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knwoledgment and expierence of families of children with thalassemia about their children disease in Thi-Qar, 2021

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Dedication

To those who labored the flower of their lives for us... To... Muslim Qandeel, who was the light of our minds and became the light of our souls... And who bestowed upon us the richness of his knowledge with all sincerity, to the immortals in our minds and our souls... Muslim Qandeel and Ali Jaafar and who spent this year, the heroes of the White Army

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Abstract:

Thalassemia is a chronic blood disease, which imposes adverse effects on patients and their families. Parents of such patients, given that they had the thalassemia trait, hold themselves responsible for their children's disease in addition to other difficulties, bear the burden of guilt and hopelessness and worry about the health and future of their children. This study aimed to explore the experiences and knwoledgment of families of children with thalassemia.The present research was conducted using a descriptive phenomenological approach. A purposive sampling was carried out until data saturation. Participants included 100 parents of children with thalassemia who were referred to the Thalassemia Center of thiqar to perform therapeutic procedures for their child in 2021.The results revealed that parents of children with thalassemia experience a wide range of problems in different aspects, such as physical, emotional, mental, social, economic and familial dimensions. Their experiences are valuable and can help in achieving a better understanding of their problems, which in turn can enable the members of the treatment team to play a more active role and the society to have a better understanding of this disease.Caregivers' knowledge regarding thalassemia was not at all satisfactory. Regular counseling of caregivers should be done addressing the knowledge lacunae's among them .

Keywords:

Thalassemias, family, knwoledgment, Iron, transfusion, herediatary, anemia.

Chapter 1

1.Introduction

Thalassemias are a heterogeneous grouping of genetic disorders that result from a decreased synthesis of alpha or beta chains of hemoglobin (Hb). Hemoglobin serves as the oxygen-carrying component of the red blood cells. It consists of two proteins, an alpha, and a beta. If the body does not manufacture enough of one or the other of these two proteins, the red blood cells do not form correctly and cannot carry sufficient oxygen; this causes anemia that begins in early childhood and lasts throughout life. Thalassemia is an inherited disease, meaning that at least one of the parents must be a carrier for the disease. It is caused by either a genetic mutation or a deletion of certain key gene fragments(1).

1.I Alpha thalassemia is caused by alpha-globin gene deletion which results in reduced or absent production of alpha-globin chains. Alpha globin gene has 4 alleles and disease severity ranges from mild to severe depending on the number of deletions of the alleles. Four allele deletion is the most severe form in which no alpha globins are produced and the excess gamma chains (present during the fetal period) form tetramers. It is incompatible with life and results in hydrops fetalis. One allele deletion is the mildest form and is mostly clinically silent.(1).

1.II. Beta thalassemia results from point mutations in the beta-globin gene. It is divided into three categories based on the zygosity of the beta-gene mutation. A heterozygous mutation (beta-plus thalassemia) results in beta-thalassemia minor in which beta chains are underproduced. It is mild and usually asymptomatic. Beta thalassemia major is caused by a homozygous mutation (beta-zero thalassemia) of the beta-globin gene, resulting in the total absence of beta chains. It manifests clinically as jaundice, growth retardation, hepatosplenomegaly, endocrine abnormalities, and severe anemia requiring life-long blood transfusions. The condition in between these two types is called beta-thalassemia intermedia with mild to moderate clinical symptoms.(1)

One mutated gene: Mild signs and symptoms. The condition is called thalassemia minor.

Two mutated genes: Signs and symptoms will be moderate to severe. This condition is called thalassemia major, or Cooley anemia. Babies born with two mutated beta hemoglobin genes are usually healthy at birth but disease starts to manifest after 6 months of life when fetal hemoglobin (Hb-gamma) disappears and is replaced by adult Hb.

The excess unpaired alpha-globin chains in beta-thalassemia aggregate and form precipitates that damage red cell membranes and result in intravascular hemolysis. This premature death of erythroid precursor cells leads to ineffective erythropoiesis and later results in extramedullary expansion of hematopoiesis. (2)

Coinheritance of alpha thalassemia: Beta-thalassemia patients with coinheritance of alpha thalassemia have a milder clinical course due to a less severe alpha-beta chain imbalance.

Coexistence of sickle cell trait: The presence of sickle cell trait with beta-thalassemia is a major hemoglobinopathy and results in manifestations of sickle cell disease. Unlike sickle cell trait in which major Hb is HbA, in the co-existence state the major Hb is HbS which constitutes more than 60% of Hb depending on the nature of the disease (beta-zero or beta-plus0.)

Hemoglobin (HbE) is also a common Hb variant found in Southeast Asia population. It has a correlation with a beta-thalassemia phenotype, as people with thalassemia in this territory are commonly found to have HbE.

Two new terminologies being used more often in clinical settings are transfusion requiring and non-transfusion requiring thalassemias and all the basic classification falls into these two types depending on the requirement of frequent blood transfusions or not.(2).

1.2Etiology

Thalassemia is autosomal recessive, which means both the parents must be affected with or carriers for the disease to transfer. It is caused by mutations or deletions of the Hb genes, resulting in underproduction or absence of alpha or beta chains. [4] .

1.3Clinical Manifestation

Thalassemia presentation varies widely depending on the type and severity. A complete history and physical examination can give several clues that are sometimes not obvious to the patient themselves. **The following findings can be noted (3)**

1.3.1.Skin

Skin can show pallor due to anemia and jaundice due to hyperbilirubinemia resulting from intravascular hemolysis. Patients usually report fatigue due to anemia as the first presenting symptom. Extremities examination can show ulcerations. Chronic iron deposition due to multiple transfusions can result in bronze skin.(2)

1.3.2.Musculoskeletal

Extramedullary expansion of hematopoiesis results in deformed facial and other skeletal bones and an appearance known as chipmunk face. (2)

1.3.3.Cardiac

Iron deposition in cardiac myocytes due to chronic transfusions can disrupt the cardiac rhythm, and the result is various arrhythmias. Due to chronic anemia, overt heart failure can also result.(3)

1.3 4.Abdominal

Chronic hyperbilirubinemia can lead to precipitation of bilirubin gall stones and manifest as typical colicky pain of cholelithiasis. Hepatosplenomegaly can result from chronic iron deposition and also from extramedullary hematopoiesis in these organs. (3)

1.3.5.Hepatic

Hepatic involvement is a common finding in thalassemias, particularly due to the chronic need for transfusions. Chronic liver failure or cirrhosis can result from chronic iron deposition or transfusion-related viral hepatitis.

1.3.6.Slow Growth Rates

Anemia can inhibit a child's growth rate, and thalassemia can cause a delay in puberty. Particular attention should focus on the child's growth and development according to age.(3)

1.3.7 Endocrinopathies

Iron overload can lead to its deposition in various organ systems of the body and resultant decreased functioning of the respective systems(3). The deposition of iron

in the pancreas can lead to diabetes mellitus; in the thyroid or parathyroid glands can lead to hypothyroidism and hypoparathyroidism, respectively. The deposition in joints leads to chronic arthropathies. In the brain, iron prefers to accumulate in the substantia nigra and manifests as early-onset Parkinson's disease and various other physiatry problems. These symptoms fall in the vast kingdom of hemochromatosis.

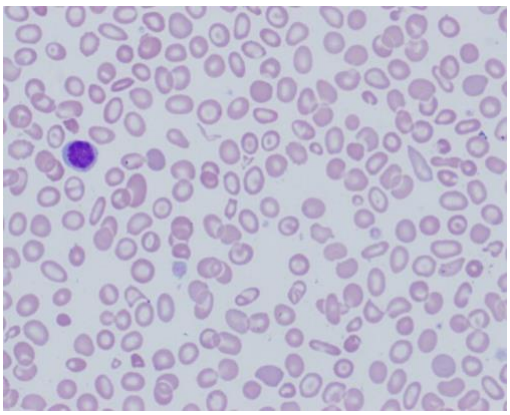
1.4Evaluation

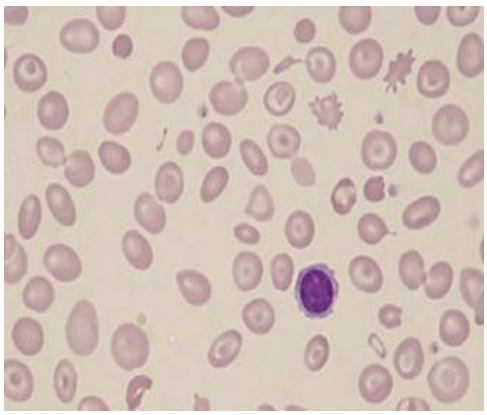
Several laboratory tests have been developed to screen and diagnose thalassemia:

1.4.1.Complete blood count (CBC): CBC is often the first investigation in a suspected case of thalassemia. A CBC showing low hemoglobin and low MCV is the first indication of thalassemia, after ruling out iron deficiency as the cause of anemia. The calculation of the Mentzer index (mean corpuscular volume divided by red cell count) is useful.(5)

1.4.2.Peripheral blood smear: A blood smear (also called peripheral smear and manual differential) is next, to assess additional red cell properties. Thalassemia can present with the following findings on the peripheral blood smear (5).

- **Microcytic cells (low MCV)**
- **Hypochromic cells**
- **Variation in size and shape (anisocytosis and poikilocytosis)**
- **Increased percentage of reticulocytes**
- **Target cells,Heinz bodies**





- **Figure. 1Peripheral blood with features of beta-thalassemia minor. Microcytosis and frequent target cells are characteristic.**
- **Figure2. Peripheral blood picture of beta thalassemia major patient showing hypochromic, microcytic red blood cells along with target cells.(5).**

1.4.3.Iron studies (serum iron, ferritin, unsaturated iron-binding capacity (UIBC), total iron-binding capacity (TIBC), and percent saturation of transferrin) are also done to rule out iron deficiency anemia as the underlying cause. Erythrocyte porphyrin levels may be checked to distinguish an unclear beta-thalassemia minor diagnosis from iron deficiency or lead poisoning. (5).

1.4.4.Hemoglobin electrophoresis: Hemoglobinopathy (Hb) evaluation assesses the type and relative amounts of hemoglobin present in red blood cells. Hemoglobin A (HbA), composed of both alpha and beta-globin chains, is the type of hemoglobin that typically makes up 95% to 98% of hemoglobin for adults. Hemoglobin A2 (HbA2) is normally 2% to 3% of hemoglobin, while hemoglobin F usually makes up less than 2% of hemoglobin in adults.(5)

Beta thalassemia disturbs the balance of beta and alpha hemoglobin chain formation. Patients with the beta-thalassemia major usually have larger percentages of HbF and HbA2 and absent or very low HbA. Those with beta-thalassemia minor usually have a mild elevation of HbA2 and mild decrease of HbA. HbH is a less common form of hemoglobin that may be seen in some cases of alpha thalassemia. HbS is the hemoglobin prevalent in people with sickle cell disease.

Hemoglobinopathy (Hb) assessment is used for prenatal screening when parents are at high risk for hemoglobin abnormalities and state-mandated newborn hemoglobin screening.

1.4.5.DNA analysis: These tests serve to help confirm mutations in the alpha and beta globin-producing genes. DNA testing is not a routine procedure but can be used to help diagnose thalassemia and to determine carrier status if needed.(6)

Since having relatives carrying mutations for thalassemia increases a person's risk of carrying the same mutant gene, family studies may be necessary to assess carrier status and the types of mutations present in other family members. Genetic testing of amniotic fluid is useful in those rare instances where a fetus has an increased risk for thalassemia. This is particularly important if both parents likely carry a mutation because that increases the risk that their child may inherit a combination of abnormal genes, causing a more severe form of thalassemia. Prenatal diagnosis with chorionic villi sampling at 8 to 10 weeks or by amniocentesis at 14 to 20 weeks' gestation can be carried out in high-risk families.(6)

1.4.6 Multisystem evaluation: Evaluation of all related systems should be done on a regular basis due to their frequent involvement in the disease progression. Biliary tract and gall bladder imaging, abdominal ultrasonography, cardiac MRI, serum hormone measurements are a few examples that can be done or repeated depending on the clinical suspicion and case description. (6).

1.5Management

Thalassemia treatment depends on the type and severity of the disease.

Mild thalassemia (Hb: 6 to 10g/dl):

Signs and symptoms are generally mild with thalassemia minor and little if any, treatment is needed. Occasionally, patients may need a **blood transfusion**, particularly after **surgery**, following childbirth, or to help manage thalassemia complications.(7)

Moderate to severe thalassemia (Hb less than 5 to 6g/dl):

1.5.1.Frequent blood transfusions: More severe forms of thalassemia often require regular blood transfusions, possibly every few weeks. The goal is to maintain Hb at around 9 to 10 mg/dl to give the patients a sense of well being and also to keep a check on erythropoiesis and suppress extramedullary hematopoiesis. To limit transfusion-related complications, washed, packed red blood cells (RBCs) at approximately 8 to 15 mL cells per kilogram (kg) of body weight over 1 to 2 hours are recommended.(7)

1.5.2.Chelation therapy: Due to chronic transfusions, iron starts to get deposited in various organs of the body. Iron chelators (deferasirox, deferoxamine, deferiprone) are given concomitantly to remove extra iron from the body.

1.5.3.Stem cell transplant: Stem cell transplant, (bone marrow transplant), is a potential option in selected cases, such as children born with severe thalassemia. It can eliminate the need for lifelong blood transfusions.(8). However, this procedure has its own complications, and the clinician must weigh these against the benefits. Risks include including graft vs. host disease, chronic immunosuppressive therapy, graft failure, and transplantation-related mortality.(9).

1.5.4.Gene therapy: It is the latest advancement in severe thalassemia management. It involves harvesting the autologous hematopoietic stem cells (HSCs) from the patient and genetically modifying them with vectors expressing the normal genes. These are then reinfused to the patients after they have undergone the required conditioning to destroy the existing HSCs. The genetically modified HSCs produce normal hemoglobin chains, and normal erythropoiesis ensues.(9).

1.5.5.Genome editing techniques: Another recent approach is editing genomic libraries, such as zinc-finger nucleases, transcription activator-like effectors, and cluster regulated interspaced short palindromic repeats (CRISPR) with Cas9 nuclease system. These techniques target specific mutation sites and replace them

with the normal sequence. The limitation of this technique is to produce a large number of corrected genes sufficient to cure the disease.(10)

1.5.6.Splenectomy: Patients with thalassemia major often undergo splenectomy to limit the number of required transfusions. Splenectomy is the usual recommendation when the annual transfusion requirement increases to or more than 200 to 220 mL RBCs/kg/year with a hematocrit value of 70%. Splenectomy not only limits the number of required transfusions but also controls the spread of extramedullary hematopoiesis. Postsplenectomy immunizations are necessary to prevent bacterial infections, including Pneumococcus, Meningococcus, and Haemophilus influenzae. Postsplenectomy sepsis is possible in children, so this procedure is deferred until 6 to 7 years of age, and then penicillin is given for prophylaxis until they reach a certain age. (10).

1.5.7.Cholecystectomy: Patients can develop cholelithiasis due to increased Hb breakdown and bilirubin deposition in the gallbladder. If it becomes symptomatic, patients should undergo cholecystectomy at the same time when they are undergoing splenectomy.(10)

1.5.8.Diet and exercise:

Reports exist that drinking tea aids in reducing iron absorption from the intestinal tract. So, in thalassemia patients tea might be a healthy drink to use routinely. Vitamin C helps in iron excretion from the gut, especially when used with deferoxamine. But using vitamin C in large quantities and without concomitant deferoxamine use, there is a higher risk for fatal arrhythmias. So, the recommendation is to use low quantities of vitamin C along with iron chelators (deferoxamine).(10).

1.6Differential Diagnosis

1.6.1.Iron deficiency anemia: This is ruled out by iron studies and Mentzer index.

1.6.2.Anemia of chronic disease and renal failure: Elevated markers of inflammation (CRP, ESR) point in this direction.(11)

Sideroblastic anemias: These are ruled out by iron studies and peripheral blood smear.(11)

1.6.3.Lead poisoning: This is ruled out by measuring serum protoporphyrin level.

1.7Prognosis

Thalassemia minor is usually asymptomatic and has a good prognosis. It normally does not increase morbidity or mortality.

Thalassemia major is a severe disease, and the long-term prognosis depends on the treatment adherence to transfusion and iron chelation therapies.(11).

1.8Complications

Thalassemia major can produce the following complications[12][13]:

1.Jaundice and gall stones due to hyperbilirubinemia

2.Cortical thinning and distortion of bones due to extramedullary hematopoiesis

3.High output cardiac failure due to severe anemia, cardiomyopathies, and arrhythmias – cardiac involvement is the major cause of mortality in thalassemia patients

4.Hepatosplenomegaly due to extramedullary hematopoiesis and excess iron deposition due to repeated blood transfusions

5.Excess iron can lead to findings of primary hemochromatosis such as endocrine abnormalities, joint problems, skin discoloration, etc.

6 Neurological complications such as peripheral neuropathies

7.Slow growth rate and delayed puberty

8.Increased risk of parvovirus B19 infection(12)

1.9 Deterrence and Patient Education

Patients should be educated to keep a check on their disease by following an appropriate treatment plan and adopting healthy living habits.

Avoid excess iron. Unless the doctor recommends otherwise, patients should avoid multivitamins or other supplements that contain iron.

Eat a healthy diet. Eating a balanced diet that contains plenty of nutritious foods can help the patient feel better and boost energy. Doctors sometimes also recommend taking a folic acid supplement to help make new red blood cells.

Avoid infections. Patients should try maximally to protect themselves from infections, especially following a splenectomy. (12).

1.10Aims of study

1.Is to find out the experience and knowledge of parents of thalassemic children about the disease, complications, management of their children.

2.increase level of education of families of thalassemic patients and educate community to this disease and the importance of blood donation.

Chapter 2

2.Methodology

This study was conducted in November from 2020 to February of 2021 at the Thalassemia Center in Nasiriyah city / Iraq and included 100 families of Thalassemia patients f involving 100 families we ask them questions about their children disease involving defintion of thalassemia, causes, complications, treatment , awareness about condition of their child. We involved in this study families of patients from 5 to 15 years old. The data regarding patient demographic characteristics including (level of education of families, number of thalassemic children in family physiology of thalassemia and causes, awareness about antental screening, and modalities of treatment.

2.1Data collection, included 100 families of Thalassemia patients from the age of 5 to 15 years old , excluding those under 5 years or older than 15 years.

2.2Statistic study, Cross-sectional study, was conducted in the Excel program to find out the families' experience about their children's disease, its cause, methods of treatment and its problems.

2.3Ethical issue, A written consent was taken from the Thalassemia Center and a verbal consent was taken from the families participating in this study.

2.4A special questionnaire was designed for the purpose of the study including the following data:

We asked in this study about Age of their child , gender of participant, the level of education, whats the meaning of thalassemia, Do you have a gene for thalassemia?,What are the types of thalassemia and causes, Do you know about signs and symptoms of thalassemia?, Do you know that thalassemia can be detected during pregnancy?, Do you about gene screening before marriage?, Do you think that regular blood transfusions is the only treatment?,Do you think that thalassemia transmission can occurs due to drugs of infections ? What are the modalities of treatment that you know? Are the foods or drugs that contain Iron are appropriate for patients with thalassemia?.

Chapter 3

3.Results

3.1Table (1) distribution in families according to gender.

Results showed most relative to the patient with thalassemia are the women (mostly mothers of them) 75 %were females while 25% were males.

Gender	Frequency	Percent
Male	25	25%
Female	75	75%

3.2 Table (2):level of education in families of thalassemia children.

Most females read without degree 51%,while Males have secondary degree 11%. Only 2%of 75 female had a bachelor degree, while males are only 4%.

Level of education of female	Frequency	Male	Female	Percent
Bachelor	6	4	2	6%
Diploma	14	4	10	14%
Secondary	24	11	13	24%
Read & write	56	5	51	56%
Total	100			100%

3.3Table (3) :Response of questions regarding thalassemia awareness.

Most of families are not Well educated about disease especially in antenatal screening or screening before marriage,also involving questions about genes treatment, medications, food.

Questione	Yes	No
Do you have thalassemia gene?	35%	65%
Do you know thalassemia can be detected during pregnancy?	14%	86%
Do you know about screening test for thalassemia gene detection before marriage?	23%	77%
Can thalassemia be spreed by food medications or infections?	17%	83%
Do you think regular blood transfusions is the only treatment?	81%	19%
Is the iron containing food is healthy for thalassemic patients?	82%	18%
Total	100%	100%

3.4Table(4).variable questions about knwoledgment of families of children with thalassemia involving defintion of anemia 30% know, questions about method of transmission of disease, ,screening, counseling, type of thalassemia.

Questions	Percent
Defintion of thalassemia	30%
Do you know how this disease caused? Yes No	 57% 43%
Cause of thalassemia as specified by caregiver: Correct knwoledge Incorrcet knwoledge Don't know	 42% 10% 44%
Have you ever heard about premarital counseling: Yes No	 66% 34%
Have you ever heard about antental screening: Yes No	 44% 66%
Do you know about treatment Yes No	 92% 8%

modalities of treatment as specified by caregiver: Blood transfusion Iron chelation Both blood&Iron Spelenectomy Don’t know Total	 43% 0% 25% 17% 15% 100%
level of awareness among parents of children with thalassemia: Unaware Limited knwoledge Aware well	 30% 47% 23%
Parents knowledge regarding the sings of thalassemia: I Know Uncertain I Don’t know	 64% 22% 14%
Parents knowledge regarding the types alpha And beta thalassemia: I Know Uncertain I don't know	 26% 14% 60%

Parents knowledge regarding the causes of each of alpha And beta types of thalassemia: I Know Uncertain I don't know	 26% 14% 60%

Chapter 4

4.1.Discussion

The sample of the study consist of (100) families of thalassemic patients who they come with their children to thalassemia center in Alnasiyria city to seek for treatment to their child. Table (1) the results shows that (75%) of the sample are female and this is from the point of view of the researchers that the females are more free to be in company with their children to the hospital in the treatment time and the Males 25% (fathers and brother) are connected to work and support the family economically . Other study done in Karachi, Pakistani by Hasan Abbas Zaheer not agreed to our study, participants were males (64.2%), (35.8 %) were females(12). According to level of education in this study Table (2) around (56%) of the sample are in level of read and write while just (6%) have bachelor degree of education ,14% had diploma and 24% had secondary degree. While in other studies done tehran hospital, Hassan Abolghasemi Iran, tehran medical Science, around (20%) of the sample are in level of read and write of education while 66%% have bachelor degree of education while (18 %)of the sample had secondary degree. (14).Regarding parents awareness in this study Table(3) 35% of parents have thalassemia gene 86% Don't know thalassemia that can be detected during pregnancy Only 23% participant know about screening test for thalassemia gene detection before marriage while 77% Don't know.Regarding treatment 82% of participant said that iron containing food is healthy for thalassemic patients .In other study done In Bahrain (15) National Hereditary Anaemia Society ,done by Amani Al Hajer and Shaikha Al Arrayed, Ministry of Health, Kingdom of Bahrain Results showed that 75% of parents had thalassemia gene, 43% of them don't know that thalassemia gene can be before marriage. Table (4) The questions was conducted on 12 items to assess the thalassemic parents knowledge toward thalassemia regarding to definition, general information, sign and symptoms, types and treatment. Concerning the children's parents knowledge , the study indicated that they have high rates (30%),(64%)(55%),(26%) of acceptable level in knowledge related to definition, singes and symptoms, the treatment method and classification of alpha and beta thalassemia.And from our point of view this it will be because of the parents will experienced the disease its signs and symptoms and the treatment with the long time of the disease years in their children and follow up to their treatment. Which it is also agreed with what (16) published by (Ayman A.et al., 2008). While the parents have a high rate of unacceptable level in the knowledge regarding the genetic factor

that causes the disease(62%), signs and symptoms in carriers (78%),the genetic role in disease transmission (78%), the cause of each types of thalassemia (60%),Pathophysiology (94%), diagnosis methods (74%) and treatment of minor thalassemia (70%). this will be agreed with the result of our study regarding the level of education of the sample which they contain 56% of sample are in level of read and write in education level and only there is 6% have bachelor degree which also are supported by what published in study about the parents attitudes toward genetic diagnosis in Pakistan by Towell T, Cartwright T. (17). And also this be supported by study carried out in Greece about thalassemia ,a social problem in Greece by (Bener A, Hussain R)(18). .which they said there is a wide variable spectrum of problems arising in parents of children with homozygous thalassemia. They depend upon a number of factors, the most important being the educational, economic, social and temperamental status of the family. And this will be supported by what is published in National Center on Birth Defects and Developmental Disabilities about health education and health literacy Amber E, Maurice-Stam H, (19) which he ask to support outreach and education activities for people with thalassemia. Focus groups have been used to better understand the issues related to living with thalassemia and have education and support programs. For that there must be more emphasis regarding information in giving care to patients with thalassemia in the health policy , to perform the parents and the care giver effectively and satisfactory for themselves and for their patients and this will be through educational program, and supporting program to these families.(19) And this supported by (Hamamy H. & Bittles A.H, 2009) in their publishing in Meeting Individual, Family and Community Needs.

4.2Conclusion

1. Most relative of thalassemic patients are females , but most of them don't have a degree, just read and write.
2. Education most families are not Well educated about disease, only samll Percent had bachelor degree
3. Parental knowledge about thalassemia defintion, causes, types, was inadequate. It is required to educate not only parents but also general public to create awareness about thalassaemia so that the disease can be eradicated.
4. Most families had good knowledge about treatment with types of food,blood transfusion and Iron . But other treatment modalities are not well experienced.
5. Caregivers' knowledge regarding thalassemia investgations and screening tests was not at all satisfactory.
6. Regarding thalassemia counseling most families don't know about it.

4.3.Recommindations

1. educational program for the parents and families of the children who experienced blood disease including thalassemia.
2. Establishing a special consulting unites for the families of blood disease children's to answer their questions.
3. Encourage the families and parents of these children to work as a volunteers in the consulting unites to help the new cases of thalassemia and their parent to be oriented with their new situations.
4. Provide a Social and economic supports to thalassemic patients and to their families.
5. Concentrate on thalassemia and its complications and management in study program in nursing educational program to preparing them to be in good support to the thalassemic patients and their families.
6. More public education about thalassemia in hospital, health center.
7. The screening of children and pregnant women who visit clinicians is an effective strategy to limit the disease morbidity. The social worker should ensure that the caregiver/patient has adequate support and financial resources so that they can continue with treatment. Nurses should educate patients on the importance of treatment compliance to avoid serious complications, as well as monitoring treatment progress.

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Appendix

عمر الطفل المصاب بالثلاسيميا :

جنس ولي الأمر المشارك في الدراسة:

الشهادة :

يقرأ ويكتب الثانوية الدبلوم البكالوريوس

مامعنى الثلاسيميا؟

هل لديكم جينات للثلاسميا؟

ماهي أنواع الثلاسيميا؟ وماهي أسبابها؟

هل تعرف الأعراض والعلامات للثلاسيميا؟

هل تعرف ان الثلاسيميا يمكن أن تُعرف خلال الحمل؟

هل تعرف عن فحص الجينات للثلاسيميا قبل الزواج؟

هل تعتقد أن نقل الدم المنتظم هو العلاج الوحيد؟

هل تعتقد أن الثلاسيميا يمكن أن تحدث بسبب الأدوية أو الالتهابات؟

ما هي طرق العلاج التي تعرفها؟

هل الأدوية والأطعمة التي تحتوي الحديد مناسبة لمرضى الثلاسيميا؟