

Regular Reminding of the Potential Serious Complications of Poor Adherence to Treatment: A Strategy for Improving Treatment Adherence in Beta-Thalassemia Major Patients

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Dear Editor-in-chief,

Beta-Thalassemia Major (β -TM) is a childhood illness characterized by a severe hemolytic anemia. Globally, β -TM is the most commonly inherited hemoglobinopathy with a high incidence rate in Southeast Asia, the Middle East and Mediterranean countries (1, 2). Iran is one of the high-prevalent areas of β -TM among the Eastern Mediterranean region. Beta-Thalassemia Major is an important public-health challenge in Iran. According to reports, there are nearly 3 million carriers and 25,000 β -TM patients in Iran (2). Patients with β -TM are usually diagnosed within the first two years of life (3). Given the chronic nature of the disease, β -TM patients require lifelong adherence to their distressing treatment regimens, including regular blood transfusions and daily chelation therapy (4). Although, regular blood transfusion is a lifesaving therapy in these patients, it is a major source of iron overload. Occurrence of transfusion-related iron overload complications, such as heart failure and cardiomyopathy, liver fibrosis, impairment of the endocrine and exocrine functions and etc., are associated with higher morbidity, mortality risk and shorter survival (1, 5). Fear of developing transfusion-related iron overload complications is one of the greatest concerns in β -TM patients and their caregivers (5, 6). To prevent these complications, β -TM patients require regular iron chelation therapy (1, 4).

Despite its clinical importance, poor adherence to chelation therapy remains a prevalent and persistent problem in β -TM patients (7). Also, to date, cost-effective interventions to improve adherence to this therapeutic regimen in these patients are yet unavailable (4, 7). Delayed occurrence of iron overload complications is a factor which may deteriorate the adherence to the prescribed treatment regimen in β -TM patients. Feeling healthy, despite lack of chelation therapy adherence, is a reason for refusing this treatment in β -TM patients (5, 8). Previous studies found that delay in the occurrence of complications regarding the interruption of treatment can potentially lead to discontinue or irregular following of prescribed regimens by the β -TM patients (5, 6). However, lack of immediate consequences of insufficient iron chelation therapy unavoidably escalates the risk of developing iron overload complications in future (9, 10).

***Please cite this article as:** Emami Zeydi A, Heydari A, Karimi Moonaghi H. Regular Reminding of the Potential Serious Complications of Poor Adherence to Treatment: A Strategy for Improving Treatment Adherence in Beta-Thalassemia Major Patients. *Int J Pediatr* 2017; 5(12): 6201-2. DOI: **10.22038/ijp.2017.25718.2190**

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Received date: Aug.11, 2017; Accepted date: Aug. 22, 2017

Healthcare providers can play a pivotal role in improving patients' adherence to treatment (11). Despite this fact, it has been previously shown that most of the β -TM patients' family members have disappointed for asking support and help from health professionals, because they are constantly busy (12). Although, heavy workload is a major barrier to patients' education, counseling and supervision by healthcare providers (13), the positive effect of healthcare provider-led adherence promotion interventions on patients' adherence to treatment has been demonstrated (11). We believe that healthcare providers are in a unique position to improve treatment adherence in β -TM patients. It is need that they continually emphasis the importance of regular chelation therapy and assessment of body iron to patients for improving their survival chance. Regular reminding about the potential serious complications of poor adherence to treatment to β -TM patients and their caregivers, as one of their major concerns, by health care providers is a practical and potentially useful strategy for improving treatment adherence in these patients; especially patients with lower socioeconomic status that seem to be at higher risk for poor adherence to their prescribed treatment.

Key Words: Adherence, Beta-Thalassemia, Chelation therapy, Iron overload.

REFERENCES

1. Darvishi Khezri H, Emami Zeydi A, Sharifi H, Jalali H. Is Vitamin C Supplementation in Patients with beta-Thalassemia Major Beneficial or Detrimental? Hemoglobin. 2016;40(4):293-4.
2. Khodaei GH, Farbod N, Zarif B, Nateghi S, Saeidi M. Frequency of Thalassemia in Iran and Khorasan Razavi. International Journal of Pediatrics. 2013;1(1):45-50.
3. Kohne E. Hemoglobinopathies: clinical manifestations, diagnosis, and treatment. Dtsch Arztebl Int. 2011;108(31-32):532-40.
4. Al-Kloub MI, MA AB, Al Khawaldeh OA, Al Tawarah YM, Froelicher ES. Predictors of non-adherence to follow-up visits and deferasirox chelation therapy among jordanian adolescents with Thalassemia major. Pediatr Hematol Oncol. 2014;31(7):624-37.
5. Borgna-Pignatti C, Gamberini MR. Complications of thalassemia major and their treatment. Expert Rev Hematol. 2011;4(3):353-66.
6. Ganzella M, Zago MM. The experience of thalassaemic adults with their treatment. Rev Lat Am Enfermagem. 2011;19(4):968-76.
7. Dehshal MH. Addressing adherence to treatment: a longstanding concern. The patients' perspective. Thalassemia Reports. 2014;4(3): 27-8.
8. Borgna-Pignatti C, Cappellini MD, De Stefano P, Del Vecchio GC, Forni GL, Gamberini MR, et al. Survival and Complications in Thalassemia. Annals of the New York Academy of Sciences. 2005;1054(1):40-7.
9. Olivieri NF. Adherence to deferoxamine therapy: heeding Hippocrates and Osler. Am J Hematol. 2004;76(4):415-6.
10. Ward A, Caro JJ, Green TC, Huybrechts K, Arana A, Wait S, et al. An international survey of patients with thalassemia major and their views about sustaining life-long desferrioxamine use. BMC Clin Pharmacol. 2002; 2: 3.
11. Wu YP, Pai AL. Health care provider-delivered adherence promotion interventions: a meta-analysis. Pediatrics. 2014;133(6):e1698-707.
12. Sapountzi-Krepia D, Roupa Z, Gourni M, Mastorakou F, Vojiatzi E, Kouyioumtzi A, et al. A qualitative study on the experiences of mothers caring for their children with thalassemia in Athens, Greece. J Pediatr Nurs. 2006;21(2):142-52.
13. Karimi Moonaghi H, Emami Zeydi A, Mirhaghi A. Patient education among nurses: bringing evidence into clinical applicability in Iran. Invest Educ Enferm. 2016;34(1):137-51.