Stress among Parents and Caregivers of Differently Abled Children

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ABSTRACT

Purpose: Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Caregivers play a central role in the lives of children, and their own well-being is inextricably linked to that of their children. Two major social trends make the consideration of caregiver health particularly relevant. Caregiver syndrome or caregiver stress is a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent. The present study aims at stress among the care givers of the differently abled children.

Methodology: In the present study descriptive and corrdational research design is used for obtaining a good grasp of the phenomena of interest and for advancing knowledge through good theory building. To assess the level of stress the perceived stress scale was used.

Result : Stress among parents/caregivers of disable children were considered as The parents of disabled children’s having the moderate stress, in which female parent have higher stress rather than the male. The preposition of stress is equally high among the both parents of differently abled children. The level of stress is more high under the age group 25-30 years adults, they are having more stress due to their child disability, as well as the parents of the children under the age group of 31-35 years. The early adults have a more stress due to the disability of their child. There is low stress among the age group of 41-45 years and 45-50 years old parents. The level of high stress can be measures under the parents those having graduates. The level of stress is high among the parents under the income group of 10,000-30,000. A very stress is seen under the range of the 80,000 – above.

Conclusion: The level of stress is high among the parents and caregivers of the differently abled children due to many factors, which affects the life and also their life style. There is a wide disparity in how caregivers adjust to the specific demands of care. Of the parameters studied, regarding overload and stress in caregivers. This study was highlighted factors predictive of stress in parents and caregiver of differently abled children. It is difficult to completely change the stress behavior of the parents and caregivers of the differently abled children.

Keywords: Disability, parents -caregivers, stress.
INTRODUCTION

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.

People with disabilities have the same health needs as non-disabled people — for immunization, cancer screening etc. They also may experience a narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings (World Health Organization. Retrieved 11 August 2012).

Caregivers play a central role in the lives of children, and their own well-being is inextricably linked to that of their children (Schor, 2003). Two major social trends make the consideration of caregiver health particularly relevant. First, there has been a decided shift towards community-based rehabilitation (CBR) of children with disabilities (ILO, UNESCO, UNICEF, WHO, 2007). In addition to maximizing opportunities for social inclusion, CBR recognizes caregivers as partners in the provision of care. Second, the principles of family-centered care have been embedded in health policy and embraced by health and social services agencies providing services to children with disabilities and their families (Dunst et al 2002). Here, too, caregivers are instrumental partners who take an active role, influencing the nature and direction of the care their child receives (Rosenbaum, 1998). These trends place greater emphasis on caregiver voice and involvement, but also represent an extraordinary parental responsibility. Caregivers of children (4–16 years of age) with a chronic health condition and disabilities as well as caregivers of children with brain based health problems had more physical, mental health and adjustment problems than caregivers of children without these conditions. Conversely, others have found that these caregivers do not differ in their rates or levels of physical health or psychological distress.
RATIONALE OF THE STUDY

Family support is the support of families with a member with a disability, which may include a child, an adult or even the parent in the family. Family support includes "unpaid" or "informal" support by neighbors, families and friends, "paid services" through specialist agencies providing an array of services termed "family support services", school or parent services for special needs such as respite care, specialized child care or peer companions.

Parents attach to children through core-level dreams, fantasies, illusions, and projections into the future. Disability dashes these cherished dreams. The impairment, not the child, irreversibly spoils a parent's fundamental heart-felt yearning. Disability shatters the dreams, fantasies, illusions, and projections into the future that parents generate as pan of their struggle to accomplish basic life missions. Parents of impaired children grieve for the loss of dreams that are key to the meaning of their existence, to their sense of being. Recovering from such a loss depends on one's ability to separate from the lost dream, and to generate new, more attainable, dreams. As disability bluntly shatters the dreams, parents face a complicated, draining, challenging, frightening, and consuming task. They must raise the child they have, while letting go of the child they dreamed of. They must go on with their lives, cope with their child as he or she is now, let go of the lost dreams, and generate new dreams. To do all this, the parent must experience the process of grieving.

A caregiver or caretaker is an unpaid or paid person who helps another individual with impairment with his or her activities of daily living. Any person with a health impairment might use care-giving services to address their difficulties. Care-giving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder.

Typical duties of a caregiver might include taking care of someone who has a chronic illness or disease; managing medications or talk to doctors and nurses on someone's behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone. With an increasingly aging population in all developed societies, the role of caregiver has been increasingly recognized as an important
one, both functionally and economically. Many organizations which provide support for persons with disabilities have developed various forms of support for carers as well.

The present study aims at stress among the care givers of the differently abled children. Hence the present study is taken up with the following

**OBJECTIVE**

To measures the level of stress among the parents and caregivers of the differently abled children.

**HYPOTHESIS**

**Ho** - There exist no significant difference between stress among the parents and caregivers of the differently abled children across various disabilities.

**METHODOLOGY**

**Research design** - In the present study descriptive and correlational research design is used for obtaining a good grasp of the phenomena of interest and for advancing knowledge through good theory building.

**Locale of the study** – Lucknow city was selected as the locale of the study, as it is convenient for the researcher to conduct the study.

**Sampling procedure** – For selection of the respondent’s purposive random sampling technique was adopted. A simple random sample is a sample of size \( n \) drawn from a population of size \( N \) in such a way that every possible sample of size \( n \) has the same chance of being selected.

**Sample size** – The desire sample size in the present research was identified purposively from the population.

**VARIABLES OF THE STUDY**-

**Independent variables**- Age, sex, type of disability, education of caregivers, socio-economic status.

**Dependent variable**- Stress among parents.

Stress among parents/ caregivers of disable children were considered. It was assumed that the level of stress of caregivers/parents may high due to mobility as well as with different disabilities of their children.
Parents/ caregivers stress

TOOLS AND TECHNIQUES USED-
To carry out the present study the following tools were used.

Demographic data sheet – this section included questions related age, gender, family composition of the child as well as the caregivers, education, address etc.


The Perceived Stress Scale (PSS) is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one’s life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress. The PSS was designed for use in community samples with at least a junior high school education. The items are easy to understand, and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents were asked how often they felt a certain way.

Evidence for Validity:
• Higher PSS scores were associated with (for example):
  • failure to quit smoking
  • failure among diabetics to control blood sugar levels

Cerebral palsy
Visual Impairment
Heari
Mentally retarded
• greater vulnerability to stressful life-event-elicited depressive symptoms
• more colds


Temporal Nature: Because levels of appraised stress should be influenced by daily hassles, major events, and changes in coping resources, predictive validity of the PSS is expected to fall off rapidly after four to eight weeks.

Scoring: PSS scores are obtained by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. A short 4 item scale can be made from questions 2, 4, 5 and 10 of the PSS 10 item scale.

Analysis of data- In the present study frequency and percentage were computed for analyzing the age, religion, caste, class, family background and family type, assessment of the level of occupational stress, assessment of the life satisfaction and body discomfort and different parameters were also calculated with the help of frequency, percentage, mean, and standard deviation were conducted.

Statistical Analysis-Data collected was analyzed statistically with the help of various statistical techniques using PAS software.

RESULTS-

Level of stress among the parents of differently abled children

Stress among parents/ caregivers of disable children were considered. It was assumed that the level of stress of caregivers/parents high due to mobility as well as with different disabilities of their children.
Table no-1-level of stress among parents of differently abled children

<table>
<thead>
<tr>
<th>Levels of stress</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>5(55.6)</td>
<td>4(44.4)</td>
<td>9(8.5)</td>
</tr>
<tr>
<td>Moderate</td>
<td>31(47.0)</td>
<td>35(53.0)</td>
<td>66(62.8)</td>
</tr>
<tr>
<td>High</td>
<td>15(50.0)</td>
<td>15(50.0)</td>
<td>30(28.6)</td>
</tr>
<tr>
<td>Total</td>
<td>51(48.6)</td>
<td>54 (51.42)</td>
<td>105(100)</td>
</tr>
</tbody>
</table>

(Figure in parenthesis indicate percentage)

Fig: 1-level of stress among parents of differently abled children

From the data the majority of the parents having the moderate stress, in which female parent have higher stress rather than the male. The preposition of stress is equally high among the both parents of differently abled children. The level of moderate stress is higher than the low. It is evidence that the level of stress among the parents is high due to the disability of their children.

According to Mobarak et al.(2000). The parents, other members of the family, relatives, friends and even neighbors of a child with disabilities may all experience problems in caring for a child. Most children with disabilities live in developing countries; the majority of families are already living under difficult conditions. The strongest predictor of maternal stress in
Multivariate analysis was child behavior problem, especially those related to burden of caring. Ensuring practical help for mother and advice on managing common behavior problem are important components of intervention, as they may directly help to relieve stress on mother of young disabled children in developing countries.

Table no-2- Level of stress among parents of differently abled children across parental age (in 2015).

<table>
<thead>
<tr>
<th>Levels of Stress</th>
<th>23-30</th>
<th>31-35</th>
<th>36-40</th>
<th>41-45</th>
<th>45-above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>2(5.6)</td>
<td>5(10.9)</td>
<td>2(10.5)</td>
<td>---</td>
<td>---</td>
<td>9</td>
</tr>
<tr>
<td>Moderate</td>
<td>27(75.0)</td>
<td>26(56.5)</td>
<td>10(56.6)</td>
<td>2(100)</td>
<td>1(50.0)</td>
<td>66</td>
</tr>
<tr>
<td>High</td>
<td>7(19.4)</td>
<td>15(32.6)</td>
<td>7(36.8)</td>
<td>---</td>
<td>1(50.0)</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>46</td>
<td>19</td>
<td>2</td>
<td>2</td>
<td>105</td>
</tr>
</tbody>
</table>

X²:5.699**p: 0.000

Ho- There exist no significant difference between stress among the parents and caregivers of the differently abled children across various disabilities.
fig- 2 - Level of stress across parental age.

From the data it is evident that the level of stress is more high under the age group 25-30 years adults, they are having more stress due to their child disability, as well as the parents of the children under the age group of 31-35 years. The early adults have a more stress due to the disability of their child. There is low stress among the age group of 41-45 years and 45-50 years old parents. The cri-square value of the level of the stress among parents across the parental is highly significant $X^2:5.699\text{**}p: 0.000$.

Table no- 3 -Level of stress among parents of differently abled children across parental education.

<table>
<thead>
<tr>
<th>Level of stress</th>
<th>High school</th>
<th>Intermediate</th>
<th>Graduate</th>
<th>Post-graduate</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>---</td>
<td>3(8.6)</td>
<td>4(8.2)</td>
<td>3(33.3)</td>
<td>9</td>
</tr>
<tr>
<td>Moderate</td>
<td>7(58.8)</td>
<td>20(57.1)</td>
<td>35(71.4)</td>
<td>4(44.4)</td>
<td>66</td>
</tr>
<tr>
<td>High</td>
<td>5(41.7)</td>
<td>12(34.3)</td>
<td>10(20.4)</td>
<td>3(33.3)</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>35</td>
<td>49</td>
<td>9</td>
<td>105</td>
</tr>
</tbody>
</table>

$X^2:6.608\text{**}p: 0.000$
Fig: 3- Level of stress across parental education.

From the data it seems that the level of high stress can be measures under the parents those having graduates. Majority of the respondents are having their graduate degree and the level of stress is moderate among them. There is relationship between the qualification of the parents and the level of stress. Stress is due to the disability of their child which is more genuine.

Table no-4 - Level of stress among parents of differently abled children’s across various disabilities

<table>
<thead>
<tr>
<th>Level of stress</th>
<th>Hearing</th>
<th>Visual</th>
<th>Mental</th>
<th>Cerebral palsy</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>2(6.7)</td>
<td>4(13.3)</td>
<td>2(6.7)</td>
<td>1(6.7)</td>
<td>9</td>
</tr>
<tr>
<td>Moderate</td>
<td>19(63.3)</td>
<td>21(70.0)</td>
<td>17(56.7)</td>
<td>9(60.0)</td>
<td>66</td>
</tr>
<tr>
<td>High</td>
<td>9(30.0)</td>
<td>5(16.7)</td>
<td>11(36.7)</td>
<td>5(33.3)</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
<td>30</td>
<td>30</td>
<td>15</td>
<td>105</td>
</tr>
</tbody>
</table>

X²: 3.875**p: 0.000
Fig: 4 - Level of stress among parents of differently abled children’s across various disabilities

It is evidence that all the parents of differently abled children having the moderate level of stress. The more parents of visually impaired children having high moderate level of stress among all the disabilities. The parents those where facing the problems regarding the disability of the children like mental, hearing, visual and cerebral palsy where also have a high level of stress. The majority of parents were having the moderate level of stress.

Table no 5 - Level of stress among parents of differently abled children’s across parental income.

<table>
<thead>
<tr>
<th>Level of stress</th>
<th>&gt;10,000</th>
<th>10,000-30,000</th>
<th>30,000-50,000</th>
<th>50,000-80,000</th>
<th>80,000-above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>0</td>
<td>5(8.5)</td>
<td>4(12.9)</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Moderate</td>
<td>2(33.3)</td>
<td>36(61.0)</td>
<td>22(71.0)</td>
<td>5(71.4)</td>
<td>1(50)</td>
<td>66</td>
</tr>
<tr>
<td>High</td>
<td>4(66.7)</td>
<td>18(30.5)</td>
<td>5(16.1)</td>
<td>2(28.6)</td>
<td>1(50)</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>59</td>
<td>31</td>
<td>7</td>
<td>2</td>
<td>105</td>
</tr>
</tbody>
</table>

X²: 8.414** p: 0.000

Fig: 5 - Level of stress across parental income
The level of stress is high among the parents under the income group of 10,000-30,000. A very stress is seen under the range of the 80,000 – above, because they are able to afford easily good assistive devices, helping devices for their children to improve their life style and their quality of life. Like electronic wheelchairs, scooters etc. these type of mobility aids make the user (child) self independent. They are able to use or control the function of their devices.

DISCUSSION

There is a wide disparity in how caregivers adjust to the specific demands of care. Of the parameters studied, regarding overload and stress in caregivers, our study finds that two factors are important: The characteristics of the affected person regarding the degree of disability and dependence; and the caregiver characteristics regarding mood state and self-efficacy strategies. However, it seems that contextual factors regarding environmental quality of life, social support and family functioning do not have a significant effect on the perceived burden of the caregivers.

This study was highlighted factors predictive of stress in parents of children with disability. It is difficult to completely change the stress behavior of the parents and caregivers of the differently abled children. There are many factor which causes the stress to the parents and caregivers of the differently abled children’s like disability of the children, mobility aids of the children’s or the main and main factor of the stress of the parents / caregivers is the socio-economic status of the family, which leads more stress to them.

The levels of stress of care on parents and caregivers of differently abled children’s and its determinants were examined. As we noted in the results section, the most important predictors of the stress in our study were degree of disability, depression and self-efficacy. An important aspect of caregivers stress is the demands of caring. Our study has also shown that family functioning is not a significant predictor of caregiver stress. However, other studies with caregivers of differently abled children have found that family functioning can affect the caregiver’s well being directly or indirectly through self-perception, social support and stress.

Hence, the level of stress is high among the parents and caregivers of the differently abled children due to many factors, which effects the life and also their life style. The level of stress is high among the parents and caregivers of the differently abled children due to many
factors, which affects the life and also their life style. There is a wide disparity in how caregivers adjust to the specific demands of care. Of the parameters studied, regarding overload and stress in caregivers. This study was highlighted factors predictive of stress in parents and caregiver of differently abled children. It is difficult to completely change the stress behavior of the parents and caregivers of the differently abled children.

REFERENCES
