Psychosocial Burden and Quality of Life in Parents of Children with Thalassemia and Cerebral Palsy: A Comparative Study
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Abstract
The present study investigated, ‘Psychosocial burden and quality of life among parents having children with Thalassemia and Cerebral Palsy’. The sample for the present study, consisted of 60 participants (caregivers), aged 18 years and above, with children having confirmed diagnosis of Thalassemia Major/ Cerebral Palsy, aged 4 years and above. Out of 60 participants, 20 participants were taken as control group, having children with no chronic physical or mental disease, disability or illness. Zarit Burden Interview (Zarit et al., 1980), WHOQOL-BREF (Murphy et al., 2000), in a semi structured interview form were administered. Results indicated that psychosocial burden was greater in Thalassemic group participants, followed by Cerebral Palsy group, as compared to the control group. Further, the overall perception of quality of life and health was also found to be very poor and dissatisfied in the caregivers of Thalassemic and Cerebral Palsy group participants, as compared to the control group participants. Due to the complex treatment and regular visits to hospitals, the environmental aspects of quality of life of caregivers, was most affected in the Thalassemic group participants, as compared to the psychological aspects in the caregivers of Cerebral Palsy group.

Key Words: Thalassemia, Psychosocial burden, Children, Parents, Quality of life

INTRODUCTION
Thalassemia refers to a group of genetic disorders, characterized by insufficient production of hemoglobin. According to (Choudhary, 2000), 3.9 percent of the existing population in India, carries the thalassemic genes. Although optimal medical management has reduced the difficulties faced by thalassemics and their families, but psychosocial impact, on the development of the victim and family is a continuous process, throughout life. Children with thalassemia for survival have to regularly attend the hospital for blood transfusion, which creates a lot of burden for the families (Nahalla & Futzgerald, 2003). Also many causes including the chronicity of disease burden, of treatment modalities, morbidities and the expectation of early death, resulting from disease complications, of thalassemia, may lead to psychosocial burden in parents, which was reported by (Yesim et al., 2005).

Apart from thalassemia, another pediatric chronic motor disability, which requires access to and utilization of extensive health care resources, overtime and extensive caregivers support, is Cerebral Palsy. Altinda et al., (2007), evaluated the, depression and anxiety levels in mothers of children with cerebral palsy and found relation between functional disability level in children and psychological distress in mothers.

Since, above mentioned literature review, reveals that most of the research is done in the west, therefore, present study was designed to study the above mentioned caregivers groups, in a select Indian population, with the following objective to study the psychosocial burden and quality of life among parents having children with Thalassemia and Cerebral Palsy.

METHOD
Sample
The study was conducted in two service agencies in Delhi, with the availability of Thalassemics and Cerebral Palsy group participants (caregivers) there i.e., Dayanand Hospital, and Home for Spastics. The sample for the present study, consisted of three groups, consisting of 20 participants (caregivers), aged 18 years and above,
with children aged 4 years and above having confirmed diagnosis in each group- Thalassemia 20, Cerebral Palsy 20, and Control group 20. The subjects in the control group were matched in all parameters to the other two group subjects, except them having no physical or mental disease, disability or illness, and they were taken from the adjoining locality, of the other two service agencies.

**Measures**
In addition to the Basic Data Identification Schedule, which was used to elicit information regarding demographic details of caregivers, the following tools were used:
- Zarit Burden Interview, developed by Zarit, Reever & Bach, (1980). This interview schedule contains 22 items, and for each of the 22 items, caregivers were asked to respond about the impact of the patient’s illness on their life, by indicating how often they felt in a particular way, ( “never”, “rarely”, “sometimes”, “quite frequently”, “nearly always”).
- WHOQOL-BREF, developed by Murphy et al., (2000), of 26 items, was used to measure quality of life. Its 26 items are rated on a 5 point scale, which gives a profile with four domain scores (physical health, psychological health, social relationship and environment) and two individually scored items about an individual overall perception of quality of life and health (Q1 and Q2). The four domains are scaled in positive direction, with a score range of 0-100 and higher score denoting higher quality of life.

**Procedure**
The procedure of the study, started with identifying the service agencies, from where the participants (caregivers), could be selected. Following the identification of these service agencies, the participants (caregivers), for the control group, were approached in the adjoining locality, from where the data was to be collected. Before the collection of the data, inform consent, was taken from all the caregivers, and they were assured about the confidentiality, with telling them about the purpose of the study. Information gathering, started with Basic Data Identification Schedule, which comprised of basic demographic details of caregivers and some other questions related to the child’s disorder. Thereafter, other measures were completed.

**RESULTS AND ANALYSIS:**
For the statistical analysis, Mean Standard deviation, Chi-square and ANOVA was calculated.

**Table 1: Shows the $\chi^2$ for the Zarit Burden Interview**

<table>
<thead>
<tr>
<th></th>
<th>Little</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thalassemia group</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Cerebral palsy group</td>
<td>0</td>
<td>2</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Control group</td>
<td>16</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

$\chi^2$, 128.24, df 6, found to be significant at .01 level.

**Table 2 : $\chi^2$ for Item No. 1, WHOQOL-BREF**
<table>
<thead>
<tr>
<th></th>
<th>Very Poor</th>
<th>Poor</th>
<th>Neither Poor</th>
<th>Neither Good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thalassemia group</td>
<td>6</td>
<td>8</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cerebral palsy group</td>
<td>12</td>
<td>13</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Control group</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>16</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

χ², 64.94, df 8, was found to be significant at .01 level.

**Table 3: χ² of WHOQOL-BREF; Item No. 2 (Overall Perception of health)**

<table>
<thead>
<tr>
<th></th>
<th>VS</th>
<th>D</th>
<th>N.S. N.D.</th>
<th>S</th>
<th>V.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thalassemia group</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Cerebral palsy group</td>
<td>2</td>
<td>11</td>
<td>6</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Control group</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>3</td>
</tr>
</tbody>
</table>

χ², 47.78, df 8, was found to be significant at .01 level.

**Table 4: Mean & Standard Deviation of 4 domains of WHOQOL-BREF in each of the three groups**

<table>
<thead>
<tr>
<th></th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thalassemia group</td>
<td>x = 41.65</td>
<td>x = 33.1</td>
<td>x = 37.95</td>
<td>x = 29.55</td>
</tr>
<tr>
<td></td>
<td>σ = 13.27</td>
<td>σ = 9.37</td>
<td>σ = 14.39</td>
<td>σ = 12.40</td>
</tr>
<tr>
<td>Cerebral palsy group</td>
<td>x = 40.85</td>
<td>x = 36.6</td>
<td>x = 50.75</td>
<td>x = 44.45</td>
</tr>
<tr>
<td></td>
<td>σ = 9.96</td>
<td>σ = 7.35</td>
<td>σ = 15.49</td>
<td>σ = 9.09</td>
</tr>
</tbody>
</table>
The mean for the Thalassemic group, in the four domains of WHOQOL-BREF, was found to be lowest in the environmental domain, followed by psychological domain, social and physical. On the other hand the table shows that the mean for Cerebral Palsy group was lowest in the, psychological domain, followed by physical, environmental and social domain. In the control group, there was not much difference found in the mean of the four domains.

Table 5: Showing the F (AVONA) values for the 4 domains of WHOQOL-BREF, for the three groups

<table>
<thead>
<tr>
<th>Domain</th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>F Values</td>
<td>66.82</td>
<td>68.13</td>
<td>52.79</td>
<td>268.21</td>
</tr>
</tbody>
</table>

F values in all the four domains were significant at .01 level.

RESULTS AND DISCUSSION

Psychosocial burden
In the sphere of Psychosocial burden, the results signify that as compared to the control group, there was greater burden in the Thalassemic group participants, followed by Cerebral Palsy group participants. (Table 1) shows the Chi-Square values, which was found to be significant, thus indicating difference in the burden in three groups. Thalassemic group and Cerebral Palsy group participants reported being more stressed strained, embarrassed and afraid of their child’s future, during the semi structured interview. These findings are in consonance with the studies of the literature. Prasomsuk et al., (2007), in an exploratory study, focusing on lived experiences of 15 mothers, caring for children with Thalassemia Major in Thailand, found six themes: lack of knowledge about thalassemia, psychosocial burden, concerns about the future, social support systems, financial difficulties and effectiveness of health care services. The findings of the study revealed that a holistic, culturally sensitive approach should be considered when caring for thalassemia. High level of anxiety (82%) and financial problems were reported by parents having children with beta thalassemia, in a study done by Canatan et al., (2003). Parent caregivers of children with Cerebral Palsy were screened for psychological distress and quality of life by Geeta et al., (2007), and results indicated that, the family based interventions aimed at improving the spousal relationship and education about the illness and its treatment might ameliorate the psychological distress and thereby improve quality of life.

Quality of life
Talking about the Quality of Life, the results of the study revealed that, overall perception of quality of life and perception of health (WHOQOL-BREF), was very poor and dissatisfied, in the Thalassemic group participants, followed by Cerebral Palsy group participants, as compared to the control group participants, among whom quality of life was found to be good. The Chi-Square for Item no 1 &2 of WHOQOL-BREF (Table 2&3) was found to be significant, thus indicating difference in the quality of life and perception of health in the three groups. Mothers of children with thalassemia and cerebral palsy reported greater no of physical problems and feelings of meaninglessness of life and dissatisfaction with their life, during the semi structured interview of data collection. Similar results were reported in the studies done by (Shaligram, Girimaji & Chaturvedi, 2007), who studied 45
caregivers, having children with thalassemia, with the aim of assessing the contribution of psychiatric problems and concerns to the QOL and to correlate these with psychological problems of QOL of the youngsters. The results indicated that 57% of the caregivers had psychiatric problems, with depressive disorders and QOL was affected in 50%. The study revealed that caregivers support through psychological intervention or medication would alleviate psychiatric problems and contribute towards a better QOL. Thalassemia Major as chronic illness has a negative impact on quality of life of mothers was reported by Caro et al., (2002).

Psychological distress and quality of life in caregivers of cerebral palsy was studied by Geeta et al., (2007). Caregivers of children with cerebral palsy were screened for psychological distress using the (GHQ-12), and (WHOQOL-BREF) respectively. The results of the study indicated that QOL- social; child’s age and child’s sex were predictors of psychological distress. GHQ scores emerged as the best predictor of quality of life. Further results of the study revealed that family based interventions, at improving the spousal relationship and education about the illness and its treatment might ameliorate psychological distress and thereby improve quality of life.

Four domains of WHOQOL-BREF
Results of the study also signify that there was a significant difference in four domains of WHOQOL-BREF, in the three groups. The ANOVA values (Table 4), in the three groups for the four domains, came out to be significant, thus indicating difference in four domains of QOL, in three groups.

In the Thalassemia group participants, the quality of life was found to be poorest in the environmental domain of WHOQOL-BREF (Mean=29.55), followed by psychological domain( Mean=33.1), social domain (Mean=37.95), and physical domain ( Mean=41.65), Whereas on the other hand, in Cerebral Palsy group, the quality of life was poorest in the domain of psychological domain (Mean=36.3), followed by physical domain (mean=40.85), environmental domain (mean=44.45), and social domain (mean= 50.75). Table 5). The results thus indicates that, caregivers of Thalassemic children were more dissatisfied with the present health services, amount of information provided to them, the means of transport and their financial conditions rather than the negative feelings like, despair, anxiety, depression, meaninglessness of life which were more reported by the cerebral palsy group participants.

The findings of this study confirm the findings of earlier studies:-
Altinda et al., (2007), evaluated depression and anxiety levels, in mothers of children with Cerebral Palsy, and its relation with the functional limitations in their children. Results indicated the relation between functional disability and psychological distress.

To conclude, the results of the present study points, that since there is greater psychosocial burden and poor quality of life, among parents of Thalassemia, followed by Cerebral Palsy group participants, therefore it is imperative to provide psychosocial support, including promotion of a clear understanding of the disease to these participants. However, our results should be interpreted in the light of small sample size and more studies with large sample sizes and statistical tests employing in-depth analysis, like post hoc comparison is required.

References:

Washington, D. C.