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## Psychological Problems of Pediatric Patients with Thalassemia: A Narrative Literature Review

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### ABSTRACT

Thalassemia is a chronic condition with a variety of clinical and psychological complications. The onset of symptoms, the rigors of therapy, and frequent absences from school significantly strain the emotional and interpersonal resources of children and their families. This review aimed to describe psychological problems in patients with thalassemia. Adolescents with thalassemia major often experience pain and should be given restrictions in terms of activity. This restriction must be done to maintain the condition of adolescents with thalassemia major who are quickly tired. Psychosocial is part of the quality of life of adolescents with thalassemia major, so when the psychosocial of adolescents is disturbed, it will affect their quality of life. Social isolation, decreased self-esteem, low academic achievement, and a terrible stigma will lead to the psychological burden of thalassemia adolescents. In conclusion, psychosocial problems arise in adolescents with thalassemia caused by body image disturbances experienced so that they feel distrustful and limit their association with their peers, restrictions on activities provided by health workers and parents, and low academic achievement that makes thalassemic adolescents experience psychological and psychological problems decreased quality of life.

### 1. Introduction

The most common form of hemolytic anemia is beta thalassemia, and around 60,000 newborns with thalassemia are born each year around the world. Thalassemia is a blood disorder that is inherited.<sup>1</sup> Beta-thalassemia is a genetically determined chronic hematological condition characterized by severe hemolytic anemia due to a disorder of synthesis of hemoglobin chains resulting in variable phenotypes ranging from severe anemia to clinically asymptomatic individuals. Three primary forms have been described; thalassemia major, intermedia, and minor. Individuals with thalassemia major usually present with severe anemia within the first two years of life, requiring regular red blood cell transfusions.

Anemia requires frequent blood transfusions to sustain life, whereas hemosiderosis and other illness consequences require a long and distressing treatment program. Patients with thalassemia frequently experience severe problems such as heart failure, cardiac arrhythmia, liver disease, endocrine issues, and infections. Children with chronic physical illnesses exemplified by thalassemia are vulnerable to emotional and behavioral problems.<sup>2-4</sup> This review aimed to describe psychological problems in patients with thalassemia.

#### Psychological problems in thalassemia

Thalassemia is a chronic condition with a variety of clinical and psychological complications. Physical

deformities, growth retardation, and delayed puberty are all possible consequences of thalassemia. It hurts physical appearance, such as bone abnormalities and short height, contributing to a negative self-image. The onset of symptoms, the rigors of therapy, and frequent absences from school significantly strain the emotional and interpersonal resources of children and their families.<sup>5</sup>

A child with thalassemia has emotional and cognitive requirements vastly different from adolescents seeking independence and identity. According to 80% of children with thalassemia are likely to experience psychological issues such as oppositional defiant disorder, anxiety disorders, and depression. Although children with all forms of blood disorders face similar challenges, those with thalassemia are special in that they must visit the hospital regularly for blood transfusion.<sup>6,7</sup>

A study of adolescents with thalassemia found that those with psychiatric symptoms had a lower quality of life.<sup>8</sup> Because of the chronic nature of thalassemia and its intense and demanding treatment, patients and their families face a considerable psychological burden. Social isolation, low self-esteem, poor academic performance, and stigmatization contribute to psychological distress. Patients with thalassemia major require additional psychological care to alleviate mental stress and improve their competitiveness. Additional psychological assistance is required for patients with thalassemia major to alleviate emotional stress, develop competence, and improve therapeutic compliance in daily life.

A previous study using structured interviews with study results showed that thalassemia has an impact on education, adolescent socialization does not participate in playing outside the home with their peers, adolescents feel dissatisfied with their body image, and adolescents feel.<sup>9</sup> In contrast to their siblings, adolescents receive the same attention from their parents, adolescents feel a burden to their parents, and adolescents feel that thalassemia disease limits their social life. Adolescents feel that

there is a high psychosocial burden. Adolescents with thalassemia major often experience pain and should be given restrictions in terms of activity. This restriction must be done to maintain the condition of adolescents with thalassemia major who are quickly tired. A study showed that significant thalassemia adolescents have difficulty carrying out extracurricular activities at school. This is because their bodies are weak and tired easily. Therefore, they are given restrictions in terms of activities so that their body condition can be stable. Restrictions on physical activity given to thalassemia major adolescents certainly make them feel sad and frustrated. Physical restrictions also impact the social relationships of thalassemia major adolescents because it isolates them from peers and the people around them.<sup>9-11</sup>

Psychosocial is part of the quality of life of adolescents with thalassemia major, so when the psychosocial of adolescents is disturbed, it will affect their quality of life. Social isolation, decreased self-esteem, low academic achievement, and a terrible stigma will lead to the psychological burden of thalassemia adolescents. The need to implement programs targeting the patients' perceived issues relevant to their disease, including psychosocial support to improve their self-image and self-esteem and facilitate a normal lifestyle. Moreover, educational programs that consider the educational backgrounds of the parents and are centered on handling complications promptly, safe transfusion practices, and ensuring the regular and correct use of chelators would be instrumental. Adolescents with thalassemia major need additional support and psychological factors to reduce stress, strengthen competence, and adhere to therapy for daily living.<sup>12</sup>

## **2. Conclusion**

Psychosocial problems arise in adolescents with thalassemia caused by body image disturbances experienced so that they feel distrustful and limit their association with their peers, restrictions on activities provided by health workers and parents,

and low academic achievement that makes thalassemic adolescents experience psychological and psychological problems decreased quality of life. Therefore, more attention is needed on the psychological and social welfare of thalassemia adolescents by providing facilities such as counseling and adolescent mentoring programs to prevent and reduce psychosocial problems that often occur in adolescents with thalassemia.

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