Stress and Coping Among Mothers of Cerebral Palsy Clients with a View to Prepare a Management Protocol

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Abstract
The purpose of the study to assess the stress and coping among the mothers of children with cerebral palsy. Children with cerebral palsy display prominent motor dysfunction associated with other developmental disorders. Parenting a child with cerebral palsy presents a number of challenges and stress. The children with CP, parents are heavily involved in self care activities which may add an additional challenges and stress to the parents. The incidence of cerebral palsy is about 2 per 1000 live births. The study was conducted in selected rehabilitation institutes in Amritsar. The study sample comprising 150 mothers of cerebral palsy children. Subjects were selected with the snowball sampling method. The research design used was descriptive design. Each subject was evaluated using Berry parental stress scale for stress and 5 point Likert’s scale for coping. The majority of mothers 80% were with moderate level of stress, 20% were with severe stress and no mothers were with mild level of stress, the majority of mothers 34.6% were with moderate level of coping, 33.3% were with low level of coping and only 32.1 % were with high level of stress. The highest level of coping with the mean percentage around 80 % was in the aspect of sleep. A negative correlation was found between stress and coping among mothers. There is significant association between Age of the child ($\chi^2 = 8.52$), Gender of the child ($\chi^2 = 8.52$), Occupation ($\chi^2 = 3.91$), Type of family ($\chi^2 = 10.55$), Number of children ($\chi^2 = 39.7$) and level of stress. There is significant association between Income of the parent ($\chi^2 = 18.8$), No of the children ($\chi^2 = 11.5$) and level of coping. Mother who had higher level of stress in caring their children with cerebral palsy were not following adequate coping strategy so, the investigator concluded that there is a need to develop management protocol, in that management protocol encourage the mothers to find ways for the child to interact with the environment to promote development and early interventions can helps the mothers to learn and meet their Child’s special needs such as physical, occupational, speech therapy and educational needs. The nurse can helps the mothers to meet these needs of the child with cerebral palsy in preschool, offices, clinics and other setting and nurse can refer to them to appropriate support group to an organization private as well as government in India for the cerebral palsy children.

Keywords
Cerebral Palsy, Stress, Coping and Mothers, Management Protocol

I. Introduction
Children are like the blossoming flowers of the garden and these flowers nourish under the care and tenderness of parenthood. Some children are neglected and considered as thorns just because they lie behind in their mental development, children suffering from disorders like Down syndrome, ADHD, Dyslexia, Cerebral palsy etc. Actually these children need special care and love of parents to flourish. Also special education should be imparted to them for learning out their hidden talents therefore instead of neglecting these children must be considered “SPECIAL”. Cerebral palsy children’s are also one of the special children.

Cerebral palsy refers to injured central nervous system and palsy refers to lack of voluntary muscle strength and control so Cerebral palsy non progressive central nervous based disorder of strength muscle control posture due to brain injury during early brain growth, any central nervous system disease it can have three types Pyramidal (60%), extra pyramidal (25%) mixed type (15%). Morlow et al., (1988) [1]. Caused by congenital hypoxic, Ischemic and infectious intra uterine effect on the central nervous system. Injury to immature peri ventricular white matter in fetus and pre mature infant is most common cause of cerebral palsy. Neonatal sepsis, hyperbilirubinemia can cause high risk in infant. In young children central nervous system infection and head trauma is the main cause of infection. In Cerebral palsy children can normal muscle tone, lack of coordination, visual defects such as strabismus, hearing loss, and language delay, difficulty in feeding, learning disability, and diminished reflex response (jane w. ball et al 2001) [2]. Treatment is based on the person’s symptoms and the need to prevent complications., Self and home care include:, Getting enough food and nutrition, Keeping the home safe, Performing exercises recommended by the health care providers, Practicing proper bowel care (stool softeners, fluids, fiber, laxatives, regular bowel habits), Protecting the joints from injury. Put the child in regular schools with special education schooling. The child can learn and communicate with the help of Glasses, Hearing aids, Muscle and bone braces, Walking aids, Wheelchairs. The child with Cerebral palsy need physical therapy, occupational therapy, orthopedic help, or other treatments may also be needed to help with daily activities and care [3].

II. Literature Review

A. Parkes Jackie et al., (2011)
drafted a study on Parenting stress and children with cerebral palsy in nine regions in Europe. The aim of this study was to describe stress in the parents of children with cerebral palsy & investigate associations with very high stress. A cross-sectional survey was conducted on parents of 818 children aged 8 to 12 years. Families were eligible to participate if they were living in one of the specific geographic areas. Parental stress was captured using Parenting Stress Index Short Form, which has 36 items & takes 10 minutes to complete. Parents rate items on a 5-point Likert scale, with higher score indicating higher stress. The Short Form yields scores on three subscales & a Total stress Score. A trained research associate administered the questionnaire in the child’s home & visits lasted 90 to 120 minutes. All data collected were reported by parents unless otherwise stated. The Total Stress Score on the Parenting Stress Index was dichotomized into scores of less than 99, the latter indicating ‘very high’ stress. Most respondents were mothers (94%), & 26% reported very high stress levels. The parents of children with communication impairment had higher odds for very high stress. 95% confidence interval than those whose child has no such impairment, the parents of children with moderate or severe pain had higher odds for very high stress [4].
B. The Nemours Foundation (2011)

Studied that kids with CP have varying degree of physical disability. Some have only mild impairment, while others are severely affected. Associated medical problems may include visual impairment or blindness, hearing loss, food aspiration, gastro esophageal reflux, speech problems, drooling, tooth decay, sleep disorders, osteoporosis and behavior problems. Seizures, speech and communication problems, and mental retardation are also common among kids with severe form of CP. Many have problems that may require ongoing therapy and devices such as braces or wheel chairs [5].


Conducted a study on Survey of mothers of children with cerebral palsy. The study was conducted in the CP pediatric department of China Rehabilitation Research Center (CRRC). A questionnaire including 25 closed questions was designed as a tool for collecting data. The sample mothers of CP children were introduced to the survey before answering the questions and answered this questionnaire totally and separately. The result shows that rehabilitation fee for CP children are from 63.9% fathers, 19.4% mother and 16.7% from other sources. It was found that Over half of mothers of CP children think that the child is the most important member in her family. 61.1% of mothers of CP children are unwilling to talk about their children with others and 41.7% mothers of CP children are reluctant to take their child to the Public. 41.7% mothers of CP children in this survey are still not able to take their disabled children to be with them in public. 69.4% expressed that they neglected their own parents (grandparents of CP children); 80.6% mothers admitted that they became solitary and their social activities decreased. 80.6% mothers isolate themselves and even reduce their social communications to as few people as possible [6].

D. Guyard a Et Al (2010)

Conducted a study on Impact on parents of cerebral palsy in children. The aim of the present paper is to report the current knowledge on this parental impact, highlighting consensus and disagreement. Seven parental impact dimensions were distinguished: time spent, occupational restrictions, social relationships, family relationships, psychological well-being, physical health, and financial burden. Of40 selected references, the studies were mostly cross-sectional, although longitudinal studies highlighted the causal relationship between factors. Researcher study shows that parents of CP children have greater risk of experiencing a sense of burden than parents of typically normally developing children. The level of intellectual impairment also has a negative influence on family relationships and on the parent’s psychological well-being. Research is needed before a complete model of the CP child’s impact on parents can be tested in view of providing guidelines to professionals for identifying families with a risk of maladaptation and suggesting solutions to decrease the negative impact [7].


Conducted a study on stress among mothers of children with cerebral palsy attending special schools in Kerala state, India. The study reveals that stress experienced by mothers of these children is at moderate level and the pessimism expressed regarding the child’s ability towards achieving self sufficiency, is found to be most stress producing factor. A descriptive method was used to achieve the objective of study. The tools used included case sheet record & questionnaire on resources & stress. The stress experienced by 50 mothers of children with cerebral palsy is 22.8% which is at moderate level. Out of 50 mothers, 16 mothers expressed mild stress, 23 mothers showed moderate stress & 11 mothers expressed severe stress. The mean stress experienced by mothers of boys with cerebral palsy was 23.4% and that of girls with cerebral palsy was 21.90%. Among the child related and mothers related variables, only multiple disabilities along with cerebral palsy is a significant variable in deciding the difference in the severity of stress among the mothers [8].

III. Purpose of the Study

The purpose of the study was to find out the stress and coping level of mother with cerebral palsy children. Mothers of the cerebral palsy children have more stress than mothers of normal children. The mothers of the cerebral palsy children allow verbalizing the impact of cerebral palsy on the family and giving the occasion to meet the other parents with cerebral palsy children and social group and it helps in exploring the community services for rehabilitation and respite care, child care and other needs. During the home and office visit nurse can review the child achievement and can praise the family for care provided for the cerebral palsy children. She can teach the family regarding skills needed to manage the child care such as medication administration, muscle stretching, than physical rehabilitation and seizure management.

IV. Methodology

The goals of the research were to help the mothers to cope with the stress they were having due to cerebral palsy children. The research design used was descriptive design. The study was conducted in selected rehabilitation institutes in Punjab. The study sample comprising 150 mothers of cerebral palsy children. Subjects were selected with the snowball sampling method as per availability mothers were approached among the diagnosed cerebral palsy children. Each subject was evaluated using Berry parental stress scale for stress and 5 point Likert’s scale for coping. For this present study, the researcher used the tool which consists of three parts. They are as follows;

**A. Part I**

Demographic variables of the samples prepared by investigator. Consist of Age, Gender of child, Income of the parents, Education of mother, Occupation, Type of family, No of children and Type of disability.

**B. Part II**

Berry Parental Stress Scale, year 1988. Consist of 18 items related to stress with the score of maximum 5 and minimum 1 for each item. This tool was developed by using Berry parental stress scale. In this 8 positive items are scored reversely and maximum score for stress among mothers was 90.

**C. Part III**

Five Point Likert’s Scale, Consist of Five point liker’s scale of 40 items on coping strategies among mothers of cerebral palsy clients. The scoring was five as maximum and one as minimum score for each item. The Five points used was strongly Agree (SA), Agree (A), Undecided (UD), Disagree (DA), and Strongly Disagree (SDA).and maximum score for coping among mothers was 200. Reliability of the tool was done by using Carl Pearson formula with the split of technique. The ‘r’ value of 0.98 obtained, hence it was highly reliable and informed consent was obtained from each subject. Permission for conducting the research was
obtained from the director of Institution.

V. Data Analysis

The study sample comprising 150 mothers of cerebral palsy children. In regard with the age group of the children above 9 years were in majority ie 62 (42%). The majority of children were males 119 (79%) and 31 (21%) were females. The higher number of parents 68 (45%) were earning below Rs10000. In regard with education the higher number of mothers had 65 (44%) Graduate & above education. In relation to occupation majority of mothers 110 (73%) had private job, in regard with type of family majority 98 (65%) of mothers belongs to joint family The majority mothers 112 (75%) had 1-2 children, In regard with type of disability majority children 105 (70%) were having dependent mobility.

Table 1: Frequency and Percentage Distribution of Socio-Demographic Characteristics of Mothers

<table>
<thead>
<tr>
<th>Sl No.</th>
<th>SAMPLE CHARACTERISTICS</th>
<th>FREQUENCY</th>
<th>PERCENTAGE (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Age of the child (in years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. 3 – 4</td>
<td>57</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>b. 5 – 6</td>
<td>17</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>c. 7 – 8</td>
<td>14</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>d. &gt; 9</td>
<td>62</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Gender of the child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Male</td>
<td>119</td>
<td>79</td>
<td></td>
</tr>
<tr>
<td>b. Female</td>
<td>31</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Income of the parent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. &lt; 10,000</td>
<td>68</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>b. 10,000 – 20,000</td>
<td>28</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>c. 20,000 – 40,000</td>
<td>20</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>d. &gt; 40,000</td>
<td>34</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Education of the mother</td>
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<td></td>
</tr>
<tr>
<td>a. Primary</td>
<td>44</td>
<td>29</td>
<td></td>
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<tr>
<td>b. Higher secondary</td>
<td>41</td>
<td>27</td>
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</tr>
<tr>
<td>c. Graduation &amp; above</td>
<td>65</td>
<td>44</td>
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</tr>
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<td>5</td>
<td>Occupation</td>
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<td>a. Public</td>
<td>40</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>b. Private</td>
<td>110</td>
<td>73</td>
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<td>6</td>
<td>Type of family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Nuclear</td>
<td>52</td>
<td>35</td>
<td></td>
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<tr>
<td>b. Joint</td>
<td>98</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Number of children</td>
<td></td>
<td></td>
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<tr>
<td>a. 1 – 2</td>
<td>112</td>
<td>75</td>
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</tr>
<tr>
<td>b. 3 – 4</td>
<td>29</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>c. 5 – 6</td>
<td>09</td>
<td>06</td>
<td></td>
</tr>
<tr>
<td>d. &gt; 6</td>
<td>00</td>
<td>00</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Type of disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Independent in mobility</td>
<td>45</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>b. Dependent mobility</td>
<td>105</td>
<td>70</td>
<td></td>
</tr>
</tbody>
</table>

A. Level of Coping Among Mothers of CP Children

Table 2 Frequencies and Percentage Distribution of Level of Coping among Mothers of Cerebral Palsy Children

<table>
<thead>
<tr>
<th>Sl No.</th>
<th>Level of Coping</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
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<td>1</td>
<td>Low</td>
<td>50</td>
<td>33</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
<td>52</td>
<td>35</td>
</tr>
<tr>
<td>3</td>
<td>High</td>
<td>48</td>
<td>32</td>
</tr>
</tbody>
</table>
The majority of mothers 120 (80%) were with moderate level of stress, 30(20%) were with severe stress and 00(0%) were with mild level of stress.

B. Level of Stress Among Mothers of CP Children

Table 3: Frequency and Percentage Distribution of Level of Stress Among Mothers of Cerebral Palsy Children

<table>
<thead>
<tr>
<th>Sl No.</th>
<th>Level of stress</th>
<th>Frequency</th>
<th>Percentage (%)</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Mild</td>
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<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
<td>120</td>
<td>80</td>
</tr>
<tr>
<td>3</td>
<td>Severe</td>
<td>30</td>
<td>20</td>
</tr>
</tbody>
</table>

The majority of mothers 52 (34.6%) were with moderate level of coping, 50 (33.3%) were with low level of coping and 48(32.1%) were with high level of stress.

C. Association Between Stress and Demographic Variables

Table 4: Association Between Levels of Stress Among Mothers of Cerebral Palsy Children with their Demographic Variables

<table>
<thead>
<tr>
<th>S No.</th>
<th>Demographic characteristics</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Chi Square value ($\chi^2$)</th>
<th>Table value</th>
</tr>
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<td>Age of the child (yrs)</td>
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</tr>
<tr>
<td></td>
<td>3-4</td>
<td>51</td>
<td>34</td>
<td>06</td>
<td>4</td>
<td>8.7*</td>
</tr>
<tr>
<td></td>
<td>5-6</td>
<td>12</td>
<td>8</td>
<td>05</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7-8</td>
<td>08</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; 9</td>
<td>49</td>
<td>33</td>
<td>13</td>
<td>9</td>
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</tr>
<tr>
<td>2</td>
<td>Gender of the child</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Male</td>
<td>101</td>
<td>67</td>
<td>18</td>
<td>12</td>
<td>8.52*</td>
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<tr>
<td></td>
<td>Female</td>
<td>19</td>
<td>13</td>
<td>12</td>
<td>08</td>
<td>3.84</td>
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<td>3</td>
<td>Income of the parent</td>
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<td>39</td>
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<td>200001-40000</td>
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<td>40001&amp; above</td>
<td>24</td>
<td>16</td>
<td>10</td>
<td>07</td>
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<td>Education of the mother</td>
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<td>Higher secondary</td>
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<td>Graduation &amp; above</td>
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<td>11</td>
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<td>5</td>
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<td>08</td>
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<td>Private</td>
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<td>12</td>
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<td>Type of family</td>
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<td></td>
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<td>11</td>
<td>07</td>
<td>8.5*</td>
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<td></td>
<td>Joint</td>
<td>79</td>
<td>53</td>
<td>19</td>
<td>13</td>
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<td>Independent in mobility</td>
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<td>1.8</td>
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<td></td>
<td>Dependent mobility</td>
<td>87</td>
<td>58</td>
<td>18</td>
<td>12</td>
<td>3.84</td>
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</table>

* Significant at 0.05 level
N.S - Not significant at 0.05 level

Association between level of stress and demographic variables of mothers of cerebral palsy children at the level of P < 0.05. The chi-square value with comparison of table value revealed that there is significant association between Age of the child ($\chi^2 = 8.52$), Gender of the child ($\chi^2 = 8.52$), Occupation ($\chi^2 = 3.91$), Type of family ($\chi^2 = 10.55$), Number of children ($\chi^2 = 39.7$) and there were no significant association with other demographic variables such as income of the parent ($\chi^2 = 3.79$), education of the parent ($\chi^2 = 1.92$) and type of disability ($\chi^2 = 1.8$).
Table 5: Association Between Level of Coping Among Mothers of Cerebral Palsy Children with their Demographic Variables

<table>
<thead>
<tr>
<th>S No.</th>
<th>Demographic characteristics</th>
<th>Low F %</th>
<th>Moderate F %</th>
<th>High F %</th>
<th>Chi Square value (χ^2)</th>
<th>Table value</th>
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</thead>
<tbody>
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<td>1</td>
<td>Age of the child (yrs)</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>a. 3-4</td>
<td>14</td>
<td>09</td>
<td>21</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>b. 5-6</td>
<td>10</td>
<td>07</td>
<td>05</td>
<td>03</td>
<td>02</td>
</tr>
<tr>
<td></td>
<td>c. 7-8</td>
<td>06</td>
<td>04</td>
<td>04</td>
<td>03</td>
<td>04</td>
</tr>
<tr>
<td></td>
<td>d. &gt; 9</td>
<td>20</td>
<td>13</td>
<td>22</td>
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<td>Gender of the child</td>
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* Significant at 0.05 level
N.S - Not significant at 0.05 level

Association between level of coping and demographic variables of mothers of cerebral palsy children at the level of P < 0.05. The chi-square value with comparison of table value revealed that there is significant association between Income of the parent (\(\chi^2 = 18.8\)), No of the children (\(\chi^2 = 11.5\)) and there were no significant association with other demographic variables such as Age of the child (\(\chi^2 = 8.4\)), Gender of the child (\(\chi^2 = 0.02\)), education of the parent(\(\chi^2 = 14.2\)), Occupation (\(\chi^2 = 2.6\)), Type of family (\(\chi^2 = 4.17\)) and type of disability(\(\chi^2 = 0.36\)). The income of the parent and number of children in the family influences the coping level of mothers of cerebral palsy. The obtained (\(\chi^2\)) value 18.8 and 11.5 is more than the table value, revealing a significant association.

VI. Limitation and Research Needed
The study was limited to only mothers of cerebral palsy children attending rehabilitation institute. Sample size was limited to only 150 mothers of cerebral palsy children. The study recommendations are, Study can be conducted on large sample size, Subjects can be selected through random sampling technique, and Future study can conduct on preventive measures for stress reduction technique for the same samples, The same study can be done in future with different design.

VII. Conclusion
Children with cerebral palsy display prominent motor dysfunction associated with other developmental disorders. Parenting a child with cerebral palsy presents a number of challenges and stress. For many children with CP, parents are heavily involved in self care activities which may add an additional challenges and stress to the parents. The incidence of cerebral palsy is about 2 per 1000 live births. The incidence is higher in males than in females. The findings of the present study revealed that 80% of mothers of cerebral palsy children had moderate level of stress which affects their selfimage, health status, family & social environment, occupational status and psychological status. These findings were supported by Janeen Manuel (2002) [9], about stress and adaptation in mothers of children with cerebral palsy, which...
revealed that mothers of children with cerebral palsy may be at risk for depression. Similar findings were reported by Ong LC et al (1998) [10], those mothers of children with cerebral palsy experienced higher levels of stress. Findings were also consistent with another study conducted by Ozlem Altingdag et al (2006) [11], on anxiety and depression levels of children with cerebral palsy revealed that caregiver stress is related with the child’s disability level. It was concluded that the mothers of handicapped children should be given a regular psychological support and coping technique. Also Reaz Mobarak et al (1999)[12], concluded that high proportion of mothers of children with cerebral palsy suffer from stress due to behavioral problems in the children. The present study findings revealed that majority 35 % of mothers of cerebral palsy children had low level of coping when there are majority of mothers were with mild stress. These findings were supported by Anna Cheshire et al (2010) [13], which concluded that positive reinterpretation appeared to be an adaptive coping strategy used to deal with emotional stresses experienced by parents. Similar study conducted by Dahlbeck et al (2009) [14], concluded that high positive affect had high life satisfaction. Also Preston A Britner (2003) [15], concluded that mothers of children with cerebral palsy reported lower stress level by the use of self reported family functioning according to presence or severity of the child’s disability.

The present study findings revealed that the mothers of cerebral palsy children were not following adequate coping according to their stress level. There was negative correlation between stress and coping. Findings were supported by A Gupta et al. (2000).

References

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