Thalassaemia

Update

Issue 41 • February 2015

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We would like to wish you and your families a New Year full of health, happiness and prosperity.

Sankalp India Foundation's Program for Thalassemia Prevention Management and Cure

Rajat Agarwal

On 14th November 2011, Sankalp India Foundation joined hands with Indira Gandhi Institute of Child Health, Bangalore to provide wholesome care and management to the children suffering from thalassemia. The facility which was receiving 60 kids flourished after systematic management and cure was offered, and the number of children increased steadily to 250 kids. It is then that the organisation worked together with Rashtrotthana Blood Bank, the largest blood bank in Karnataka to start Samraksha Thalassemia Day Care Centre in August 2013. Combining two centres the organisation is facilitating the offering of care and management to 400 children. We are happy to share our work and experience with thalassemia management. Let us see each important aspect one at a time:

1. Blood Transfusion

Our centres use packed red blood cells collected within last 7 days as the transfusion product of choice. Blood is sourced from the blood bank attached to the centre or a small number of blood banks which following 100% voluntary blood donation practice. In-line with the mandate of the Government and NACO, all blood products transfused to the patients are issued by the blood banks free of charge. In 2011, we organised a state level workshop on 'The Role of Blood Transfusion Medicine in Thalassemia' - to strengthen blood banking services with focus on needs of thalassemia.

We follow hypertransfusion regimen for thalassemia management attempting to keep the pretransplant hemoglobin at 9 gm/dl. Our organisation provides strong support in terms of weekly (or more frequent) blood donation camps to the blood banks. We also maintain a registry of blood donors which is used in the rare event of blood not being available in any of the blood banks.

We have introduced strict quality control of blood bank services for the thalassemia clinic. This is done by comprehensive monitoring of:

- type of blood product
- the age of the blood products
- the source of blood
- the time taken for delivery of service by blood banks
- transfusion associated reactions.

Quarterly screening for hepatitis-B, hepatitis-C and HIV adds to the monitoring of the quality of transfusion products. To make transfusions safer we also made available filters at discounted rates locally to ease the logistics for purchase for the parents.

The patients who switched to our centres for management of the disease reported remarkable decline in the transfusion associated reactions. We do not give prophylactic drugs before transfusion to suppress any mild reactions. If reactions happen, they are noted and followed up in detail. Such follow-ups have led to the discovery of abnormal antigens and antibodies. We attribute the low rate of reactions to the quality of blood products made available by the blood banks and the process of saline washing the units prior to transfusion. Future blood products to patients with abnormal blood groups are chosen accordingly.

2. Regular Monitoring and Management

We strongly believe in early detection and prevention of complications. For this purpose, we have drawn up a periodic medical investigations schedule. Prior to transfusion, the staff checks whether the child is due for any medical investigation including serology, biochemistry, endocrine, cardiac, orthopaedic lab investigations.

We have established collaboration with well reputed and accredited labs for the purpose of investigations. Samples are collected at the centre itself. This arrangement has made it possible for us to bring down the cost of the investigations for the patients substantially.

ThalCare - a web based application which we use for the purpose of thalassemia management, allows us to track all the lab investigations and also highlights abnormal values. Necessary follow-up and interventions are put in place at the first sign of abnormalities. In order to achieve this we have established working relationships with multi-disciplinary specialists who offer consultation for our patients via tele-medicine and in-person when needed. This mechanism enables substantial saving for the patients even with high standards of care and management.

An important aspect of the management priorities is to preserve the spleen of the children suffering from thalassemia. Modern medicine offers options to save the spleen by timely intervention and we are are shaping our management program to try and minimise the need for splenectomy.

3. Iron Chelation

All chelators for the patients are made available through the centers.

- Patients from economically weaker background are placed under support program.
- Some patients in the middle class pay a token amount for access to chelators.
- Those from the economically stable background pay for the medicines at cost basis.

Nevertheless, no patient at our centers goes without proper and monitored chelation therapy.

We track the consumption of chelators on a per patient basis to enable establishing the degree of

adherence. In the absence of T2* MRI at an accessible healthcare facility in Bangalore, we use quarterly ferritin reports to track the effectiveness of the chelation therapy.

4. Compliance to treatment

We guarantee the availability of timely blood products, lab investigations, clinical management and medication to all the patients who attend the centers supported by us. Since we established an effective support program cost of treatment does not come in the way of proper management. We have good compliance with more than 90% patients coming to the centre for transfusions on time.

We focussed on the remaining 10% of the patients are sought approaches into making them compliant as well. While counselling helped improve compliance for some, others were too financially weak to come to the centre on time. To the aid of these patients we started the transport support program.

5. Prevention

We are not undertaking population screening because of limited resources. However, we initiated the process of enquiring the parents if there were any new pregnancy in their family each time they came. This led to identification of couples who were at risk of giving birth to a thalassemia major child. Antenatal screening is offered to such couples allowing us to judiciously use the limited resources and yet prevent the births of thalassemia major children in the family of the patients who come to us.

6. Cure

We firmly believe that each child must be given an option for complete cure irrespective of their financial status. Our centres are involved in early screening of children fit for transplant. We offer HLA typing to such families. We have collaboration with Cure2Children, Italy to offer affordable transplants to the children. We also undertake the down-staging of children who are eligible for transplants. We are happy to share that the first few transplants from our centre are underway in December, 2014.

Our Experience

We would like to highlight the role of technology and networking in strengthening the delivery of care and management to the children attending the day care clinics supported by us. We started the thalassemia centres with limited prior experience at thalassemia management within the institutions where the day cares were initiated. However we reached out to the experts in the field who were willing to share their knowledge and collaborate with us in our effort.

We developed ThalCare (www.thalcare.net)–a web based application for systematic management of the disorder. ThalCare made possible to ensure that the delivery of care is in accordance with evidence based clinical guidelines. We streamlined the management of information and disease management at our centres, enabling these experts to participate in enhancing disease management effectively.

Samraksha - one of our centres, works on sundays to enable fewer children to miss school. While children wait at for transfusions, they draw, paint and play at the day cares. Periodically we organise celebrations, magic show and meetings for the parents and the children alike. In all we try to reduce the burden of disease management.

We were able to get the centres up and running in short time frames and streamline all aspects of care and management of thalassemia. We have been working to come up with models which can be applied to other similar thalassemia care setups. Our work on the role of web based applications (WWW.THALCARE.NET and WWW.BMTPLUS.NET) in thalassemia management has been recognised globally and has been presented at prestigious forums including 40th Annual Meeting of the European Society for Blood and Marrow Transplantation, Milan, Italy in April 2014, Congress of of the Asia Pacific Blood and Marrow Transplantation, Hangzhou, China in October 2014 and Meeting of the Indian Society of Hematology and Blood Transfusion, Hyderabad in November 2014.

The initiative received the 'Spirit of Humanity Awards-2014' and 'Manthan Awards - 2013' for the innovation and work done in the field of Thalassemia management.

About Sankalp

Sankalp India Foundation is a voluntary youth organisation committed to ensuring no one suffers due to shortage of blood. The organisation along with its technology partner – Jagriti Innovations is committed to enabling evidence based, comprehensive yet accessible care and management for thalassemia to every individual irrespective of their financial background.

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