

CORRESPONDENCE

COVID 19 pandemic and lockdown: A double whammy for patients with thalassemia

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To the Editor,

The first case of COVID 19 in India was reported on 30th January 2020 and it has affected approximately 82,29,313 people of which nearly 1,22,607 patients have succumbed to the illness and the count is only increasing (as per data accessed on 3/11/2020 from *mygov.in*). The Government of India announced a total lockdown on 25th March 2020 to prevent the spread of the infection. Many health care facilities in the government sector were converted to COVID 19 dedicated hospitals, shutting their doors to patients with non-COVID illnesses. The decision although necessary had a dire impact on patients with chronic diseases such as hemoglobin disorders in particular thalassemia as continued timely care is essential. Difficulties in getting drugs, transportations, and blood supply have been reported in the literature during the COVID-19 pandemic. Furthermore, many clinicians and patients with chronic diseases have highlighted the problem of access to and utilization of services^{1,2}. A survey by Thalassemia International Federation documented serious challenges in accessing iron chelation therapy in 56% of patients^{3,4}. However, before the pandemic, the adherence to deferasirox has been reported to be nearly 90% in multiple studies from India.^{5,6}

We surveyed patients with thalassemia major using google forms regarding the adherence to iron chelation between 25th March to 25th July (a period of 4 months). The Google form was a multiple choice-based questionnaire that collected basic information

like the demographic profile of the patients, places for blood transfusion, missed chelation during the lockdown period, source of iron chelation, etc. Participation in the survey was voluntary. We received replies from 333 patients from 16 states across India and 3 from other countries. The maximum number of responses were from Punjab followed by Delhi, Chandigarh, and Haryana. Seven responses were invalid, 7 patients had not been started on chelation therapy and 3 patients were from other countries, hence were excluded from the analysis. The median age of patients was 21 years (range 8 months to 51 years) and male:female ratio of 1.9:1.

A total of 154 (48.7%) patients were buying their chelation drugs on their own, whereas 141 (44.6%) patients were dependent on government supply and 21 (6.6%) patients were being supported by non-governmental organizations (NGO's) for their chelation. Poor adherence to iron chelation therapy was reported by 55.4% (n=175) of patients during this period due to COVID 19 pandemic and lockdown. The prevalence of non-adherence was similar in both sexes (58.3% in females vs 53.8% in males) (p=0.152). An age-wise analysis revealed better compliance in children vs adolescents and adults (p=0.01). The prevalence of non-adherence amongst patients who were buying chelators on their own, getting it from government supply and those receiving medicines from NGO's was 59.1%, 47.5% and 80.1% respectively (Figure 1). The non-adherence was statistically higher in patients buying their medicines (p=0.007).

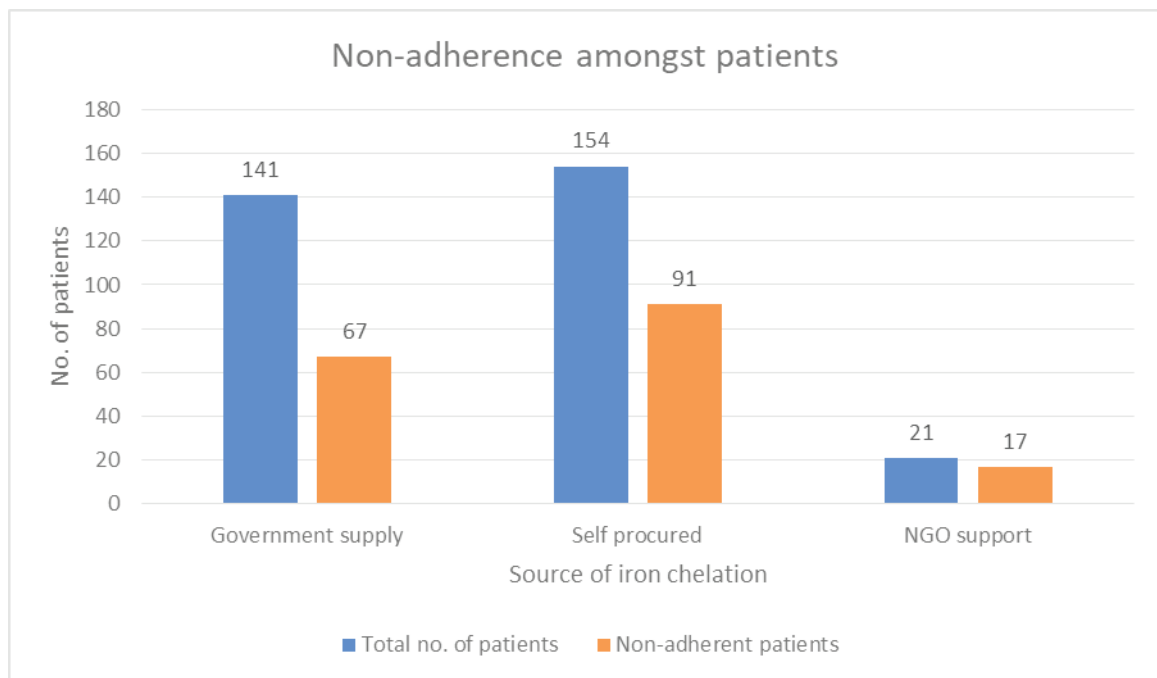


Figure 1. Prevalence of non-adherence in patients with transfusion-dependent thalassemia.

The average duration of missed iron chelation was 23.6 days. The commonest cited cause was the unavailability of the drugs (47.9%) followed by a lack of finances to buy the iron chelation (22.8%). Financial difficulties leading to borrowing money from various sources were reported by 23.3% of patients. Routine investigations like those for monitoring of iron overload were missed by 90% of the patients as funds were being used for basic amenities and none were able to get specialist appointments.

The COVID 19 pandemic led to increased prevalence of non-adherence from nearly 10 % to 55% due to various causes. Regular monitoring of adherence to drugs must be ensured to predict the complications and comorbidities related to iron overload. Compliance is an independent predictor of outcome in many chronic diseases and it must be checked at all times irrespective of the pandemic.

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