Thalassemia Among Children and Its Impact on Parents A Review Article

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***Abstract*—The existence of a life-threatening disease like thalassemia in children causes physical and psychological stress in parents and that can predispose them to psychological disorders. This paper reviews the overview of thalassemia among children and its impact on parents with an objective to improve the quality of life of parents and ways to overcome it.**

***Index Terms*—Life-threatening, Thalassemia, Quality of life.**

I. THALASSEMIA AMONG CHILDREN AND ITS IMPACT ON PARENTS

Parents are important primary caregivers as they are the key Individuals who take on the crucial role of caring for children and encounter multiple challenges that affect their quality of life. Child's quality of life depends largely on the corresponding parents' quality of life.[1] Parents of thalassemic children have many concerns regarding the appearance of the child, bone deformities, short stature, poor self-image, frequent hospital visits for blood transfusion, delayed or absent sexual development and impaired fertility and other associated complications. They feel depressed, worried, frustrated, despaired, hopeless and helpless and also have numerous physical, emotional, psychosocial and financial sufferings. A significant psychological impact, parents experience emotional burden, hopelessness, and difficulty with social integration, negative thoughts about their life, guilt, increased anxiety and low self-esteem. The life expectancy and prognosis of thalassemia children were improved due the availability of modern treatments, the life-long measures create an impact on the parent's life and those measures are expensive and needs proper adherence for the significant results. Thus, it is important to determine the quality of life of parents of children with thalassemia.[2]

II. PREVALENCE OF THALASSEMIA

Global Carriers

About 1.5% (80-90 million) of the global population carries the beta-thalassemia trait.

Thalassemia prevalence varies significantly by country, with highest carrier rates (up to 10-20%) in Mediterranean, Middle Eastern, South Asian (India, Pakistan, Bangladesh), and Southeast Asian populations (e.g., Cyprus, Papua New Guinea), while lower rates exist in the Americas and Europe.

India: Known as the "thalassemia capital of the world," India has an estimated 20 million beta-thalassemia carriers, with a mean carrier prevalence of 3.3% in the general population. The prevalence in certain communities can be much higher (10-15% in Gujarat). India has the world's largest number of affected children, and carrier rates can exceed 40% in some specific Indian and Middle Eastern communities, often linked to consanguinity and malaria-prone regions. Thalassemia has a significant burden in India, with an average national carrier rate of 3-4% for beta-thalassemia, translating to millions of carriers (around 35-45 million people) and thousands of new major cases annually. The prevalence of thalassemia ranges between 0.6% and 15% across south India.[3]

Karnataka: Thalassemia is a significant health issue in Karnataka, with estimates of around 10,000 patients and a growing number due to limited awareness.

District-Level: Studies highlight high prevalence in districts like Hassan (over 35% thalassemia cases), Chitradurga (27.3%), and Davanagere (25.5%).

Overview on Thalassemia

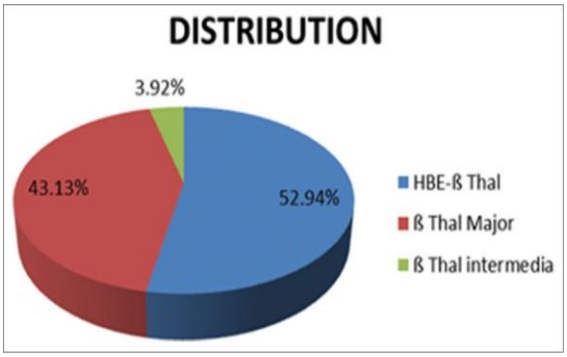

Fig:1 Distribution of types of thalassemia.

Meaning: The name thalassemia is derived from the Greek word "thalassa" meaning "the sea" because the condition was first described in populations living near the Mediterranean Sea. Thalassemia in children is an inherited blood disorder where the body can't make enough haemoglobin or Thalassemia is an inherited disease of faulty synthesis of hemoglobin.[4]

Definition: Thalassemia is an autosomal recessive disease in which a genetic mutation causes a decrease in the synthesis rate of one of the globin chains that comprise haemoglobin (Hb).[5]

There are two main forms of thalassemia that are more serious. In alpha thalassemia, at least one of the alpha globin genes has a mutation or abnormality. In beta thalassemia, the beta globin genes are affected.

What is haemoglobin?

Haemoglobin 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.[3]

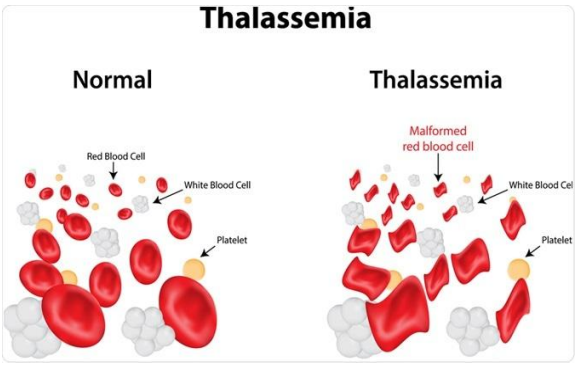

Fig:2 Difference between Normal and abnormal RBCs (Thalassemia)

Causes and risk factors:

- Inherited genetic mutations
- Family history
- Ethnic background
- Carrier status

What are the Symptoms of Thalassemia?

The symptoms of thalassemia can vary. Includes

- Bone deformities,
- Dark urine
- Delayed growth and development,
- Excessive tiredness and
- Fatigue
- Yellow/ pale skin
- Shortness of breath
- Jaundice
- Cold hands and feet
- Abdominal swelling
- Poor appetite and frequent infections
- Fast heartbeat and leg cramps

How is thalassemia diagnosed?

- ✓ A Complete blood count
- ✓ A Reticulocyte count
- ✓ Haemoglobin electrophoresis
- ✓ Genetic testing
- ✓ Iron studies
- ✓ Peripheral blood smear
- ✓ Parental testing

How is thalassemia treated?

- ✓ A Blood transfusion
- ✓ Iron chelation
- ✓ Folic acid supplements
- ✓ Bone marrow and stem cell transplant

- ✓ Gene therapy
- ✓ Supportive care
- ✓ Pharmacological agents
- ✓ Early diagnosis

Complications of thalassemia:

- ➢ Hepatosplenomegaly
- ➢ Bone problems
- ➢ Iron Overload
- ➢ Heart Problems
- ➢ Delayed puberty and hormonal issues
- ➢ Increased infections[6]

III. CONCLUSION

Care-giving is a normal part of being the parent of a young child, but this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence.[7] Effective coping styles reduce the negative effects of stress and the ability of management of environmental and internal stressors. Effective coping is an important source to create a well-being feeling and psychological adjustment in stressful situations. Families without an appropriate coping behavior do not provide enough supports for their sick child. There is a great need to plan and implement health awareness programs for caregivers. The Improved mental health of parents will ensure restorative care of the child. [8]

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