

Letter to Editor

Improving Adherence to Treatment in Patients With β -thalassemia Major: The Importance of Qualitative Research



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Dear Editor

Non-adherence to treatment is a major worldwide concern for healthcare providers. This is especially important in chronic diseases where patients have to follow the prescribed treatment for a long time [1, 2]. Adherence to the treatment of patients with chronic diseases in developed countries is at an average of 50%, and this rate is lower in developing countries [3]. Despite many studies on non-adherence to treatment, it has remained an unresolved issue for the past four decades [4]. On the other hand, commonly used interventions and practices have not successfully improved adherence to prescribed treatments in patients with chronic diseases. Moreover, the available theories of adherence have little explanatory power to justify this issue [5].

β -thalassemia major (β -TM) is a chronic, complex, and debilitating disease. Patients with β -TM need regular treatment with blood transfusions chelation therapy, and continuous medical supervision [6]. Therefore, appropriate adherence to treatment is a key component of this disease management. However, poor adherence

to treatment remains a significant problem in patients with β -TM [7]. The results of previous studies indicate that despite all the interventions made to improve adherence to the treatment, 30% to 50% of these patients exhibited poor adherence to prescribed treatments which is associated with worsening of the patients' clinical status and outcome [8, 9]. On the other hand, better adherence to the treatment in β -TM patients results in better patient-related outcomes [10]. Therefore, due to the relatively high rate of non-adherence to treatment in patients with β -TM and its potential debilitating and negative consequences, conducting further studies to identify the various aspects of treatment adherence is an important step toward improving health outcomes in these patients [11].

The process of adherence to treatment can be influenced by a variety of factors, including patient-related, disease-related, and socio-cultural factors [12]. In various previous studies on adherence to the treatment, aspects of the disease and its management that are outside of biomedical causes have not been well studied; therefore, it should be the subject of further studies [11]. Paying more attention to patients' experience of the disease and the meaning of prescribed treatment in

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their daily lives is an effective approach to investigating the phenomenon of treatment adherence [2]. Adhering to a treatment is not a simple practical or technical task, but a part of daily life experiences with a chronic illness. Accordingly, to assess and improve adherence to the treatment, the personal and socio-cultural context of patients should be evaluated first [13, 14]. Studies in patients with β -TM have often dealt with the disease and its physical, social, and psychological consequences and treatment separately. However, to survive, these patients must use a grueling treatment regimen for life, and they also need continuous evaluation and monitoring of care and treatment, which poses serious challenges in following their treatment regimen [11].

Our knowledge about the process, context, and effective factors of adherence to the treatment in patients with β -TM is not adequate [15]. The persistence of this problem as a serious and growing health, family, and social problem after decades of studies and interventions, can be due to the type of perspective and studies related to this phenomenon [11]. Interactions between patients, family, community, and healthcare providers play a key role in the adherence to treatment in patients with β -TM, but the role and interaction of these factors in the available studies have not been well explained [16]. On the other hand, currently, the value of the client-centered approach and participation of patients in care planning and decision-making processes has been widely highlighted. Since each person's performance is shaped by social structures, cultural contexts, and personal experiences and beliefs, certainly without knowing the experience of patients, their family members, and healthcare providers, it is not possible to design the most appropriate care and therapeutic plan for improving adherence to treatment in these patients [17]. Therefore, for the study of complex phenomena, such as adherence to treatment, qualitative research is an appropriate and responsive method [2].

Despite the importance and beneficial role of the results of quantitative studies in this regard, conducting qualitative studies and its results can provide richly detailed insights and contextual explanations for many of the challenges faced by β -TM patients in the process of treatment adherence and potentially help healthcare providers for designing effective strategies for improving adherence to recommended treatments.

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