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Counseling for Thalassaemic Patients and their Parents

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Abstract:
Thalassaemia is a heterogeneous grouping of genetic disorder that result from a decreased synthesis of alpha of or beta chains of haemoglobin (H.G) Haemoglobin serves as the oxygen carrying components 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 con not carry sufficient oxygen, this Courses anaemia that begins in early childhood and lasts throughout life.

Psychological counselling is essential for Thalassaemicpolieut and their parents for better quality of life. Patient should be educated to keep a cheek on their disease by following as appropriate treatment plan and adopting healthy living holists.

Keywords: *Thalassaemia, polieut, Courses anaemia, Haemoglobin*

1. Introduction

Thalassaemia is an inherited disease of the blood. It is known as Cooley's anemia in the United States. It reduces the amount of haemoglobin our body can make, so it can cause anaemia. Thalassaemia is an autosomal recessive disease. The carriers usually being clinically normal are not aware of the risk till an affected child is born in the family. Advancements in biochemical and molecular understanding of this disorder have led to the development of diagnostic tests, which can be successfully used for detection of carriers. The carrier detection by population screening provided an opportunity of primary prevention of the disorders i.e., the couple at risk can be identified before giving birth to an affected child an can be provided the option of pre-natal diagnosis to prevent the birth of an affected child. beta Thalasaemia is a very good candidate disease for adopting the approach of primary prevention. The feasibility of such an approval has been validated by the success of Mediterranean countries in reducing the incidence of β - thalassaemia by 90%.

2. β -Thalassaemia in Indian Population

β-Thalassaemia is one of the most common genetic disorder in India with 3-4% prevalence of β-Thalassaemia carriers in general population. The carrier rate varies with in different subgroups in India depending on their geo- ethnic origin. The rate is highest among Sindhi and Punjabi population originally belonging to province of Pakistan, while the prevalence rate in others varies between1% to 10%. More then 10,000 thalassemic children take birth every year in India. More than 200 children of Lucknow city and adjacent areas are getting treatment regularly fromSanjai Gandhi Postgraduate Institute, Lucknow.

The Thalassaemia refer to a syndrome of genetic diseases characterized by decreased or absent production of one or more globin charms. The symptoms of thalassaemia depend on the genetic defect

and its severity ranging form mild American to transfusion depending on Treatment for severe forms of Thalassaemia involves blood transfusion and chelation therapy. Recent advances is hematopoietic stem cello transplant and gene therapy hold promises as curative treatments for these inherited blood disorders psychotherapy can make their life more effective and positive. Thalassaemia is inherited disease of the blood. It is known as Cooley's anemia in the United States.

3. Thalassaemia

3.1 Overview

- Caused by a genetic disorder of red blood cells.
- Symptoms depend on the type and severity of the disease.
- Spleen hyperplasis may be caused by iron accumulation inside it rather than being reused.
- For prevention, a comprehensive medical examination must be conducted before marriage.
- Consult your doctor before taking any medicine or dietary supplement.

3.2 Definition

Thalassemia A genetic disorder that occures in blood cells, in which hemoglobin (the main component of red blood cells and oxygen transporter) is lower than normal, causing a decrease in blood oxygen level.

3.3 Other Names

Also called Mediterranean anemia because the disease originated in the Mediterranean basin.

3.4 Types

The types of thalassemia depend on the following:

- The affected part of hemoglobin (alpha or beta).
- Severity.

3.4.1 Alpha Thalassemia

Hemoglobin consists of four genetic chains of alpha type, two from the father and two from the mother. When there is an imbalance or failure in these chains produce so-called (Thalassemia alpha).

- When there is an issue in one chain
  A person is a carrier of the infected gene with no apparent symptoms.
- When there is an issue in two chains
  A person with these genes has minor symptoms that may not appear but can be detected by a blood test.
- When there is an issue in three chains
  The patient would have severe anemia, symptoms vary between moderate and severe, and may develop an enlarged spleen and bone deformity.
- When there is an issue in four chains
  Cause of death of the fetus before birth or immediately after birth.

3.4.2 Beta Thalassemia

Hemoglobin consists of two beta chains, each of which is inherited by a parent, and when a malfunction occures, the so-called beta thalassemia is produced.

- When there is an issue in one chain (minor thalassemia):
  No apparent symptoms are experienced except for a mild anemia that appears during routine blood tests. The patient needs blood transfusion to be able to live normally.
- When there is an issue in two chains (major thalassemia):

The patient suffers from severe anemia, bone deformity and spleen enlargement, and needs regular blood transfusions to survive normally. These symptoms do not appear when the baby is born; But begin to appear during the first two years of life.

3.5 Causes

It is caused by a genetic defect that affects the process of producing hemoglobin, and this defect is geneticallly transmitted from parents to children.

3.6 Symptoms

Depending on the type and severity of the disease, some children develop symptoms from birth, while others develop symptoms during the first two years of life and may not show symptoms in patients with the disease (with disorders in one gene).

4. Main symptoms include

- General weakness or tiredness.
- Pale, yellowish skin.
- Darkening of urine.
- Slow growth.
- Shortness of breath.
- Pale Skin
- Flatulence.
- Bone deformities.
- Frequent inflammations.

5. Complications

- Whorsening anemia and a sense of fatigue and constant tiredness.
- Delyed child development and delayed puberty.
- Enlarged spleen and flatulence due to iron accumulation inside the spleen rather than being reused.
- Blood clotting because of splenectomy, which increases the number of platelets.
- Lacking Folic acid and vitamin B_{12}.
- Bone deformities.

6. Treatment

Treatment of thalassemia depends on the type and severity of thalassemia.
Treatment of mild to severe conditions includes:

6.1 Blood transfusion

Frequent red blood cell transfusions are the main treatment for people with moderate or severe thalassemia.

6.2 Stem cell transplant (and bone marrow transplant).

Stem cell transplant can be used to treat severe thalassemia.

6.3 Treatment of iron accumulation

Doctors remove excess iron from the body. Some may use some medications to treat iron overcrowding; it may be a liquid medicine that is given slowly under the skin, or a contraceptive.

6.4 Health Tips for Thalassemia patients

- Avoid taking iron tablets, vitamins or other iron-containing supplements without doctor supervision.
- Eat a healthy, balanced diet.

- Folic acid may be recommended to help the body produce red blood cells, as well as taking calcium and vidamin D to maintain bone health.
- Take care of personal hygiene to avoid infection, especially in cases where the spleen is removed.
- Make sure to take vaccines (such as: Annual flu vaccine and others to prevent infection.

7. Psychological Treatment

Psychological treatment is especially important for thalassaemic patients. The diagnosis of thalassaemia usually comes at an early and crucial time in the life of a child and the parents are not prepared for the diagnosis of a chronic illness.Usually, the parents do not even know what thalassaemia is. When they learn about the disease, they are shocked, disheartend, and disappointed. They are in a state of despair because they do not know how to cope with such an unforeseeable and tragic event in their life and the life of their child. Parents pass through a period of shock and grief, and they feel responsible. Often the presence of the illness brings the parents closer together to help each other deal with the common misfortune in their life. However, it can push them apart, if the mother becomes completely preoccupied with the ill child and ignores her partner and any other children. It is obviously not an easy task to deal with this unexpected event.

After diagnosis of thalassaemia the role of counsellor begins. Firstly, parents need to be informed and helped to understand with thalassaemia is. They need a lot of support and encouragement to learn how to deal with it in the most effective way. Doctors and counsellors should educate parents about this disease so that they can cope effectively with this tragic event. The presence of thalassaemia has adverse effect on each developmental stage of the child.

Having thalassaemia is not some thing a counsellor can change but he can change how patient and his attendents feel about having it. Very often people, including parents as well as medical professionals believe that a child who is ill is weak, vulnerable, needs more protection, and constant surveillance. However, this attitude may communicate an idea that the child is inferior and less capable than other children. The fear that something may happen to the child or that the child will not be capable of making it on his own interferes with the physical and psychological development of the child. Fear, overprotection, and the limiting factors of medical treatments may make the child with thalassaemia doubt his own ablilities and feel guilty for attempting to do things by himself.

Thus, it is very important for counsellor to educate parents and health care providers to allow thallassaemic children to express themselves and to participate in all activities, appropriate for their age. Their physical disability should not be translated into an emotional or mental handicap.

The attitude of the child towards himself should be healthy and normal. Getting these negative emotions such as anger, resentment and embarassmentuncler control will likely help the child to develop a higher level of self-esteem. Parents should not promote the felling of self pity in the child. The child should be encouraged for developing industriouseness, mut be motivated to be competent both academically and socially. He should not be made to feel inferior or less capable than other children of his age group. It is, of course, true that many adults can be very prejudiced against an ill child partly because of ignorance and partly because of their own fears of what it means to be ill. Howsever, the most important thing is how the parents deal with the illness, how they manage their own anxiety, and the message they transmit to the child and the school system.

In this context, family counselling is required bacause family enviroment plays a crucial role in the overall development of the child. Parental involvement is needed for every child. The atmosphare at home should be healthy and cordial. This will promote positive self-regard or self esteem, and a positive self-image of the thalassaemic child. The child should begin to accept and like himself. The

consellor can bring about change in the perception and behaviour of the patient and his parents through supportive and educative counselling. This change will be gradual but relatively permanent and more comfortable. The parents should nurture, protect and provide stimulating experiences to the child. They should convey their feeling to the child that having thalassaemia does not mean that they are not likeable or not worthwhile as a person. Their well being is as important as of others. Everybody has strength and weakness, good and bad sides. Not one is all good or all bad, no one is perfect. It is true and perfectly normal that the patient often feels that he is too much of a burden and this makes their life more difficult. But thourgh constant encouragement of the counsellor, they can overcome their physical deficiency in cordial and helpful atmosphere. He can boost patient's self-confidence and can make them ore decisive, independent, and sociable.Thus, the counsellor can develop strength, courage, and acceptance in patients and their parents to face the challenges of dealing with thalassaemia.

It is clear from the above discussion that usually thalassemia is a severe and chronic illness. People who have it need regular blood transfusion in order to live. But counselling may be a step to wards emotional maturity, towards acceptance and caring for their well-being. Counselling can be educatve and bring about positive thinking in the patients and their relatives. Along with medical treatment, a counsellor can improve thalassaemics quality of life and can make each moment and each day of their life a beautiful, satisfying and fulfilling experience.

8. Conclusion

Thalassaemia Associations play an important role in this regard because they show that thalassaemia is not just a problem for the patient, or his family, it involves many persons in society. These associations can bring thalassaemic patients together. Mass-communication media such as the television, films, and periodicals can help in creating public awareness of this illness.

Thalassemia is a genetic disease where it cannot be prevented or avoided. If the person is infected or carriers of the disease, it is best to see a genetic diseases specialist.

To reduce the chance of thalassemia transmission to children, it is recommended to conduct a comprehensive medical examination before marriage where it is possible to know the possibility of genes infected with the disease in men or women.

Reference

1.Kulozikae, Bails, Kar BC. Etal. Skkle cell B^+ thalassaemia in orissa state, India. Br. J Haematol. (1991; 77: 215-220(Pub Med)
2.Modell, Bernatette&Georganda, Evgenia (1995). Second Edition, Printed and distributed by the Thalassaemia International Federation, 1995.
3.Phadke, S.R., Agarwal, Sarita & Agarwal, S.S. (2002). 'Primary Prevention of β-Thalassaemia'- Paper presented in a Conference by
4.Razazian HH Jr. The ThalassaemiaSyndroms (1990). Moleculer basis and prenatal diagnosis in 1990. Sessions in Hematolog(1990;27;209-228(Nul-Med)
5.Rino,Vullo (1994). What is Thalassaemia?