Assessment of the knowledge of thalassemia in the thalassemia patients and the treatment received by them
J Upadhyay, S Chatterjee

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Abstract
An analytical study was done on 20 thalassemic patients to assess their knowledge about their disease and treatment recommended for it. Individual interviews were conducted on the basis of a prepared questionnaire which were analysed. The study revealed lack of knowledge of the patients about their disease and treatment available and recommended for thalassemia. The study also showed that patients were not receiving the ideal treatment due to lack of knowledge and financial constraints. Appropriate health education was conducted to create awareness about thalassemia and its treatment among the patients. This study sensitized us to the need for improving the knowledge of the patients about their health condition and their management.

OBJECTIVES
To assess the knowledge of the thalassemic patients about their disease and the treatment received by them.

SUBJECTS
Age group-5 to 30 years suffering from Thalassemia.

DESIGN
Individual interviews were conducted with 20 patients using a pre-prepared questionnaire.

Hemoglobin level and spleen size on the day of the transfusion was recorded.

The data collected was tabulated and analysed.

Figure 1

Figure 2

70% of the children were <80% of their ideal weight and were malnourished.

Figure 3

7 out of 20 were either lagging behind their peers of same age or had discontinued studies due to the disease.

Table 5 Surprisingly only 2 out of 20 children were born of consanguinous marriage.
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Figure 4

<table>
<thead>
<tr>
<th>consanguineous marriage</th>
<th>no. of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>2</td>
</tr>
<tr>
<td>no</td>
<td>18</td>
</tr>
</tbody>
</table>

Disease was diagnosed in 80% by the age of 3.

Figure 5

<table>
<thead>
<tr>
<th>disease diagnosed</th>
<th>no.</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>10</td>
</tr>
<tr>
<td>1-3</td>
<td>7</td>
</tr>
<tr>
<td>3-5</td>
<td>2</td>
</tr>
<tr>
<td>&gt;5</td>
<td>1</td>
</tr>
</tbody>
</table>

21% felt that the disease was infectious, 2 even related it to DPT and polio vaccines.

2 attributed it to liver disease.

Figure 6

<table>
<thead>
<tr>
<th>type of disease</th>
<th>no.</th>
</tr>
</thead>
<tbody>
<tr>
<td>contagious</td>
<td>0</td>
</tr>
<tr>
<td>infectious</td>
<td>4</td>
</tr>
<tr>
<td>genetic</td>
<td>8</td>
</tr>
<tr>
<td>blood disorder</td>
<td>5</td>
</tr>
<tr>
<td>others</td>
<td>2</td>
</tr>
</tbody>
</table>

16 out of 20 patients had some knowledge of the types of thalassemia though only 8 knew about the severity of the disease.

Figure 7

<table>
<thead>
<tr>
<th>curable</th>
<th>no.</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>7</td>
</tr>
<tr>
<td>no</td>
<td>13</td>
</tr>
</tbody>
</table>

7 out of 20 patients believed that the disease is curable.

Figure 8

<table>
<thead>
<tr>
<th>knowledge about different types of thalassemia?</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>4</td>
</tr>
<tr>
<td>yes</td>
<td>16</td>
</tr>
</tbody>
</table>

Figure 9

<table>
<thead>
<tr>
<th>severity of the disease</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>12</td>
</tr>
<tr>
<td>yes</td>
<td>8</td>
</tr>
</tbody>
</table>
Assessment of the knowledge of thalassemia in the thalassemia patients and the treatment received by them

50% of patients held the opinion that consanguinity has no role to play in thalassemia.

8 people who were not tested was due to:
- Fear of being diagnosed positive.
- Cost
- Didn’t understand the importance.
- Father abandoned the family when child was diagnosed thalassemia.

Desferral is very famous. About half of them had no idea about other options for chelation.

7 had some family history of thalassemia. One child’s mother had thalassemia and died during the delivery.
Figure 16

12 out of 20 have not heard of BMT which is probably good considering the economic background they have.

Figure 17

5 of them had not done Hb:

Due to cost

They feel they know when the child needs transfusion “bhalo lagche na”, “we give it every month”.

Figure 20

For most of the children chelation was started quite late than the ideal and fe deposition was quite evident due to the blackening of the skin.

Figure 21

Figure 22
Assessment of the knowledge of thalassemia in the thalassemia patients and the treatment received by them

Figure 23

<table>
<thead>
<tr>
<th>desferal/mth</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-15</td>
<td>3</td>
</tr>
<tr>
<td>5-10</td>
<td>6</td>
</tr>
<tr>
<td>&lt;5</td>
<td>3</td>
</tr>
</tbody>
</table>

Figure 24

<table>
<thead>
<tr>
<th>ideal chelation</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>3</td>
</tr>
<tr>
<td>no</td>
<td>14</td>
</tr>
<tr>
<td>NA</td>
<td>3</td>
</tr>
</tbody>
</table>

Only 3 were getting chelation the ideal no. times
Reasons-cost, knowledge, long distance travel.

Figure 25

OUTCOMES
1) 70% of the children were <80% of their ideal weight and were malnourished.
2) 7 out of 20 were either lagging behind their peers of same age or had discontinued studies due to the disease.
3) Disease was diagnosed in 80% by the age of 3.
4) 16 out of 20 patients had some knowledge of the types of thalassemia though only 8 knew about the severity of the disease.
5) 50% of patients held the opinion that consanguinity has no role to play
6) Reasons for the parents of 8 patients who were not tested for thalassemia included
Fear of being diagnosed positive.
Cost
Didn’t understand the importance.
Father abandoned the family when child was diagnosed thalassemia.
7) Desferoxamine was popular. About half of them had no idea about other options for chelation.
8) 12 out of 20 had not heard of bone marrow transplant.
9) 5 of them had not done Hb on the day of transfusion due to cost. 5 of them had not done Hb:
10) For most of the children chelation was started quite late than the ideal time and iron deposition was quite evident due
Assessment of the knowledge of thalassemia in the thalassemia patients and the treatment received by them

to the blackening of the skin

11) Only 3 were getting chelation the ideal no. times
12) Only 2 out of 6 patients who had undergone splenectomy, had received vaccine prophylaxis.

MEASURES
Appropriate health education was conducted to create awareness among the people on thalassemia and its treatment.

CONCLUSION
This study sensitized us to the need for improving the knowledge of the patients about their health condition which will help in improving their management.

ANNEXURE
Questionnaire to Assess the knowledge of thalassemia in the thalassemia patients and the treatment received by them

Date of interview:
Name: Address:
Age: Contact No.
Sex: I P Reg No.
Education: Informant:
Weight:
Consanguineous marriage

KNOWLEDGE ABOUT THALASSEMIA
When was the disease diagnosed (at what age)?
What type of a disease is it?
(contagious/infectious/genetic/cancer/blood disorder/others)
Is it curable?
Do you know that there are different types of thalassemia? if yes what are the types and their severity?
Do you know that consanguinity has a role in thalassemia?
Do any of the siblings have thalassemia?
Any family history of thalassemia?
Have parents been tested for thalassemia?
What is the role of chelation in thalassemia? What are the options for chelation available that you know of?
How many times are you supposed to get chelation in a month?
Do you know about splenectomy and why is it done?
Do you know the option of BMT?
Do you know the types of food to avoid?

TREATMENT RECEIVED BY THE PATIENT:
What is the hemoglobin level when they are getting transfusion?
(I recorded the Hb on the day of transfusion)
Are you getting packed cell or whole blood?
How many transfusions are you getting per year?
How many transfusions have you got so far?
When was the chelation therapy started(after how many transfusions/transfusion rate/year at that time)
How many times per month are you getting desferral?
If its less than ideal(15-20) what is the reason(cost/lack of knowledge)
Has the patient undergone splenectomy?
When? indication?
Vaccine prophylaxis given?
Have you received Hepatitis B vaccine?
Is the patient on penicillin prophylaxis after splenectomy?

References
5. Singer, K., Chernoff, A. Z. and Singer, L. Studies on abnormal hemoglobin; their demonstration in sickle cell
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