

● JULY 2019

Thalassemia & Sickle Cell Society *report*

“A psychological support is needed to reduce the emotional burden



Anjum– 8-Yrs

Many think Thalassemia is only among the family and the first question that sticks the mind is if the parents are married among the relatives. This is true to an extent but the other reality is that Thalassemia is also prevalent outside relation marriage.

This is a story of Anjum 8 year old girl full of life and happenings, ever smiling and up to some entertainment every time. She is the youngest among 4 siblings and rests all are normal except her.

Blood transfusion is a norm for this little life, this routine started when she was just 3 months old. Thalassemia did not sink in the minds of the parents. They took many opinions from different doctors to understand and confirm if this lifelong situ-

ation is in real. This was one of the kind situations for them in their entire extended family history. Today she just plays around or watched some cartoon show while the blood is transfused.

A constant comparison keeps going in the mind and many questions keep arising for the parents to answer at her level “Why me mummy, every child does not have to take blood transfusion” Thalassemia has its greatest impact on the emotional and social well-being.

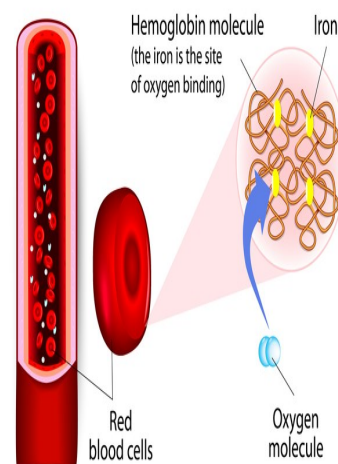
Thalassemic children feel different from their peers and elaborate negative thoughts about their life, guilt senses, increased anxiety and low self-esteem; their behavioral profile is similar to normal people, but many of them can manifest severe psychosocial problems.

A psychological support seems therefore to be useful to reduce the emotional burden of thalassemia major children and their families. Additionally, quality of life, which is an index of health care defined as an individual's perception of their position in life in the context of culture and value systems in which they live

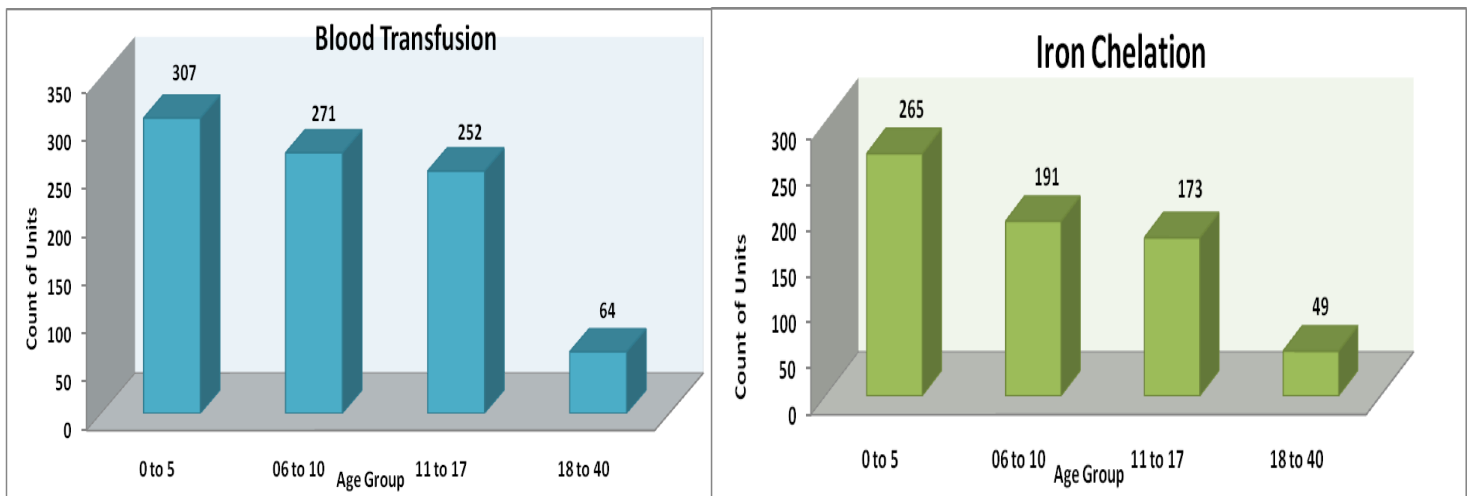
Parents find TSCS to be that one stop for all thalassemia issue for Anjum. The facility is one of the best in the city for thal care.



HEMOGLOBIN



Transfusion Details



Total number of patients for the month of **July 2019** including all patients group were **1124** some patients were given 2 units of blood, the total units provided where **1237**

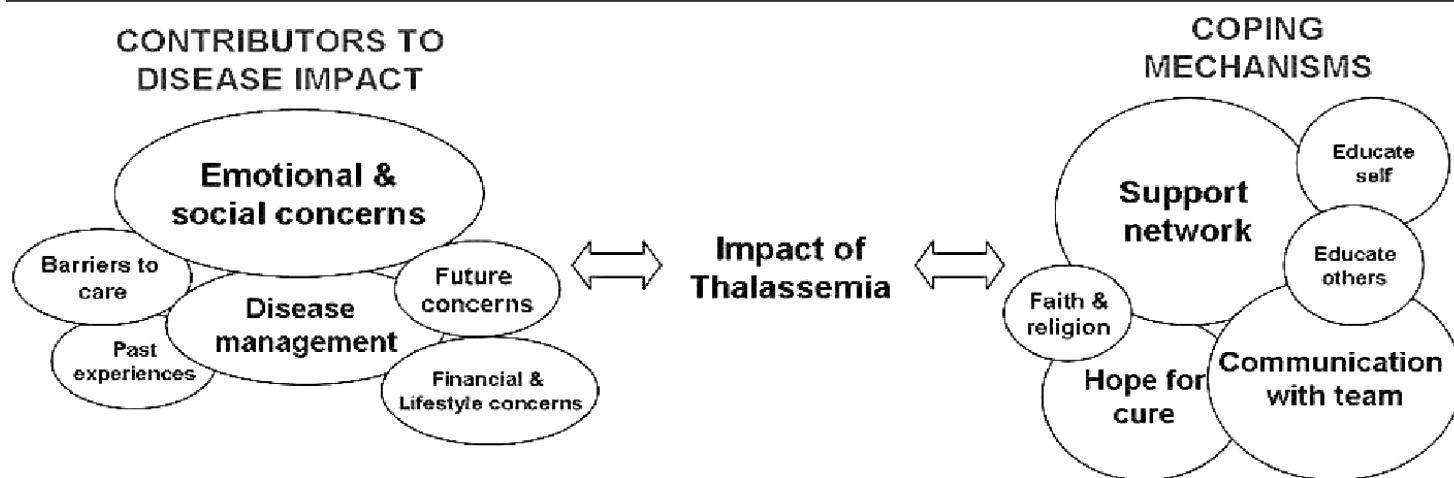
HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
53	NIL	16	0

MONTHLY DONORS FOR JULY-2019

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7	AMITABH BOSE	15	AIMS ASIA	23	MR CHANDRAKANT AGARWAL
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Burden of care

Parents of children with thalassemia face many problems when caring their child. Some parents manage their problems alone. Also, deep cognition of parents' needs was obtained considering the experiences of parents. It is necessary that health care provider provides support and education by appropriate planning. Nurses are recommended to help these parents by appropriate interventions. Training life skills to them can be very helpful in reducing the severe difficulties. Furthermore, it is helpful to determine the parents' burden of care to improve the family function.



Particulars	Units
Sensitisation programmes organised	22
Blood donation camps	19
Collected units of blood	1541
Units provided to thalassemia + general free issues	1400
General paid issues	188
FFP ISSUES	2058



Thalassemia & Sickle Cell Society

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