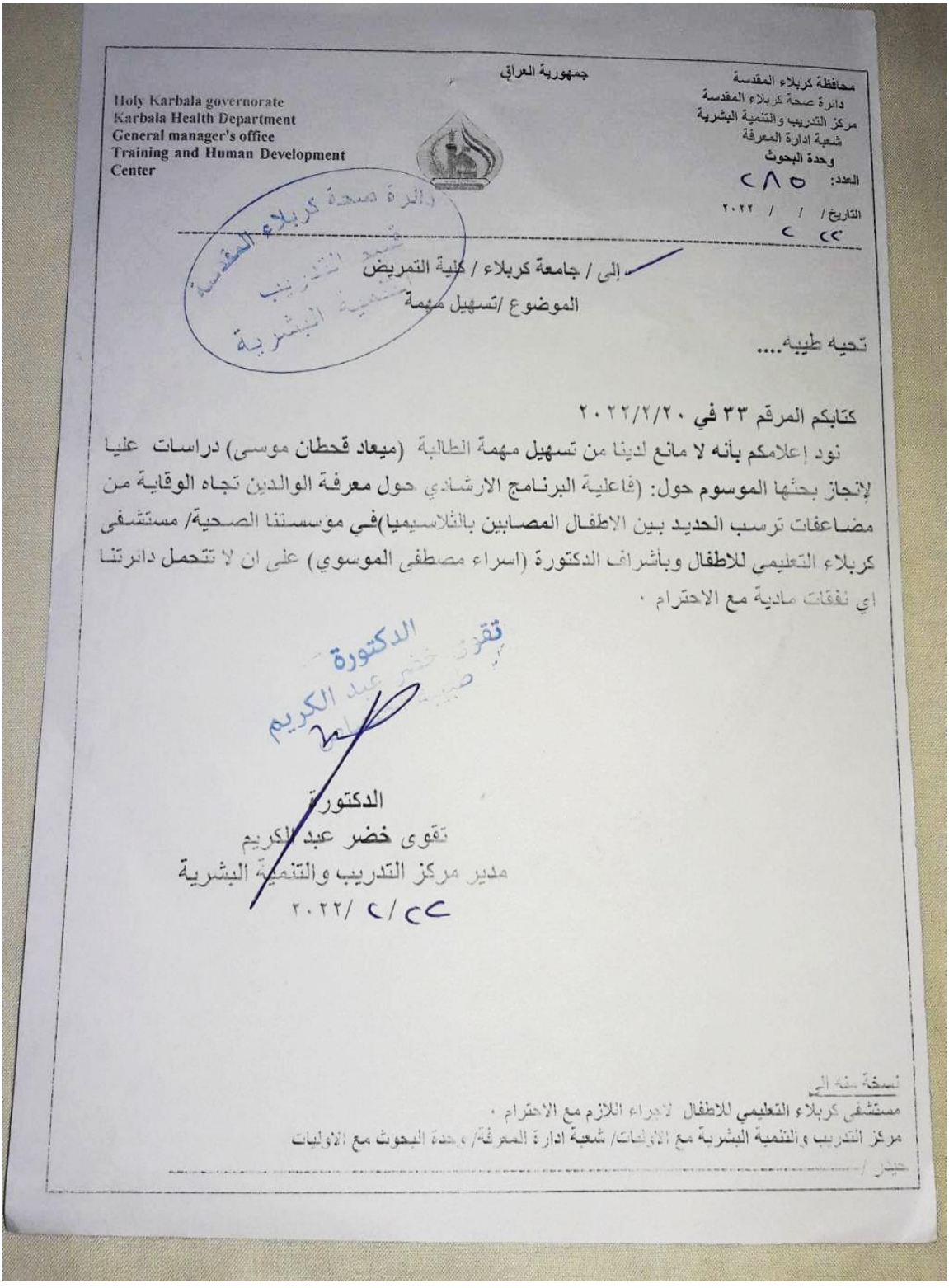
Appendices

Administrative Agreements

Appendix A-I



جمهورية العراق

محافظة كربلاء المقدسة
دائرة صحة كربلاء المقدسة
مركز التدريب والتنمية البشرية
شعبة ادارة المعرفة
وحدة البحوث
العدد: ٢٨٥
التاريخ / / ٢٠٢٢
٢٢/ ٢

Holy Karbala governorate
Karbala Health Department
General manager's office
Training and Human Development
Center

دائرة صحة كربلاء المقدسة
مركز التدريب والتنمية البشرية

إلى / جامعة كربلاء / كلية التمريض
الموضوع /تسهيل مهمة

تحيه طيبه....

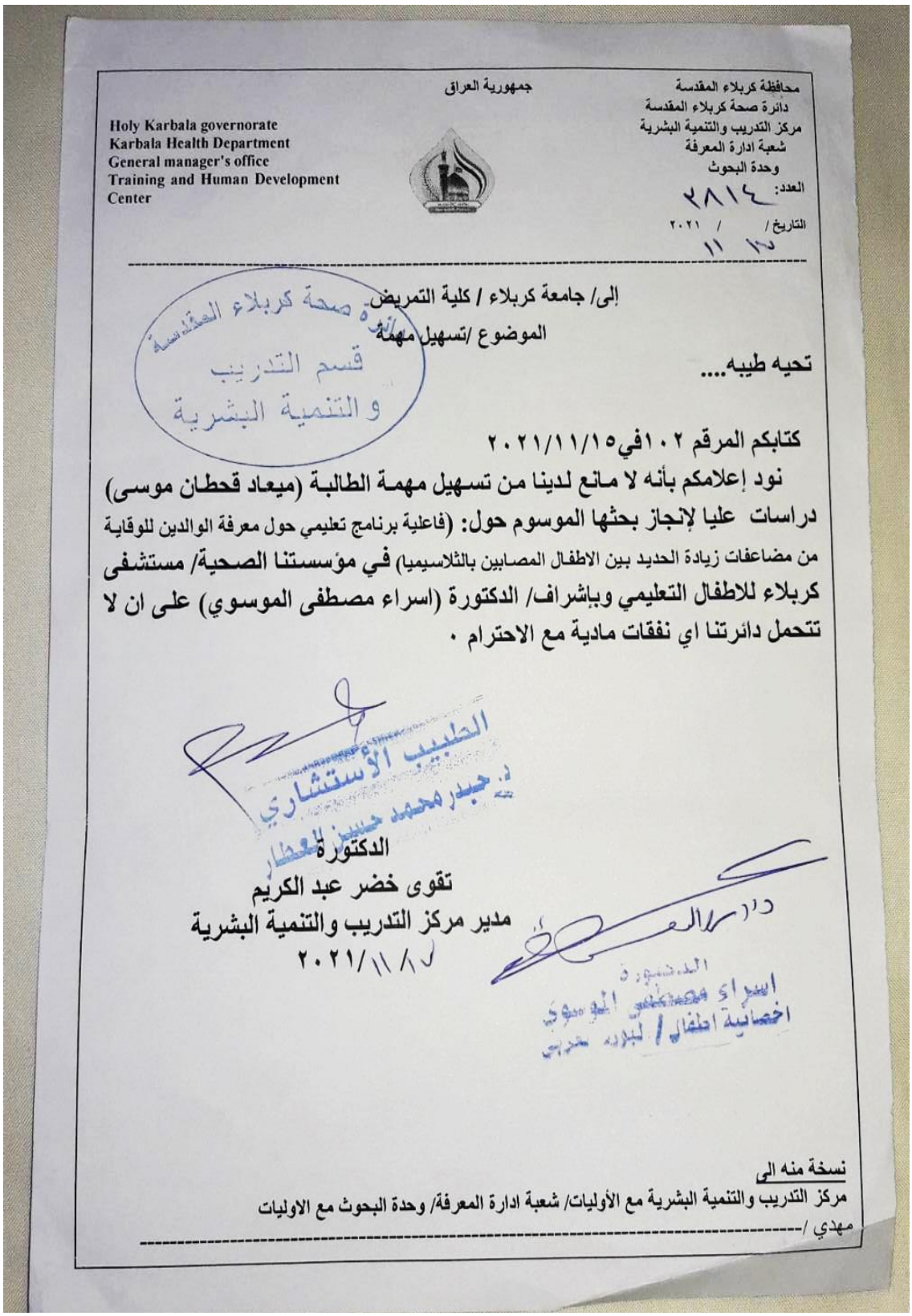
كتابكم المرقم ٣٣ في ٢٠٢٢/٢/٢٠

نود إعلامكم بانه لا مانع لدينا من تسهيل مهمة الطالبة (ميعاد قحطان موسى) دراسات عليا لإنجاز بحثها الموسوم حول: (فاعلية البرنامج الارشادي حول معرفة الوالدين تجاه الوقاية من مضاعفات ترسب الحديد بين الاطفال المصابين بالثلاسيميا)في مؤسستنا الصحية/ مستشفى كربلاء التعليمي للاطفال وبأشراف الدكتورة (اسراء مصطفى الموسوي) على ان لا تتحمل دائرتنا اي نفقات مادية مع الاحترام ٠

الدكتورة
تقوى خضر عبد الكريم
مدير مركز التدريب والتنمية البشرية
٢٢/ ٢/ ٢٠٢٢

نسخة منه الى
مستشفى كربلاء التعليمي للاطفال لاجراء اللازم مع الاحترام ٠
مركز التدريب والتنمية البشرية مع الاوليات/ شعبة ادارة المعرفة/ وحدة البحوث مع الاوليات

Appendix A-II



جمهورية العراق

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شعبة ادارة المعرفة
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العدد: ٢٨١٤
التاريخ / ١١ / ٢٠٢١

Holy Karbala governorate
Karbala Health Department
General manager's office
Training and Human Development Center

إلى/ جامعة كربلاء / كلية التمريض

الموضوع /تسهيل مهمة

تحيه طيبه....

كتابكم المرقم ١٠٢ في ٢٠٢١/١١/١٥

نود إعلامكم بأنه لا مانع لدينا من تسهيل مهمة الطالبة (ميعاد قحطان موسى) دراسات عليا لإنجاز بحثها الموسوم حول: (فاعلية برنامج تعليمي حول معرفة الوالدين للوقاية من مضاعفات زيادة الحديد بين الاطفال المصابين بالثلاسيميا) في مؤسستنا الصحية/ مستشفى كربلاء للاطفال التعليمي وبإشراف/ الدكتورة (اسراء مصطفى الموسوي) على ان لا تتحمل دائرتنا اي نفقات مادية مع الاحترام .

الطبيب الأستشاري
د. حيدر محمد حسين العطار

الدكتورة
تقوى خضر عبد الكريم
مدير مركز التدريب والتنمية البشرية
٢٠٢١/١١/١٧

الدكتورة
اسراء مصطفى الموسوي
اخصائية اطفال / لبوه حرب

نسخة منه الى
مركز التدريب والتنمية البشرية مع الأوليات/ شعبة ادارة المعرفة/ وحدة البحوث مع الاوليات
مهدي /

Appendix A-III

Republic of Iraq
Ministry of higher education & scientific research
University of Kerbala
College of Nursing

جمهورية العراق
وزارة التعليم العالي والبحث العلمي
جامعة كربلاء
كلية التمريض
الدراسات العليا

اقرار الخبير الاحصائي

اشهد بان الرسالة الموسومة :

(فاعلية برنامج ارشادي حول معرفة الوالدين بآليات الرعاية من مضاعفات تركيب الحديد بين الأطفال المصابين بالثلاسيميا)

قد تم الاطلاع على الاسلوب الاحصائي المتبع في تحليل البيانات واظهار النتائج الاحصائية وفق مضمون الدراسة ولأجله وقعت.

توقيع الخبير الاحصائي:
الاسم واللقب العلمي: م.د. إيناس عبد الكاظم أحمد
الاختصاص الدقيق: إحصاء حيوي
مكان العمل: جامعة كربلاء / كلية الإدارة والاقتصاد / الإحصاء
التاريخ: ٧ / ٦ / 2022

Appendix A-IV

«استمارة التقييم الاحصائي للبحوث والرسائل والاطاريح»

اسم الطالب : عبد الحسين عطشان سعود

عنوان البحث أو الرسالة أو الاطروحة : تأثير برنامج ارشادي حول معرفة الوالدين لحاجات الطفل المعاق بالإعاقة السمعية

الجامعة : كربلاء الكلية : الإدارة والاقتصاد نوع الدراسة: ماجستير

ت	المعايير	مستوفي	غير مستوفي
1	مدى ملائمة الفرضيات الاحصائية لمحتوى البحث او الرسالة او الاطروحة	✓	
2	مدى التزام الباحث بالاساليب الاحصائية في التحليل الاحصائي	✓	
3	التزام الباحث بالفرضيات التي وضعت للبحث او الرسالة او الاطروحة	✓	
4	مدى استخدام الباحث للاسلوب الاحصائي في عرض النتائج ومناقشتها	✓	
5	مدى التزام الباحث بتوظيف المصادر الاحصائية الحديثة في محتوى البحث او الرسالة او الاطروحة	✓	
6	النتائج التي خرج بها البحث او الرسالة او الاطروحة حسب استخدام الوسائل الاحصائية	✓	

القرار العلمي الاحصائي (الملاحظات)
☑ ارسالها للمناقشة بعد اجراء التعديلات المطلوبة من المقوم الاحصائي من قبل الباحث وباشراف المشرف، ويعرض تقرير المقوم الاحصائي على لجنة المناقشة.
☐ لا تحقق متطلبات نيل الشهادة من وجهة نظر المقوم الاحصائي للاسباب التالية

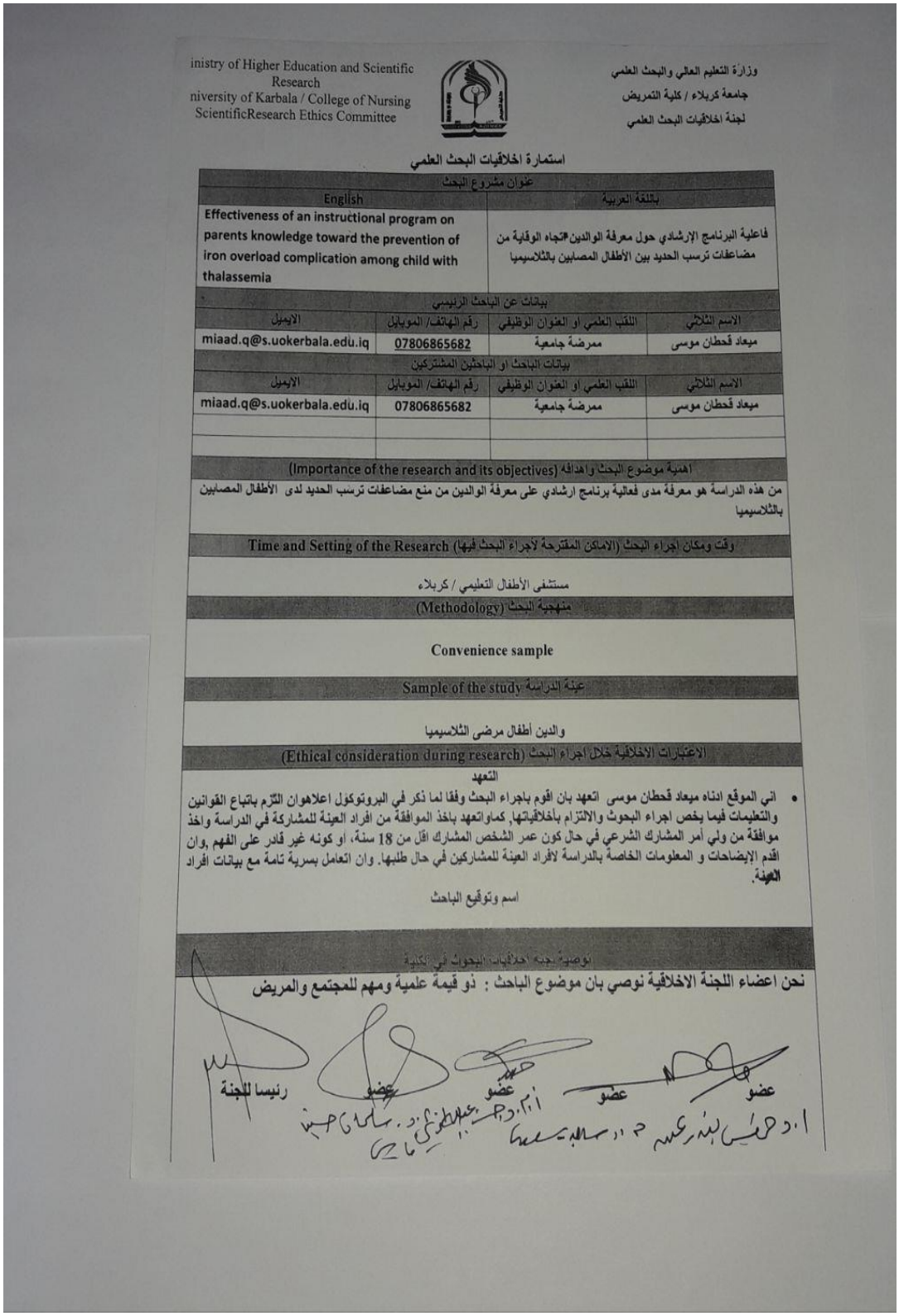
ملاحظة //في حالة وجود ملاحظات اخرى كثيرة لاعطاء القرار العلمي الاحصائي اعلاه ، يرجى كتابتها في ورقة منفصلة بالاستمارة على ان تكون موقعة من قبل المقوم الاحصائي ايضاً.

التوقيع :

اسم الاستاذ: م.د. بنا عبد الحافظ

محل عملة : جامعة كربلاء / كلية الادارة والاقتصاد / قسم الاحصاء

Appendix A-V



inistry of Higher Education and Scientific Research
niversity of Karbala / College of Nursing
ScientificResearch Ethics Committee

وزارة التعليم العالي والبحث العلمي
جامعة كربلاء / كلية التمريض
لجنة اخلاقيات البحث العلمي

استمارة اخلاقيات البحث العلمي

عنوان مشروع البحث	
English	باللغة العربية
Effectiveness of an instructional program on parents knowledge toward the prevention of iron overload complication among child with thalassemia	فاعلية البرنامج الإرشادي حول معرفة الوالدين اتجاه الوقاية من مضاعفات ترسب الحديد بين الأطفال المصابين بالثلاسيميا

بيانات عن الباحث الرئيسي			
الاسم الثلاثي	اللقب العلمي او العنوان الوظيفي	رقم الهاتف/ الموبايل	الايميل
ميعاد قحطان موسى	ممرضة جامعية	07806865682	miaad.q@s.uokerbala.edu.iq

بيانات الباحث او الباحثين المشتركين			
الاسم الثلاثي	اللقب العلمي او العنوان الوظيفي	رقم الهاتف/ الموبايل	الايميل
ميعاد قحطان موسى	ممرضة جامعية	07806865682	miaad.q@s.uokerbala.edu.iq

اهمية موضوع البحث واهدافه (Importance of the research and its objectives)

من هذه الدراسة هو معرفة مدى فعالية برنامج ارشادي على معرفة الوالدين من منع مضاعفات ترسب الحديد لدى الأطفال المصابين بالثلاسيميا

وقت ومكان اجراء البحث (الاماكن المقترحة لاجراء البحث فيها) Time and Setting of the Research

مستشفى الأطفال التعليمي / كربلاء

منهجية البحث (Methodology)

Convenience sample

عينة الدراسة Sample of the study

والدين أطفال مرضى الثلاسيميا

الاعتبارات الاخلاقية خلال اجراء البحث (Ethical consideration during research)

التعهد

- اني الموقع ادناه ميعاد قحطان موسى اتعهد بان اقوم باجراء البحث وفقا لما ذكر في البروتوكول اعلاهوان التزم باتباع القوانين والتعليمات فيما يخص اجراء البحوث والالتزام بأخلاقياتها, كماواتعهد باخذ الموافقة من افراد العينة للمشاركة في الدراسة واخذ موافقة من ولي أمر المشارك الشرعي في حال كون عمر الشخص المشارك اقل من 18 سنة، او كونه غير قادر على الفهم ,وان اقدم الإيضاحات و المعلومات الخاصة بالدراسة لأفراد العينة للمشاركين في حال طلبها. وان اتعامل بسرية تامة مع بيانات افراد العينة.

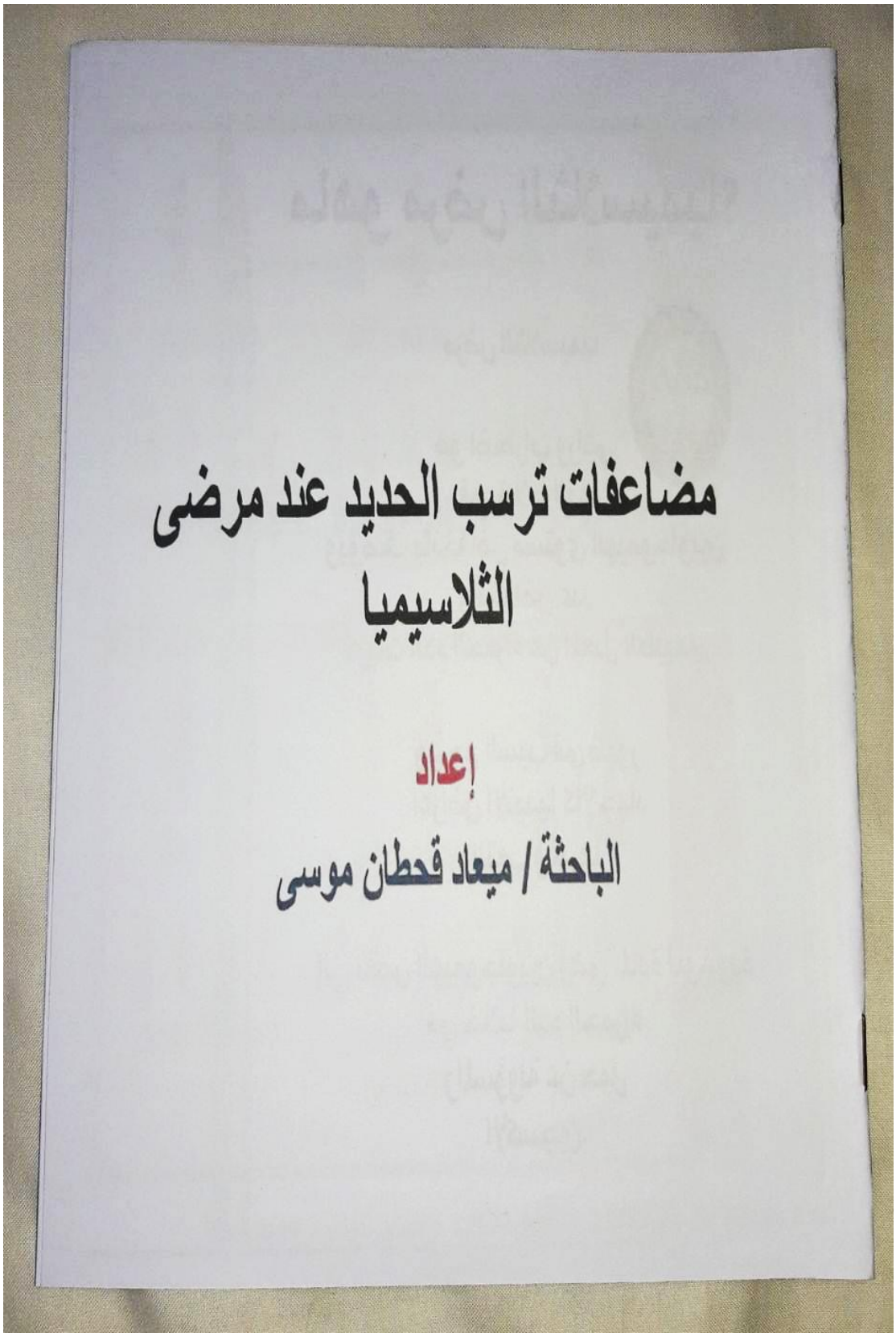
اسم وتوقيع الباحث

توصية لجنة اخلاقيات البحوث في الكلية

نحن اعضاء اللجنة الاخلاقية نوصي بان موضوع الباحث : ذو قيمة علمية ومهم للمجتمع والمريض

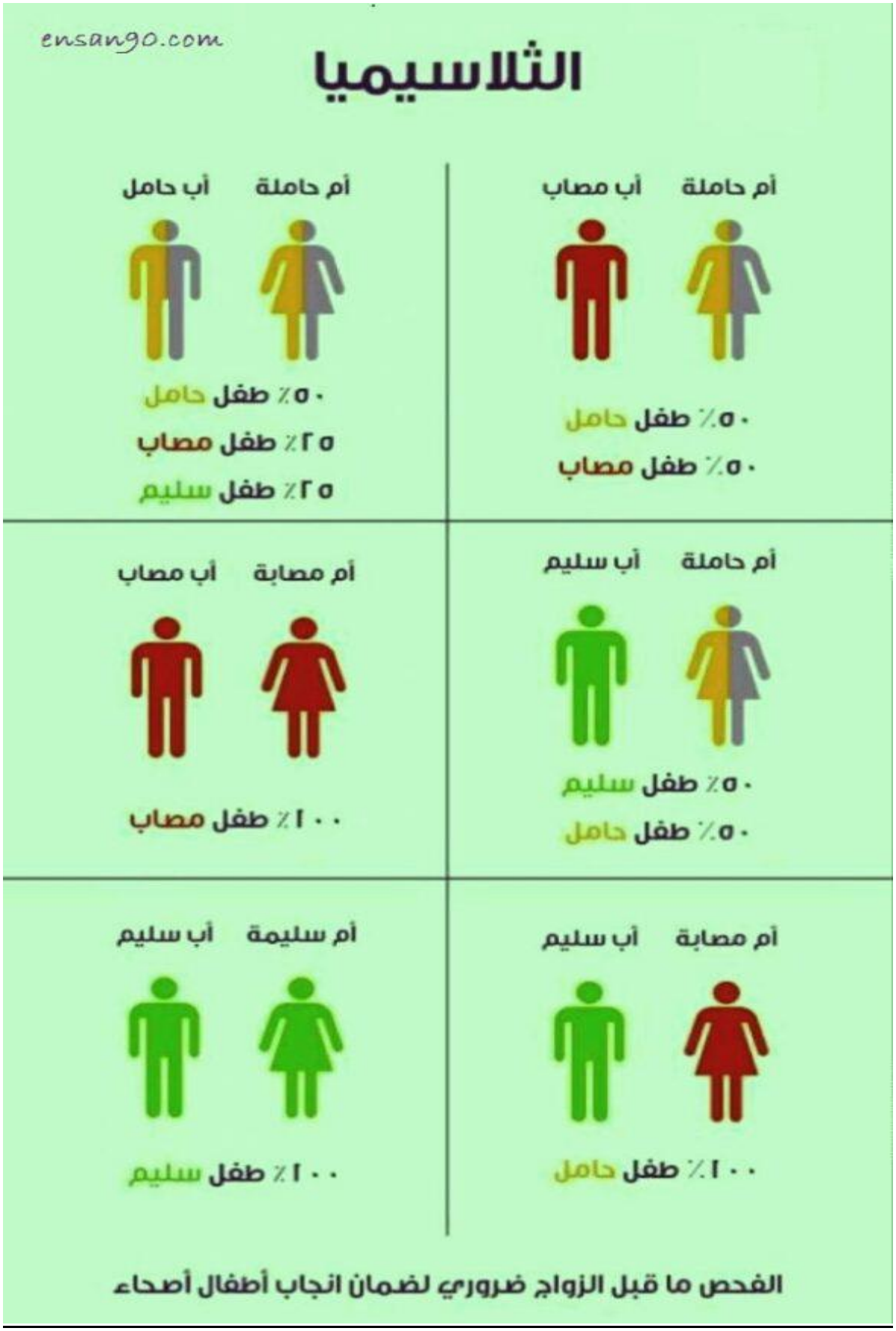
رئيسا للجنة — عضو — عضو — عضو

Program
Appendix B



- **<u>الثلاسيميا:</u>** هو اضطراب دم وراثي يؤدي إلى انخفاض نسبة الهيموغلوبين في الجسم عن المعدل الطبيعي.
- يُمكِّن الهيموغلوبين خلايا الدم الحمراء من حمل الأكسجين.
- قد تسبب الثلاسيميًّا فقر الدم؛ مما يجعلك تشعر بالإرهاق.

مرض الثلاسيميًّا الخفيفة، فقد لا تحتاج إلى علاج. ولكن قد تتطلب الأشكال الأكثر حدة عمليات <u>نقل دم منتظمة</u>. اتخاذ خطوات للتعايش مع الإرهاق، مثل <u>*اختيار نظام غذائي صحي وممارسة الرياضة بانتظام*</u>


ensango.com
الثلاسيميا
أم حاملة
أب مصاب
٥٠٪ طفل حامل
٥٠٪ طفل مصاب
أم حاملة
أب حامل
٥٠٪ طفل حامل
٢٥٪ طفل مصاب
٢٥٪ طفل سليم
أم حاملة
أب سليم
٥٠٪ طفل سليم
٥٠٪ طفل حامل
أم مصابة
أب مصاب
١٠٠٪ طفل مصاب
أم مصابة
أب سليم
١٠٠٪ طفل حامل
أم سليمة
أب سليم
١٠٠٪ طفل سليم
الفحص ما قبل الزواج ضروري لضمان انجاب أطفال أصحاء

لأعراض

- تعتمد مُؤشِّرات المرض وأعراضه على نوع الحالة وشدَّتها.
- الإرهاق
- الضَّعف
- شُحوب الجلد أو اصفراره
- تشوُّهات عظام الوجه
- بُطء النمو
- انتفاخًا في البطن
- البول الداكن

الأسباب

تحدث الثلاسيميا **بسبب حدوث طفرات في الحمض النووي للخلايا المسئولة عن إنتاج الهيموغلوبين** ــ وهو مادة في خلايا الدم الحمراء مسئولة عن حمل الأكسجين في كامل الجسم. تُتوارَث الطفرات المرتبطة بالثلاسيميا من **الأهل إلى الأبناء**.

- تتكون جزيئات الهيموغلوبين من سلاسل تُسمى **سلاسل ألفا وبيتا** التي قد تتأثر بالطفرات.
- في الثلاسيميا، **يقل** إنتاج سلاسل ألفا أو بيتا؛ ما يؤدي إلى الإصابة إما **بثلاسيميا ألفا أو ثلاسيميا بيتا.**
- في ثلاسيميا ألفا، **تعتمد شدة الثلاسيميا على عدد الطفرات الجينية التي ورثتها من الأهل. وكلما زادت الجينات الطافرة، زادت شدة الثلاسيميا**.
- في ثلاسيميا بيتا، **تعتمد شدة الثلاسيميا على الموقع الذي تأثر بالطفرة في جزيء الهيموغلوبين.**

الثلاسيميا ألفا

- تشترك أربعة جينات في تكوين سلسلة هيموغلوبين ألفا. وتحصُل على اثنين منها من الوالدين. وإذا كنتَ تَرِث:
- **طفرة وراثية،** فلن تظهر إي مؤشرات أو أعراض الثلاسيميا. ولكن يعتبر حاملًا للمرض، ويُمكن أن يورثه إلى أطفال.
- **وإذا كنت تَرِث طَفْرَتَيْنِ وراثيتين،** فستكون مؤشرات وأعراض الثلاسيميا طفيفة. قد يُطلَق على هذه الحالة **سمة ثلاسيميا ألفا**.

- **وفي حالة وراثة ثلاث طفرات جينية،** فستتراوح شدة المؤشرات والأعراض ***من متوسّطة إلى شديدة.***
- ولكن من النادر وراثة أربع طفرات جينية، وعادة ما تتسبَّب في وفاة الأجنة. المواليد المولودة بهذه الحالة غالبًا ما يُتَوَفَّوْنَ بعد فترة قصيرة من الولادة أو يَلزَمهم المعالجة بنقل الدم طوال الحياة. وفي حالات نادرة، يُمكن **معالجة الطفل المولود بهذه الحالة عن طريق نقل وزراعة الخلايا الجذعية.**

ثلاسيميا بيتا

- ويشارك **اثنان من الجينات** في صنع سلسلة الهِيمُوغْلُوبِينْ بيتا. تحصل على واحدة من كلٍّ من الأهل. إذا كنت ورثت:
- **جينًا واحدًا متحوّرًا،** فسيكون لديك علامات وأعراض خفيفة. تسمى هذه الحالة بالثلاسيميا الثانوية أو الثلاسيميا بيتا.
- **اثنان من الجينات المتحوّرة،** مؤشراتك وأعراضك ستكون معتدلة إلى حادة. وتسمى هذه الحالة الثلاسيميا الكبرى، أو فقر الدم كولي.
- عادةً ما يكون الأطفال المولودون بجينيين من الهِيمُوغْلُوبِينْ بيتا المَعنيين بصحة جيدة عند الولادة، لكنهم يصابون بمؤشّرات وأعراض المرض خلال أول عامين من حياتهم.

عوامل الخطر

- **التاريخ العائلي للإصابة بالثلاسيميا.** تنتقل الثلاسيميا من الأهل إلى الأطفال عن طريق جينات الهيموغلوبين الناشئة نتيجة طفرة.
- **سُلالات معيَّنة.** أكثر من تصيبهم الثلاسيميا هم الأمريكيون الأفارقة والمنحدرون من البحر المتوسط وجنوب شرق أسيا

المضاعفات

تشمل المُضاعفات المُحتملة الثلاسيميا المتوسطة إلى الشديدة ما يلي:

- **التحميل المُفرِط بالحديد.** تزداد كمية الحديد زيادةً مُفرِطةً لدى المُصابين بالثلاسيميا إما بسبب المرض أو بسبب نقل الدم باستمرار. ويمكن أن تؤدي الزيادة المُفرِطة للحديد في جسم المريض **إلى أضرار بالقلب والكبد وجهاز الغدد الصماء الذي** يحتوي على الغدد المفروزة للهرمونات التي تُنظِّم عمليات الجسم كله.

- **العدوى.** المُصابون بالثلاسيميا تزداد خطورة إصابتهم بالأمراض المُعدية. ويحدث ذلك خاصةً إذا كان أُجريَ للمريض استئصال الطحال.

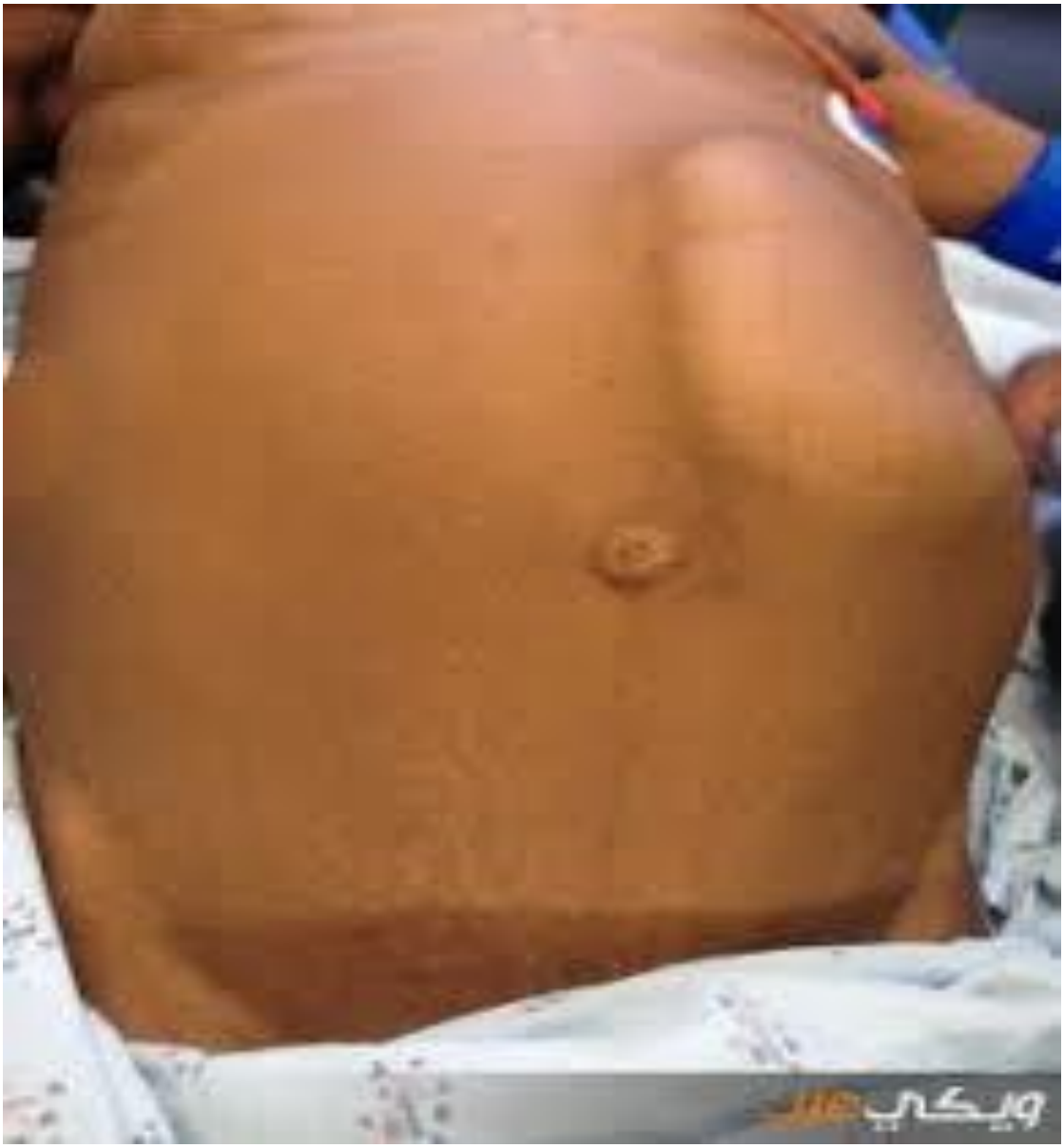
في حالات الثلاسيميا الشديدة يمكن حدوث المُضاعفات

- **تشوُّهات العظام:** تؤدي الثلاسيميا إلى تمدُّد نخاع العظم مما يجعل العظام تمتد عرضًا. وقد يؤدي ذلك إلى شذوذ بنية العظام خاصةً في الوجه والجمجمة . كما يؤدي تمدُّد نخاع العظم إلى ترقُّق العظام وهشاشتها مما يُزيد فرص كسور العظام.
- **تضخُّم الطحال:** يساعد الطحال الجسم على مكافحة العدوى وترشيح المواد غير المرغوب فيها مثل خلايا الدم القديمة أو التالفة. وعادةً ما يُصاحب الثلاسيميا تدمير عدد كبير من خلايا الدم الحمراء. وهذا يجعل الطحال يتضخّم ويجعل عمله أصعب من الوضع العادي.
- والطحال المُتضخِّم يُزيد سوء حالة فقر الدم ويُقلِّص فترة حياة خلايا الدم الحمراء المنقولة إلى الجسم . وإذا تضخَّم الطحال تضخُّمًا شديدًا، فقد يقترح طبيبك إجراء الجراحة لإزالته.
- **بُطء معدّلات النمو:** يؤدي فقر الدم إلى إبطاء نمو الطفل وتأخير البلوغ.

مشكلات في القلب: يمكن الربط بين فشل القلب وبين الثلاسيميا الشديدة

تضخم عظام الوجه من مضاعفات ترسب الحديد عند مرضى الثلاسيميا

تضخم الطحال احد مضاعفات ترسب الحديد عند مرضى الثلاسيميا



الوقاية

- في معظم الحالات، لا يُمكن منع حدوث الثلاسيميا. إن كنتَ مصابًا بالثلاسيميا، أو تحمل جين الثلاسيميا، فتحدَّث مع استشاري وراثي للحصول على المشورة إن كنتَ تُريد الإنجاب.
- هناك شكل من أشكال التشخيص باستخدام تقنيات المساعدة على الإنجاب، والذي يفحص الجنين في مراحله المُبكِّرة بحثًا عن الطفرات الوراثية المقترنة بالإخصاب في المختبر. قد يُساعد هذا الآباء المصابين بالثلاسيميا أو الآباء الحاملين لجين هيموجلوبين مَعِيب في الحصول على أجنة سليمة.

يتضمَّن الإجراء استرجاع البويضات الناضجة وتخصيبها باستخدام حيوان منوي على طبق في المختبر. تُختبَر الأجنة بحثًا عن جينات مَعِيبة، والأجنة الخالية من العيوب الوراثية فقط يتمُّ زرعها في الرحم الأغذية التي يمنع تناولها لمرضى الثلاسيميا لأنها غنية بعنصر الحديد

علاج الدسفرال الذي يقلل نسبة الحديد بالدم ويعطى عن طريق مضخة الدسفرال بطريقة الحقن تحت الجلد

الطريقة المثلى لاستعمال الاكسجيد:- يأخذ اكسجيد مرة واحدة يوميا على معدة فارغة قبل الاكل ب 30 دقيقة على الأقل ويفضل في نفس الموعد من كل يوم

- يتم وضع الأقراص في كوب من الماء أو عصير التفاح أو البرتقال - تقلب الأقراص بملعقة حتى يتم الحصول على ملعق دقيق يضمن ذوبان كل القرص

Data collection
Appendix C-I

Part one : Socio-demographic characteristics of parents

Age ☐

Residence

Urban ☐ Rural ☐

Level of education

Illiterate ☐ Read & write ☐

Secondary ☐ University ☐

Occupation

work ☐ does not work ☐

Part Two: Parents' knowledge of iron overload complications in child thalassemia :

Questions		Know	Un know
1- The most important results of iron analyzes for children with Thalassemia patients			
1-1	The normal iron level for children with thalassemia ranges between (25-200 ng/ml)		
1-2	The normal hemoglobin level in children with thalassemia is from 13.5 to 13.9 g per deciliter.		
1-3	The normal ferritin ratio for children with thalassemia ranges between (7 to 140 ng/ml).		

2- Causes of iron overload in children with thalassemia:			
2-1	Giving blood increases iron overload in children with thalassemia		
2-2	Genetic changes are the main cause of iron overload in children with thalassemia		
2-3	Iron overload in children with thalassemia due to carbonated drinks		
2-4	Iron overload in children with thalassemia due to the difference in the blood group of the parents		
2-5	Giving medications (such as cortisone) increases iron overload in children with thalassemia.		
The most important symptoms and signs of iron overload in children with thalassemia:			
3-1	Iron overload in children with thalassemia causes discoloration of the teeth.		
3-2	Iron overload causes bronze coloration of the skin in children with thalassemia		
3-3	Iron overload in children with thalassemia causes the appearance of facial bones.		
3-4	Iron overload in children with thalassemia causes short stature		
3-5	Iron overload causes weight loss in children with thalassemia		
4- The most important complications of iron overload in children with thalassemia patients:			
4-1	Iron overload causes heart failure in children with thalassemia		
4-2	Iron overload causes memory impairment in children with thalassemia.		

4-3	Iron overload leads to liver failure in children with thalassemia.		
4-4	Iron overload leads to spleen enlargement in children with thalassemia.		
4-5	Iron overload causes kidney failure in children with thalassemia.		
5- The most important prevention of iron overload in children with thalassemia:			
5-1	Prevention of iron overload It is recommended to drink tea and coffee for children with thalassemia.		
5-2	Iron overload can be prevented by periodically checking the iron content of children with thalassemia.		
5-3	Prevention of iron overload It is recommended to eat milk products for children with thalassemia		
5-4	To prevent iron overload, it is recommended to take vitamin C for children with thalassemia		
5-5	To prevent iron overload it is recommended to eat fish for children with thalassemia		
6- The most important treatment for iron overload in children with thalassemia:			
6-1	To treat ironoverload iron-repelling drugs (such as X-Jade) are given.		
6-2	To treat iron overload, desferal therapy is used		
6-3	For the treatment of iron overload, deferiprone (Celver) is used by intravenous injection		
6-4	To treat iron overload, the spleen is removed.		
6-5	To treat iron overload, a bone marrow transplant is done.		

Appendix C-II

الجزء الأول / الصفات الديموغرافية للوالدين

العمر ☐ **سنة**

الجنس

ذكر ☐ **انثى** ☐

المستوى الدراسي

لا يقراء ولا يكتب ☐ **يقرءا ويكتب** ☐ **وسطة** ☐

ثانوية ☐ **بكالوريوس فما فوق** ☐

المهنة

يعمل ☐ **لا يعمل** ☐

السكن

مدينة ☐ **ريف** ☐

عدد الأولاد المصابين ☐

الجزء الثاني /معارف الوالدين تجاه مضاعفات ترسب الحديد عند مرضى فقر الدم البحر المتوسط (الثلاسيميا)

الأسئلة		اعرف	لا اعرف
1 – اهم نتائج تحاليل الحديد لطفال مرضى الثلاسيميا :-			
1-1	نسبة الحديد الطبيعية لدى أطفال مرضى الثلاسيميا تتراوح بين (25 – 200 نانوغرام / مليلتر)		
1-2	نسبة الهيموجلوبين الطبيعية لدى أطفال مرضى الثلاسيميا (من 13.5 الى 13.9 جم لكل ديسيلتر)		
1-3	تتراوح نسبة الفرتين الطبيعية عند أطفال مرضى الثلاسيميا بين (7 إلى 140 نانوغرام / مل)		
2- أسباب ترسب الحديد عند أطفال مرضى الثلاسيميا :-			
2-1	إعطاء الدم يزيد من ترسب الحديد عند أطفال مرضى الثلاسيميا .		
2-2	التغيرات الجينية السبب الرئيسي بترسب الحديد عند أطفال مرضى الثلاسيميا .		
2-3	ترسب الحديد عند أطفال مرضى الثلاسيميا بسبب تناول المشروبات الغازية .		
2-4	ترسب الحديد عند أطفال مرضى الثلاسيميا بسبب اختلاف فصيلة دم الوالدين .		
2-5	إعطاء الأدوية(مثل الكورتزون) يزيد من ترسب الحديد عند أطفال مرضى الثلاسيميا .		
3- اهم اعراض وعلامات ترسب الحديد عند أطفال مرضى الثلاسيميا :-			
3-1	ترسب الحديد عند أطفال مرضى الثلاسيميا يسبب تلون الأسنان .		

3-2	ترسب الحديد يسبب تلون الجلد بلون البرونزي عند أطفال مرضى الثلاسيميا		
3-3	ترسب الحديد عند أطفال مرضى الثلاسيميا يسبب بروز عظام الوجه .		
3-4	ترسب الحديد عند أطفال مرضى الثلاسيميا يسبب قصر القامة .		
3-5	ترسب الحديد يسبب نقصان الوزن عند أطفال مرضى الثلاسيميا .		
4- اهم مضاعفات ترسب الحديد عند أطفال مرضى الثلاسيميا :-			
4-1	ترسب الحديد يسبب عجز القلب عند أطفال مرضى الثلاسيميا .		
4-2	ترسب الحديد يسبب ضعف الذاكرة عند أطفال مرضى الثلاسيميا .		
4-3	ترسب الحديد يؤدي إلى فشل وظائف الكبد عند أطفال مرضى الثلاسيميا .		
4-4	ترسب الحديد يؤدي إلى تضخم الطحال عند أطفال مرضى الثلاسيميا .		
4-5	ترسب الحديد يسبب الفشل الكلوي عند أطفال مرضى الثلاسيميا .		
5-اهم الوقاية من ترسب الحديد عند أطفال مرضى الثلاسيميا :-			
5-1	الوقاية من ترسب الحديد ينصح بتناول الشاي والقهوة لأطفال مرضى الثلاسيميا .		
5-2	يمكن الوقاية من ترسب الحديد بعمل فحص دوري لنسبة الحديد لأطفال مرضى الثلاسيميا .		

5-3	الوقاية من ترسب الحديد ينصح بتناول منتجات الحليب لأطفال مرضى الثلاسيميا .		
5-4	الوقاية من ترسب الحديد ينصح باخذ فيتامين سي لاطفال مرضى الثلاسيميا .		
5-5	الوقاية من ترسب الحديد ينصح باكل الأسماك لاطفال مرضى الثلاسيميا .		
6- اهم علاج ترسب الحديد عند أطفال مرضى الثلاسيميا :-			
6-1	لعلاج ترسب الحديد يتم إعطاء الأدوية الطاردة للحديد (مثل الاكس جايد) .		
6-2	لعلاج ترسب الحديد يتم استخدام علاج الدسفرال .		
6-3	لعلاج ترسب الحديد يتم اسخدام علاج الديفريبرون(كلفر) بطريقة الحقن بالوريد .		
6-4	لعلاج ترسب الحديد يتم استئصال الطحال .		
6-5	لعلاج ترسب الحديد يتم زراعة نخاع العظم .		

Expert's Panel
Appendix D

ت	اسم الخبير	العنوان الوظيفي	الشهادة	الاختصاص العلمي	سنوات الخبرة	مكان العمل
1	علي كريم الجبوري	أستاذ	دكتوراه في علم التمريض	تمريض الصحة النفسية	30	جامعة كربلاء / كلية التمريض
2	سلمان حسين فارس	أستاذ مساعد	دكتوراه في علم تمريض	تمريض صحة مجتمع	30	جامعة كربلاء / كلية التمريض
3	حسن عبد الله عذبي	أستاذ مساعد	دكتوراه في علم تمريض	تمريض البالغين	19	جامعة كربلاء / كلية التمريض
4	صافي داخل نوام	أستاذ مساعد	دكتوراه في علم تمريض	تمريض الصحة النفسية	15	جامعة كربلاء / كلية التمريض
5	فاطمة مكي	أستاذ مساعد	دكتوراه في علم تمريض	تمريض بالغين	27	جامعة كربلاء / كلية التمريض
6	نهاد محمد قاسم	مساعد	دكتوراه في علم تمريض	تمريض أطفال	35	جامعة بابل / كلية التمريض
7	زكي صباح	مدرس	دكتوراه في علم تمريض	تمريض أطفال	23	جامعة كربلاء / كلية التمريض
8	ساجدة سعدون	مدرس	دكتوراه في علم تمريض	تمريض نسائية	29	جامعة كربلاء / كلية التمريض
9	حقي إسماعيل منصور	مدرس	دكتوراه في علم تمريض	تمريض صحة مجتمع	4	جامعة كربلاء / كلية التمريض
10	حسن موسى	**استشاري**	دكتوراه اختصاص طب الأطفال	اختصاص طب الأطفال	10	مستشفى الأطفال التعليمي
11	أسراء مصطفى صالح	**استشاري**	دكتوراه اختصاص طب الأطفال	اختصاص أمراض الدم	20	مستشفى الأطفال التعليمي

المستخلص

المقدمة: الحديد الزائد هو الاضطرابات المرتبطة بالتخزين الزائد للحديد في الجسم وما يترتب على ذلك من تلف في الأعضاء الطرفية يشار إليها باسم اضطرابات الحمل الزائد للحديد..

الهدف: الهدف من الدراسة هو معرفة مدى فعالية برنامج الارشادي على معرفة الوالدين تجاه الوقاية من مضاعفات زيادة الحديد لدى الأطفال المصابين بالثلاسيميا.

المنهجية: من تشرين الأول 2021 إلى تموز 2022 أجريت دراسة شبه تجريبية في مركز الثلاسيميا في مدينة كربلاء. من مركز الثلاسيميا تم اختيار عينة غير احتمالية (هادفة) عددها (50) عينة .

النتائج: أظهرت نتائج الدراسة أن معظم الآباء المشاركين فيها هم ضمن الفئة العمرية (≥25) ، وغالبية المشاركين من الإناث (50.0٪) في الدراسة ، ونسبة (32٪) من الآباء والأمهات يعرفون القراءة والكتابة. كان معظمهم يعملون(60٪) ويعيشون في المدينة (60٪). كما أظهرت النتائج أن غالبية الآباء(96٪) لديهم طفل إلى طفلين. وأن البرنامج التعليمي فعال في التحسين معرفة الوالدين فيما يتعلق بالوقاية من مضاعفات زيادة الحديد ، حيث كان له تأثير كبير باستخدام الاختبارين اللاحقين الأول والاختبار الثاني لزيادة معرفة الوالدين في مجموعة الدراسة عند $p> 0.05$. لا توجد علاقة إحصائية بين معرفة الوالدين والعمر والجنس وعدد الأطفال ولكن توجد علاقة إحصائية مع مستويات التعليم عند$p> 0.05$

الخلاصة: وجدت الدراسة أن البرنامج الارشادي يمكن أن يحسن معارف الوالدين حول كيفية منع مضاعفات زيادة الحديد لدى الأطفال المصابين بالثلاسيميا.

توصية: تقترح الدراسة أن تكون التعليمات الإرشادية والملصقات والكتيبات والأدلة التي تهدف إلى منع مضاعفات زيادة الحديد متاحة لجميع الآباء وأن يتم تشجيعهم على استخدامها. يشجع الآباء على حضور الدورات التدريبية والمؤتمرات التي يقودها المتخصصون حول الوقاية من مضاعفات ترسب الحديد للحفاظ على المعرف الجديدة .

جامعة كربلاء / كلية التمريض

فاعلية البرنامج الإرشادي حول معرفة الوالدين تجاه الوقاية من مضاعفات ترسب الحديد بين الأطفال المصابين بالثلاسيميا

رسالة مقدمة الى مجلس كلية التمريض/ جامعة كربلاء وهي جزء من متطلبات نيل درجة الماجستير في علوم التمريض

تقدم بها

ميعاد قحطان الحسيني

بإشراف

أ. د. خميس بندر عبيد

آيلول 2022م **صفر 1444هـ**