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PSYCHOSOCIAL FACTORS ASSOCIATED WITH MAJOR THALASSEMIA

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Abstract: Thalassemia is a hereditary condition that results in the creation of defective haemoglobin molecules. Patients are diagnosed with thalassemia major after exhibiting severe clinical symptoms and profound anaemia. This study aims to investigate the major thalassemia and psychosocial aspects of it, which is a critical issue, in order to serve as a road map for better treating these patients and contribute to the literature. This study used narrative review as its method. Between 2018 and 2023, a literature review was undertaken by searching materials published in databases such as Web of Science, PubMed, Scopus, and the Google Scholar search engine. Additionally, the WHO website was searched. Thalassemia major harms the heart, liver, lungs, and endocrine organs due to anaemia and iron buildup. Furthermore, the patient could experience. Mental and social issues arise as a result of the disease's congenital aetiology and lifelong duration. Thalassemia patients face significant emotional challenges as well as therapeutic burden. There are numerous research on the prevalence and physical implications of thalassemia. However, there are insufficient papers and studies documenting the psychosocial impacts of thalassemia on patients and what may be done to mitigate these effects. As a result, this research focuses on the process of thalassemia and the psychosocial problems it causes in order to contribute to the literature and provide a road map for better managing these individuals

Keywords: significant thalassemia, blood disorders, psychological issues, and psychological support

Introduction

The anaemia that results from faulty synthesis of one or more haemoglobin chains is the hallmark of thalassemia, an autosomal recessive blood disease. Patients with thalassemia minor (carrier, heterozygous) are those whose anaemia does not require regular transfusion; patients with

significant clinical findings and deep anaemia are classified as thalassemia major (patient, homozygous); and finally, patients with very little or no anaemia despite having abnormal erythrocyte structure are classified as thalassemia intermedia (patient, homozygous) (1,2). Major health issues related to thalassemia affect 72% of 229 countries worldwide. Thalassemia affects 5.2% of the world's population, 7% of expectant mothers, and 1% of couples. The WHO estimates that 5% of people have thalassemia carriage throughout the globe (3). The thalassemia gene is present in about 17% of newborns each year (4). The prevalence of thalassemia varies throughout numerous nations and regions within those nations. Due to migration from the Middle East and the Far East, Europe and the United States of America now have a higher density of Mediterranean countries. Together with the Mediterranean region, Greece, Italy, Cyprus, Malta, Spain, the western and southern beaches of the Republic of Turkey, and the far eastern countries, the density is also rising along the coast (5). One of the most prevalent causes of anemia in the Mediterranean region is thalassemia major. Major thalassemia is a significant public health issue that is passed down from parents to their offspring. Screening programmes can help prevent this condition.

Clinical signs of thalassemia major appear between the ages of six months and two years. Anemia and iron excess cause damage to the heart, liver, lungs, and endocrine system (7). Growth retardation, altered facial, head, and tooth shapes as a result of bone abnormalities, cardiac and hepatic issues, delayed puberty, diabetes mellitus, hypothyroidism, and hypoparathyroidism are among the conditions that patients with thalassemia confront. Treatment options for thalassemia major including iron chelation therapy, erythrocyte transfusion, splenectomy, follow-up care, psychological support for related difficulties, and stem cell transplantation (6,8,9).

Thalassemia patients live longer thanks to new medical advances and therapies used in wealthy facilities. National health strategies in both developed and developing nations include "thalassemia prevention and treatment programmes." Mediterranean nations have demonstrated effectiveness in combating this illness by requiring screening tests of prospective parents or individuals seeking a child before marriage. Countries favour pre-marital screening due to its affordability and ease of use. The scan's objective is to detect high-risk couples and, through genetic counselling, enable them to have healthy children. The screening process works well to stop thalassemia from being inherited (2,10).

The lives of those with thalassemia major are impacted, just like with any chronic illness. This illness has detrimental effects on one's body, mind, and social life (11, 12). The application of transfusion protocols has demonstrated an improvement in the life expectancy and quality of life of patients, owing to advancements in the treatment of thalassemia major (6,13). However, low blood and blood product reliability, insufficient blood transfusion therapy, persistent iron deposition, or insufficient chelation therapy utilisation can all lead to treatment-related problems. Patients deal with osteoporosis issues, bone abnormalities, and musculoskeletal illnesses. Osteoporosis, acute pain, and diminished functional capacity all contribute to their declining quality of life.

Patients with thalassemia major experience psychosocial problems as a result of their illness. Physical deformities, hepatosplenomegaly, growth retardation, yellow skin tone, and a distinctive face with noticeable wrinkles similar to the illness are all present. People's self-esteem and confidence are severely impacted by this body image, which also makes them feel different from other people. As a result, patients withdraw from society and play a passive role in social settings, which has a detrimental effect on their mental and quality of life (11,14). The chronic nature of thalassemia, the need for regular transfusions throughout life, and the associated complications have a negative impact on an individual's physical and mental health, psychological state, degree of independence, social

relationships, personal beliefs, and overall quality of life, including relationships with the environment (6,15). frequent hospital stays as a result of

Anxiety, despondency, and sadness can also result from transfusion reactions, family separation, activity restrictions and pain, adverse effects of iron chelation therapy, and dread of dying. Additionally, this raises the costs to the nation and the detrimental effects of people. In individuals with thalassemia major, psychosocial maladjustment was prevalent in 80% of cases. Throughout their lives, patients may encounter a range of emotional issues, anxiety, and behavioural issues. These include somatization, low self-esteem, loneliness, irritability, helplessness, a sense of lovelessness, impatience, grief, aggression, anxiety, hopelessness, incapacity to deal with worry, fear of death, lack of confidence, and low self-respect (16–19).

A significant public health issue in the Mediterranean region is thalassemia. Patients with thalassemia have numerous psychosocial issues as a result of the aforementioned causes. In this environment, the written sources are extremely scarce. The patients experience difficulties since the psychological studies are inadequate, even in cases where the patients are physically monitored. This study sought to address the psychosocial element of major thalassemia, which is a crucial topic, in order to add to the body of literature, provide a better treatment plan for these patients, and act as a guide.

Methods

The study employed a descriptive method to examine the psychosocial issues faced by patients with thalassemia major. It focused on the relationship between the disease and its impact on the patient's body image, self-esteem, and quality of life. The research aimed to highlight the emotional, psychological, and social challenges experienced by patients due to physical deformities, growth retardation, and the need for lifelong treatment, including blood transfusions and iron chelation therapy. By analyzing previous studies and literature, the researchers sought to address the lack of psychological support available to thalassemia patients and propose a more comprehensive biopsychosocial care model.

Results and Discussion

Psychosocial Issues with Thalassemia Patients Principal

Chronic illnesses are long-lasting conditions that make it difficult for people to completely control their future. A person's life must be significantly altered by many chronic illnesses. The patient's and their family's coping strategies may be strained by the disease's flare-ups and remissions as well as by changes in their state of health. The psychological reaction to chronic illnesses is also influenced by regular changes including taking on the job of carer, modifications to one's sexual life, social connections, and material possessions. Adaptation is necessary for several mechanisms in chronic illnesses. Addiction, melancholy, denial, low self-esteem, and discord can all result from poor adaptation (11,20, 21).

Individuals with thalassemia, a chronic illness, endure psychological and physical hardship. social and psychological issues are rising as a result of the illness's favourable advances and the rise in patients who reach adulthood. Patients with thalassemia major deal with a variety of issues, just like those who have other chronic disorders. Mental health is typically disregarded in the effort to limit the disease's progression (16, 17).

Psychosocial issues are the most significant concern for thalassemia patients, even when their medical condition makes their challenges less severe. Common issues include the chronic nature of thalassemia major disease, the requirement for frequent blood transfusions throughout life, disorders

related to body image, being assessed differently from peers because of the delayed growth and development, high treatment costs, challenges in finding a suitable match, and the requirement for regular leave to continue treatment throughout one's working and educational years. Patients with thalassemia major must constantly work to overcome significant health issues throughout their lives. Consequently, psychosocial issues can be these patients' most pressing concerns (16, 17).

Anxiety can also be exacerbated by issues like social breakdown, employment issues, sexual issues, and the desire to start a family. Patients with severe anaemia experience weakness. Transfusions used to maintain an ideal level of haemoglobin assist patients have less symptoms and less anxiety. Frequent monthly blood transfusions improve patient outcomes, but they also carry additional risks, including elevated iron levels and blood-borne viral infections. Patients experience psychological emotions as a result of this (16). Ongoing chelation therapy significantly impacts patients' psychological and social well-being and becomes a significant burden in their everyday life.

The process of adjusting to both internal and external changes, including good coping and reconciliation, is known as adaptation to sickness. Psychosocial adjustment to the disease can have a good or negative impact on the disease's course, even though it is influenced by all disease- and treatment-related factors. A patient with good psychosocial adaption may be better able to manage the side effects of the illness, experience fewer complications and attacks, and experience less issues in social and familial settings. It may give the sufferer a stronger sense of control over their illness. Furthermore, the ability of the patient to accept the losses brought on by the illness and to make the most of their current potential boosts their compliance with the treatment, as demonstrated by their ability to the flexibility to change their goals when necessary (16,22,23).

Many treatment centres do not provide psychological support or treatment for psychosocial disorders. The biopsychosocial care paradigm will improve patients' biological, psychological, and social well-being as well as their level of satisfaction when treating thalassemia patients. In light of this, it's crucial to give careful thought to the psychosocial issues that thalassemia patients face.

Self-Esteem and Body Image in Patients with Thalassemia Major

An individual has a holistic structure that requires attention in terms of social and intellectual, as well as physical and mental components. The idea of the body encompasses all of an individual's perceptions and knowledge of the body's internal composition and exterior appearance. A person's entire mentality—including their personality, values, and interpersonal relationships—have an impact on their body image. An individual's perception and assessment of their own body is crucial in defining their body image, sense of self-worth, and level of confidence. Physical, psychological, and social experiences all contribute to one's body image.

A person with a positive body image exhibits a good attitude, which indicates a tendency towards a positive disposition and self-confidence. Self-worth Clinically significant is the close association between thalassemia major and psychiatric problems including altered self-esteem and body image as a result of growth retardation and bone abnormalities (25, 26).

Physical deficiencies, deformities, and physical illnesses associated with chronic illnesses cause feelings of inadequacy and alter body image, which lower self-esteem. Resistance to psychological and physiological disorders is influenced by one's degree of self-esteem and body image; people with low levels of these attributes avoid positive reinforcement and do not participate in therapy. Depression can strike people who have poor body image and low self-esteem (27). Patients suffer from a lack of confidence as a result of bodily changes and weaknesses as well as the dread and worry brought on by the chronic disease thalassemia. It's critical to address low self-esteem because it might lead to patients

Patients' Lifespan and Quality of Life after Major Thalassemia

Whether or not patients with thalassemia major follow the advised standard treatment protocols determines their lifetime and quality of life. Thanks to advancements in thalassemia diagnosis and treatment, patients' life spans and quality of life have significantly improved during the past ten to twenty years (28, 29). Effective chelation therapy decrease iron load-related problems, hence extending life expectancy. One significant development in the thalassemia treatment field was the identification and widespread application of desferal in chelation therapy. The main issue, especially in thalassemia patients, is the problems that arise from patients not taking chelator medications as prescribed. in nations have access to quality medical care. Their quality of life is directly impacted by this. Hence, in addition to educating patients about thalassemia treatment, medical practitioners and their families should also assist patients in using efficient chelation therapies (15, 30).

In the Mediterranean countries, thalassemia patients have been treated since the mid-1980s according to the guidelines established by the Thalassemia Federation. Positive changes in the patients' life duration and quality of life were noted after receiving regular Desferal chelation treatments (9,31, 32). The quality of life and life expectancy of thalassemia patients have significantly improved in the years that have followed. These improvements can be attributed to improved diagnosis and treatment of hepatic and cardiological iron overload with safe and sufficient blood transfusions, newly available oral chelators, endocrinological replacement therapies, and noninvasive magnetic resonance imaging techniques. Thanks to advancements in treatment, patients with thalassemia major are now more confident about the future and are encouraged to enjoy normal lives.

Infections, liver disorders, other causes, and particularly abrupt heart failure claimed the lives of patients in spite of the efficient conventional treatments, sufficient and trustworthy blood transfusions, and chelation therapies that had been implemented from the latter part of the 1980s. Following the advised conventional treatment procedures, the patients' life expectancy and quality of life showed the first discernible improvement, and their average life expectancy was extended (15,32).

When thalassemia patients approach maturity, they start to take charge of their lives and experience worry related to their family, career, and education. Many patients undergo significant transformations over this time and come to understand that, with the right care, they can live longer and have higher-quality lives. Patients are more inclined to follow treatment recommendations.

The primary cause of thalassemia patients' social and psychological issues is their concern over wanting to live long and meaningful lives. The efforts of specialised physicians in thalassemia centres equipped with various amenities can significantly alleviate patients' concerns and anxieties regarding their futures. educating patients' relatives on the origins and effects of the illness therefore one of the most crucial tasks for the doctor treating thalassemia should be persuading them of the need for the prescribed medicines. Things get simpler as soon as patients and their families feel relieved about the therapies and receive proper medical assistance. Patients with thalassemia are living longer, have better quality of life, and experience less fear and worry when the suggested treatments are applied correctly (15, 33).

Conclusion

The goal of treating thalassemia patients with enough and safe blood transfusions in conjunction with successful iron chelation is still being pursued in an effort to extend their lives and improve their quality of life. Patients and their families are more optimistic about the future because of the significant improvements in life quality and length that have been made possible by ongoing

therapy. Patients with thalassemia appear to have acclimated to live with a chronic illness when the thalassemia process is evaluated, but their psychosocial issues and treatment difficulties are taken into consideration. As a result, emphasis should be placed on psychological problem treatment and care. Patients should be followed up with using the psychosocial care paradigm. Furthermore, it is crucial that the patient, family, and medical staff work together.

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