

The Non-adherence to iron chelation therapy (ICT) among transfusion-dependent thalassemia (TDT) patients in Pakistan

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Madam, Thalassemia is an inherited blood disorder caused by ineffective erythropoiesis. Worldwide, it is among the most common genetic disorders. In Pakistan, around 5000 babies are born with this deadly disease every year.¹

Besides stem cell transplant the regular blood transfusion is the only treatment for thalassemia major. As one pint of blood contains 200-250 mg of iron, these transfusions ultimately lead to iron overload in the body. Consequently, excessive iron deposits in the internal organs such as the liver, heart, and endocrine organs.² To forestall iron overload in TDT patients, ICT is mandatory. Currently, three drugs are recommended, deferoxamine, deferiprone, and deferasirox.³ Although these drugs are vital for iron excretion, it has been reported that 3-8 people out of 10 are non-compliant with these drugs.⁴

Besides social, economic, and behavioural factors, patient-related, medication-related, and socio-cultural barriers play vital roles in management through ICT. According to a survey conducted in Malaysia by Chong CC et al, patients reported several factors affecting their compliance with ICT. Nescience, among patients regarding the application of intravenous chelators makes them reliant on paramedics. Furthermore, emotional stress due to this everlasting disorder drains them. Medication-related barriers include adverse drug reactions such as vomiting, burning skin sensation, dizziness and fear and discomfort among paediatric patients owing to intravenous infusing chelator. The poor doctor-patient relationship results in patient's negligence towards treatment.⁵ Poverty being a significant issue in Pakistan, has many negative impacts on the health system of its population, limiting access to medications.

Considering the hazardous situation, effective approaches should be made on the national and personal levels.

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Enlightening patients to understand the treatment regimen and its advantages could be an integral approach. Workshops, counselling sessions, and awareness campaigns must be put into place to educate the population. A social media approach will help provide the basic knowledge and preventive measures to the public. Government must ensure that patients are provided with essential medication and proper treatment. Actions including cost reduction of the medications, counselling session arrangements, and funding of TDT patients are required to reduce the burden of these patients. By adopting a multidisciplinary approach NGOs can play a vital role in fundraising and awareness through their drives and campaigns.

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