Thalassemia is a heritable, curable, treatable and preventable disorder. It is heritable as an autosomal recessive disorder. It is treatable with repeated blood transfusion, chelating therapy, curable with bone marrow transplantation and preventable through genetic expert services (diagnostic tests) and community awareness programmes.

Background

The investigator interacted with the thalassemic parents and one of them stated that they have noticed the foetus of thalassemia at seven months pregnancy. While attending the ante natal clinic for registration of her name for hospitalisation, they tried to terminate pregnancy but obstetrician refused to do that, since both mother and child were thalassemic. After that they planned to have no further issues. It is noticed that their ignorance led to giving birth to a thalassemic child that otherwise could have been prevented.

Nurses can help to develop an insight of thalassemia disease process as a genetic disorder through health teaching, which promotes a clear understanding of the disease itself and encouraging self management with safe thalassemia-free foetus in pregnancy.

Today’s population of India is 1.15 billion and growing at the rate of 2.1 percent per year. Annually about 28 million women become pregnant and about 25 million infant are born. About 8 to 10 thousands thalassemia babies are born every year in India (Agarwal, 1993).

The study conducted by the Indian Nursing Council among school children aged 11 to 18 years in Delhi, Mumbai and Kolkata showed that incidence of beta-thalassemia carrier stood at 5.5 percent, 2.6 percent and 10.2 percent respectively.

In India first regular prenatal diagnostic service for thalassemia started in 1994 (Ahmed et al, 1994). Although the disease is not of recent origin in the country, but until now a very few studies have been conducted on it and there is no reference to planning of pregnancy in thalassemic parents.

This study aimed to provide the knowledge and awareness to the people about the planning pregnancy so that they can understand the severity of the disease and the ways to protect the new generation from the disease.

As per WHO estimates, 4.5 percent of the world’s population are carriers of haemoglobinopathy. The largest concentration of thalassemia patients are seen in South East Asia, Sri Lanka, Bangladesh, North west India, Pakistan, North Africa, Greece and Italy.

According to report on extrapolation of prevalence rate of thalassemia to countries and regions, In India (2008-09), thalassemia major affects 65 lakh, thalassemia minor 1.06 million, and thalassemia carriers 30 million population.

Objectives

The study sought to (i) assess the existing knowledge of thalassemic parent from reproductive age group in relation to planning of pregnancy before planned teaching, (ii) identify the effect of planned
teaching given by investigator / researcher regarding planning of pregnancy to thalassemic adults from reproductive age group after planned teaching, and (iii) find out the effect of selected variables on knowledge of planning pregnancy of thalassemic parents before and after planned teaching.

**Research hypothesis**

H1 – There is significant increase in knowledge of planning of pregnancy to thalassemic parent from reproductive age group.

H0 - There is no increase in knowledge of planning of pregnancy to thalassemic parents from reproductive age group.

**Limitations**

1. Sample was limited to thalassemic parents from reproductive age group.
2. Thalassemic parents from reproductive age group, who were willing to participate in study, were included.

**Variables**

A- **Independent Variable**: Planned teaching in relation to thalassemia in pregnancy.

B- **Dependent Variable**: Knowledge of the thalassemic parents in relation to planning of pregnancy.

**Conceptual framework**: The Health-Belief Model by Becker (1974).

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Knowledge areas</th>
<th>Mean scores</th>
<th>SD</th>
<th>‘t’ value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pre-test</td>
<td>Post-test</td>
<td>Pre-test</td>
</tr>
<tr>
<td>1</td>
<td>Prevalence, concept &amp; meaning of thalassemia</td>
<td>5.92</td>
<td>7.46</td>
<td>0.714</td>
</tr>
<tr>
<td>2</td>
<td>Causes &amp; mode of transmission of thalassemia.</td>
<td>3.46</td>
<td>7</td>
<td>2.250</td>
</tr>
<tr>
<td>3</td>
<td>Identifiable risk factors in pregnancy of thalassemic parent</td>
<td>2.30</td>
<td>4.38</td>
<td>0.890</td>
</tr>
<tr>
<td>4</td>
<td>Different investigations in pregnancy of thalassemia.</td>
<td>4.1</td>
<td>6.88</td>
<td>1.850</td>
</tr>
<tr>
<td>5</td>
<td>Preventive measures before &amp; during pregnancy with respect to thalassemia</td>
<td>1.72</td>
<td>3.64</td>
<td>0.970</td>
</tr>
<tr>
<td>6</td>
<td>Referral genetic expert services</td>
<td>1.94</td>
<td>4.14</td>
<td>0.840</td>
</tr>
</tbody>
</table>

The sample was composed of fifty (50) thalassemic parents. Sampling technique used was purposive sampling technique.

**Inclusion criteria**: (1) Parents between age group 15 to 49 years diagnosed with thalassemia and registered in thalassemic unit / society, (2) Who could speak Marathi or English or Hindi (3) The communities were Sindhis, Muslims, Lohanas, Punjabis, Parsi, schedule castes, OBC and general, (4) Educated parents.

**Data collection method**: Semi structured questionnaire. Planned teaching on knowledge of planning pregnancy among thalassemic parent.

**Data collection procedure**: The data collection was done in 2 stages.

Pre-test stage data was collected about knowledge of planning pregnancy among thalassemic parent and administration of semi structured questionnaire with planned teaching to thalassemic parent.

In stage II (post-test) semi structured questionnaire was administered to assess the knowledge of planning pregnancy among thalassemic parent after planned teaching.

**Validity & reliability**: Split-half method was used to find reliability of the semi structured questionnaire.

Under descriptive statistics – Percentage, Mean and Standard Deviation and under inferential statistics – Chi-square and correlation co-efficient were used.

**Results (Tables 1-3)**

- Majority of thalassemia parents (28%) were from the age group of 25-30 years.
86 percent of thalassemic parents were Hindu.

Majority of thalassemic parent (82%) were from urban area.

Most of thalassemic parent (52%) had graduate

76 percent were living in nuclear family.

Pre-test knowledge score was 48.39 percent (271) and post-test knowledge score was increased with 81.96 percent (459) in the age group of 25-30 years.

Knowledge score from father were 47.87 percent (517) in the pre-test and increased post-test knowledge score was 83.61 percent (903).

Post-test knowledge score of graduate increased with 83.75 percent (871) as against pre-test knowledge score 50.86 percent (529).

The area wise assessment of knowledge score of thalassemia parent on planning of pregnancy shows that out of 40 maximum obtainable score, the pre-test mean score was 19.44 ± 7.41 which is around 49 percent of total score, which reveals thalassemia parents had poor knowledge on planning of pregnancy and post-test mean score was 33.50 ± 3.87 which is around 84 percent of total score, which reveals that thalassemia parents had increased knowledge on planning of pregnancy.

The investigator identified the views of thalassemic parents regarding planning of pregnancy, its importance to prevent their thalassemic child-birth against thalassemia through planned Teaching.

Conclusions

Planned teaching is effective to increase knowledge of thalassemia parent on planning of pregnancy regarding prevalence, concepts, meaning of thalassemia, causes, identifiable risk factors in pregnancy, different investigations, preventive measures before and during pregnancy.

Chi-square association revealed that there was significant association between pre-test knowledge and post-test knowledge of thalassemic parents when compared with their demographic variables.

According to statistical ‘t’ test null hypothesis is rejected and H1 hypothesis is accepted. Hence we concluded that planned teaching is effective to increase the knowledge of thalassemic parents from reproductive age group related to referral genetic expert services. The change in the post-test course of the thalassemic parents of reproductive age group indicates a significant effect of planned teaching.

References

1. Agarwal MB. Thalassemia towards ideal management. News letter 1993; 8(3)

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