Revista ARACÊ
ISSN: 2358-2472

# PSYCHOSOCIAL CHALLENGES IN β-THALASSEMIA: THE EFFECT OF STIGMA AND ONGOING TREATMENT ON MENTAL HEALTH

https://doi.org/10.56238/arev7n2-140

**Submitted on:** 01/12/2025 **Publication date:** 02/12/2025

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## ABSTRACT

**INTRODUCTION:** β-thalassemia is a hereditary hemoglobinopathy that results in chronic anemia and several systemic complications, impacting the quality of life of patients, in

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Revista ARACÊ
ISSN: 2358-2472

addition to bringing significant psychosocial challenges. **OBJECTIVE:** The aim of this study is to analyze the psychosocial impacts of β-thalassemia, focusing on anxiety, depression, ongoing treatment-related stress, and social stigma. **METHODOLOGY:** An integrative literature review was carried out between January and February 2025, with a search in the VHL, Google Scholar and SciELO databases. The descriptors used were: Mental Health, Quality of Life and Beta Thalassemia. Initially, 46 articles were found, of which 7 met the inclusion and exclusion criteria to compose the final sample. **RESULTS AND DISCUSSION:** The review of the studies revealed that patients with β-thalassemia often present symptoms of anxiety and depression, due to the need for regular blood transfusions, risk of iron overload, and the limitations imposed by the disease. In addition, factors such as family support, access to appropriate treatment, and public policies have a great impact on the adaptation and well-being of these individuals. **CONCLUSION:** This study highlights the importance of a multidisciplinary approach in the management of β-thalassemia, especially with regard to psychosocial support. Healthcare professionals' awareness of patients' emotional needs, as well as self-care and emotional resilience strategies, is essential to promote a better quality of life.

**Keywords:** β-thalassemia. Mental health. Quality of Life. Sickle-cell anemia.

Revista ARACÊ
ISSN: 2358-2472

## INTRODUCTION

β-thalassemia is classified as the most prevalent autosomal recessive hereditary hematological disease among populations and is developed from mutations of the gene corresponding to beta globin, located on chromosome 11. More than 350 mutations that cause such a condition are known, most of them point mutations that affect functional regions associated with the gene expression of the globin protein. These mutations can lead to a reduction in the production of the globin beta chain, which ranges from a decrease to the total absence of the protein. As a consequence, there is an excess of alpha chains that aggregate and damage red blood cells, leading to hemolysis and the development of anemia (Silva *et al*., 2023).

β-thalassemia has a high incidence, affecting approximately 1.5% of the world population, corresponding to 80 to 90 million individuals. The disease can present in three main forms: β-thalassemia major (β-TM), β-thalassemia intermedia (TI), as well as β-thalassemia minor or trait of β-thalassemia. Symptoms depend on the severity of the condition, and children with β-TM usually require regular red blood cell transfusions (RBC) to have a better quality of life or survival (Pereira *et al*., 2024).

In addition to the diseased manifestations, patients with β-TM face enormous problems in the field of psychological and social behaviour, which can affect their quality of life (QoL) (Haghpanah et al., 2013). The diagnosis of a Chronic Non-Communicable Disease (NCD), such as β-thalassemia, requires changes in lifestyle and the adoption of new habits, which can generate loneliness, sadness, insecurity, anxiety, and, in some cases, depression (Neca et al., 2022). This process can generate biochemical and neurological changes that affect the immune response, body weight, and sleep quality, and worsening the underlying disease (Costa *et al*., 2023).

Although it is recognized that chronic diseases have a devastating impact on mental health, few investigations have been conducted on the relationship between the clinical management of β-thalassemia and the psychosocial components of the disease. Therefore, the present study aims to review the scientific literature on the psychological impacts and quality of life of people diagnosed with β-thalassemia, adding to the knowledge about the challenges faced by this population.

Revista ARACÊ
ISSN: 2358-2472

## METHODOLOGY

The integrative literature review methodology used in this work, as described by Bardin (2011), seeks to gather and evaluate all relevant sources on a given subject or problem. It is a popular choice among researchers due to its ability to provide a comprehensive and in-depth view of the current state of knowledge on the subject at hand, as well as to identify gaps and trends in the literature.

During a methodological process, it is important to identify, select, evaluate, and synthesize relevant sources on a specific topic. It is important to accurately define the research problem and formulate a clear question before starting the process. For Estrela (2018), it is important to extract relevant information from the selected studies, such as authors, year of publication, methodology, results, and conclusions.

In this study, the guiding research was: What are the main psychosocial challenges faced by people with β-thalassemia and how do stigma and ongoing treatment impact their mental health?

The searches took place between January and February 2025, using the following databases: LILACS, SciELO, PubMed, as well as Google Scholar search engines. The descriptors used in the searches were: Oral Cancer, Public Health, Collective Health and Health System. For the selection of studies, the inclusion criteria were only articles in Portuguese, free for access and within the period from 2021 to 2025. As exclusion criteria, duplicate studies that did not meet the needs of this research. In all, 75 articles were consulted, of these, 50 were excluded by the exclusion criteria, leaving 25 studies, which were read title and abstract, another 16 were eliminated for not fitting the proposed scope, remaining 9 articles, which were read in full, of which only 2 more were eliminated, leaving 7 articles to compose the final sample.

## RESULTS AND DISCUSSION

After all phases of study selection, 7 articles were selected, which are included in chart 1 below, separated only by title, year, journal, objective and conclusion.

Revista ARACÊ
ISSN: 2358-2472

| TITLE | EAR | MAGAZINE | GOAL | CONCLUSION |
|---|---|---|---|---|
| UNDERSTANDING THE RELATIONSHIP BETWEEN MENTAL ILLNESS AND CHRONIC DISEASES: AN INTEGRATIVE REVIEW | 023 | **Brazilian Journal of Implantology and Health Sciences** | To understand in the available scientific literature the influence of chronic diseases on the mental health of patients. | The diagnosis of chronic diseases, especially in terminal presentation, capable of inducing feelings of insecurity, anxiety and fear, implying increasing cases of depression and suicidal ideation. |
| QUALITY OF LIFE IN IRANIAN PATIENTS WITH BETA-THALASSEMIA MAJOR USING THE SF-36 QUESTIONNAIRE | 013 | **São Paulo Medical Journal** | To determine health-related QoL and its determinants in patients with β-TM, using the SF-36 questionnaire (Short Form-36). | The presence of disease complications, poor adherence to iron chelation therapy treatment, and low economic status are predictors of worse QoL in patients with β-MD |
| LABORATORY AND SOCIAL ASPECTS OF A PATIENT WITH SICKLE CELL ANEMIA | 022 | **Scientific Journal of Faculdade Quirinópolis** | To detect the most important aspects in a patient with sickle cell anemia in order to analyze the forms of the disease, its laboratory and social aspects. | Professional psychological follow-up is recommended to increase the patient's quality of life, as well as bring improvements to her social life. |
| SICKLE CELL ANEMIA: A NARRATIVE REVIEW OF ADVANCES, CHALLENGES, AND FUTURE PERSPECTIVES | 024 | **Brazilian Journal of Implantology and Health Sciences** | Provide a comprehensive review on advancements in the understanding and management of sickle cell anemia, highlight persistent challenges in the treatment and care of patients, and explore future perspectives that may transform the panorama of this debilitating disease. | Sickle cell anemia (SCA) is a complex disease with a varied range of clinical manifestations and associated challenges. |
| ACCESSIBILITY TO PUBLIC HEALTH SERVICES FOR PATIENTS WITH SICKLE CELL ANEMIA IN THE BLACK POPULATION: UPDATE. | 024 | **Exclusive rights to this edition** | To carry out an update through studies published in a database on the difficulties of management and accessibility of patients with sickle cell anemia in the Brazilian black population. | The centralization of sickle cell anemia treatment presents challenges, such as access barriers for patients who live far from specialized centers, financial and logistical difficulties to travel, and overload of specialized services, which can result in delays in care and compromise treatment adherence. |

Revista ARACÊ
ISSN: 2358-2472

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|---|---|---|---|---|
| THERAPEUTIC ADVANCES OF BETA-THALASSEMIA: AN INTEGRATIVE REVIEW | 024 | **Periodicals Brazil. Scientific Research** | To explore through literature review the therapeutic advances of *beta-thalassemia*. | The treatment of β-thalassemia varies according to the severity of the disease. Treatment includes several interventions in order to increase the quality of life and survival of patients. |
| CLINICAL MANIFESTATIONS OF β-thalassemia MAJOR IN THE PEDIATRIC POPULATION: A SYSTEMATIC REVIEW. | 023 | **Research, Society and Development** | To carry out an update through studies published in a database on the difficulties of management and accessibility of patients with sickle cell anemia in the Brazilian black population. | The centralization of sickle cell anemia treatment presents challenges, such as access barriers for patients who live far from specialized centers, financial and logistical difficulties to travel, and overload of specialized services, which can result in delays in care and compromise treatment adherence. |

**Source:** Authors (2025)

Hemoglobinopathies, such as β-thalassemia and sickle cell anemia, constitute a relevant challenge for public health, requiring the adoption of a multidisciplinary approach for their management. These diseases can be of varying severity, ranging from asymptomatic forms to those that require continuous and intensive treatment. Additionally, in addition to the clinical manifestations, the psychosocial impacts caused by these diseases act directly on the quality of life of patients.

For Pereira et al., 2024, β-thalassemia has three main forms, and it is essential to distinguish them for proper management:

Bone changes are a frequent complication in children with β-thalassemia, with osteopenia and osteoporosis being the most common. According to El Nashar et al. (2017), patients with thalassemia have reduced levels of calcium and elevated levels of phosphorus and alkaline phosphatase, suggesting parathyroid gland dysfunction and excessive accumulation of iron in the organs.

Chronic anemia and hypoxia, aggravated by insufficient transfusions and inadequate iron chelation therapy, can impair growth, delay puberty, and cause skeletal deformities (Silva et al., 2023).

Individuals with sickle cell anemia face significant emotional and social challenges. Chronic pain, frequent hospitalizations, and physical limitations increase vulnerability to depression and anxiety. In addition, social stigma and difficulties in the school and professional environment negatively impact their quality of life.

Revista ARACÊ
ISSN: 2358-2472

Studies indicate that psychological support, participation in support groups, and educational interventions are key to the well-being and adaptation of these patients (Medeiros et al., 2024). A qualitative survey conducted in Brazil in 2018 highlighted that drug dependence and exposure to invasive procedures generate feelings of sadness, worry, and fear of death, increasing the risk of mental distress (Costa et al., 2023).

Ensuring equity in the care of patients with chronic diseases, such as sickle cell anemia, is essential to minimize the impact of the disease and improve their quality of life. For this, a joint commitment between government, health professionals and civil society is necessary, ensuring access to appropriate treatments and psychological support (Negeiros, Silva & Guerra, 2024).

Unfortunately, the prejudice and stigmas associated with these conditions still represent barriers to comprehensive care. Patients with chronic diseases often face difficulties in social insertion, which affects their self-esteem and quality of life (Lima et al., 2022).

β-thalassemia and sickle cell anemia require a multidisciplinary approach for effective management, which goes beyond the treatment of clinical manifestations and includes attention to psychosocial aspects. Strategies that promote psychological support, equity in access to health, and social awareness are essential to reduce the impacts of these diseases and provide a better quality of life for patients.

- **Thalassemia minor (thalassemia trait):** generally asymptomatic, it does not require treatment, but genetic counseling is essential to avoid the transmissibility of the mutant gene to the offspring.
- **Thalassemia intermedia:** can determine mild to moderate anemia during life. Although it allows for a relatively normal experience, patients may require regular follow-up, folic acid supplementation and, in some cases, blood transfusions. In turn, hypersplenism may appear with splenomegaly, growth retardation, and worsening of the anemic condition, which may indicate splenectomy in the most severe cases.
- **Thalassemia major:** the most severe form of the condition, requiring ongoing treatment with regular blood transfusions and iron chelation therapy to prevent iron overload.

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Revista ARACÊ
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## CONCLUSION

β-thalassemia is a genetic condition that, in addition to the physical impacts, imposes significant challenges to the mental health and quality of life of diagnosed

Revista ARACÊ
ISSN: 2358-2472

individuals. The literature review highlights that factors such as the burden of treatment, complications of the disease, and social stigma contribute to high levels of anxiety and depression, compromising psychological well-being. In addition, the need for regular blood transfusions and the risk of comorbidities affect patients' autonomy and perception of quality of life.

Given this scenario, a multidisciplinary approach is essential in the care of these people, including psychological support and strategies that encourage self-care and strengthen emotional resilience. The integration between medical care, family support and psychosocial interventions can minimize the negative impacts of the disease, favoring better adaptation and quality of life.

Finally, this study reinforces the need for future research that deepens the understanding of the psychosocial impacts of β-thalassemia, taking into account cultural, socioeconomic, and individual variables. Investing in improving care and developing inclusive public policies is essential to ensure more humanized and effective care for this population.

Revista ARACÊ
ISSN: 2358-2472

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