

Supplemental material

Details of the 2 thalassemia centers:

FFK and KITC have approximately 800 and 600 registered TDT patients respectively providing an average of 50 blood transfusions per day (25 transfusion chairs in each center).

Factors associated with poor management of myocardial siderosis:

A QI team that included a haematologist (SH), pediatric cardiologists (BSH and FA), QI experts (BSH and FA) and medical officers, was formed. Continuing medical education (CMEs), morbidity and mortality meetings (M & M), group discussions and previously published studies were used to identify factors associated with poor management of myocardial iron siderosis.

Assessment: Screening of TDT patients for cardiac dysfunction was not performed on a yearly basis. Diagnostic test such as transthoracic echocardiogram (TTE) was the only investigation advised and only when the patient presented with cardiac symptoms. Result of these investigations were not tracked or used to alter management.

Management: Follow up of TDT patients to assess compliance to chelation therapy was not structured.

Adverse events (AE): There was also a lack of compliance with chelation therapy, commonly reported due to financial constraints or variable management of chelation drug related AE.

Statistical Analysis:

Process and outcome metrics were analyzed cumulatively from both the centers (FFK and KITC). Since the QI initiative was introduced in a standardized manner in both the centers by the same team, there was no difference in implementation of intervention in the two and thus no comparative analysis was done between these centers.

Results:

Outcome metric: There was no difference ($p=0.24$) in the magnitude of change in T2* CMR value for the different age categories (10-15 years, 15-20 years, 20-25 years, 25-30 years & 30 to 35 years).

Adverse events: Other DFP induced AEs included arthralgia (19.4%, $n=16$), neutropenia (8.4%, $n=7$) and thrombocytopenia (13.4%, $n=11$). Two patients (2.4%) developed rash secondary to DFX while DFO caused infusion related local AE in 17% ($n=14$) patients. Nonspecific AEs occurred in 7.4% ($n=6$) patients such as weakness and back pain thought to be secondary to DFO ($n=4$) and DFP ($n=2$).