

## Impact of COVID-19 on Caregiver Burden among Parents of Differently Abled Children: A Survey

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### Abstract

**Introduction:** During COVID19 outbreak, parents of differently abled children have to quit their institutional rehabilitation session as a result of pandemic. Many factors lead to depressing experience on caregiver's mental health, burden, and health status. Caregiver Health SelfAssessment Questionnaire will be helpful in determining the mental behavior and health risk of parents or caregivers of developmentally delayed individuals.

**Objective:** The present study was aimed to examine the impact of COVID19 on caregivers of differently abled children and to compare the burden, stress, and health status of differently abled children's parents in terms of gender and different age group.

**Methodology:** From the period of October 2020 to March 2021, 30 caregivers of 30 differently abled children's who were under developmental therapy in child developmental center in Saveetha medical college and hospital were asked to participate in the study through telephonic interview.

**Results:** The mean stress and health status scores among parents of Female children (8 and 7.18) were much higher than parents of male children (5.73 and 4.52). On comparing the age groups, parents of preschool had high caregiver burden and stress mean value of 10 and 7.37, the mean value of school and toddler age group is (8.75, 6.28) and (6.57, 7) parents of infant age group scores lowest burden score compared to the others.

**Conclusion:** Caregivers of differently abled children's experiences burden, stress and health issues. Children with developmental disability were completely dependent on their caregivers on activities of daily living and decline in their health also inversely have an impact on health status of the caregivers. Our team is working out with home-based exercises facilitated through tele consultation and handouts to reduce the possible impact of COVID19 on these children and caregivers.

### Keywords

Family caregiver, Developmental therapy, Burden, Caregiver

### Introduction

Due to COVID19 pandemic all individuals were affected physically and mentally in which caregivers were the one who experienced a lot of burden, stress and health issues (Russell et al., 2020). Caregivers take care the activities of daily living (ADL) of individuals who were dependent. Caregivers play a major role in activities of daily living in differently abled children as well as during the therapy session (Gronski & Doherty, 2020). COVID19 pandemic leads to reduced transport facilities and other cause leads parents of differently abled children have to quit their institutional rehabilitation session as a result.

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Developmental delay refers to delay in developmental milestone (gross motor, fine motor, language and social-cognitive) compared to that of the prior group. These occurs due to antenatal, perinatal, and natal injury to the developing brain or due to chromosomal abnormality. These children have difficulty in doing ADL activities such as in self-care activities like eating, grooming, bathing, dressing, and bladder and bowel (Herbert, 2008). They also required ambulatory support. These individuals are completely or partially dependent on their caregivers (Chen et al., 2018).

They required rehabilitation therapy to achieve appropriate milestone for age and independent of ADL (Agarwal & Sharma, 2002). Many factors lead to depressing experience on caregiver's mental stress, burden, and health status. Major factor is delayed developmental milestone in children and also decline in their health inversely have an impact on health status of the caregivers (Yue et al., 2018). In addition to it COVID19 increased the stress level in all individuals (Russell et al., 2020). Caregiver Self-Assessment Questionnaire will be helpful in determining the mental behavior and health risk of parents or caregivers of developmentally delayed individuals. Patient reported outcome measure which assesses caregiver's burden, health status and stress level. There were 18 questions in which initial 16 deals with the individuals burden level such as had a crying spell, health status and stress level were measured using Likert scale of 0 to 10, in which 0 indicates no stress or health issues where as 10 indicates highest level of stress and health issues (Epstein-Lubow et al., 2010). Caregiver self-assessment questionnaire is a self-reporting with high internal consistency and reliability coefficient value of alpha 0.78 (American Medical Association, 2011).

Aim of the present study is to examine the caregiver's burden among caregivers of children with developmental disability and to compare the burden of caregivers in terms of age groups and gender.

## Methodology

**Participants:** All caregivers who were under institutional rehabilitation were included in this study. This study was approved by institutional ethical committee. From the period of October

2020 to March 2021, 30 caregivers of 30 differently abled children's who were under developmental therapy in child developmental center in Saveetha medical college and hospital, Chennai, India, were asked to participate in the study through telephonic interview. Informed consent was obtained from all participants after explaining them about the procedure and need for the study.

**Selection criteria:** Primary caregiver of differently abled individuals of both male and female, caregivers of children under institutional rehabilitation, caregivers of differently abled individuals age from 0-12, and caregiver's who were willing to participate were enrolled in this study. Exclusion criteria: Caregivers who were under home quarantine due to COVID19, caregivers of child with traumatic brain injury and with any type of fractures were excluded.

**Procedure:** 30 caregivers were explained about the caregiver self-assessment questionnaire and participants were participated through telephonic interview. Scoring was done based on the method given in the questionnaire. In caregiver self-assessment questionnaire there were 18 items with yes/no type of questions, it is a reliable and valid tool used to measure the mental state, burden or stress and health status of the caregivers of differently abled children. Data collected were compared with caregivers of male and female differently abled child and also with the different age group.

## Results

A total 30 caregivers of 30 differently abled children under institutional rehabilitation were included. Among 30 caregivers, 26 were primary parents and 4 were grandparents. The demographic of the included caregivers with mean CSAQ and their children age groups were shown in **Table 1**. Items in the questionnaire were interpreted to analyze the COVID19 related stress, burden, and health status. Based on post-test comparison of caregivers of male and female differently abled child (Figure 1) and also with the different age group (Figure 2).

In the present study, the caregiver burden significantly varied between the differently abled children of different age groups and parents of female children were tend to be more burdened than parents of male children due to additional effort taken to prevent child abuse. Based on the age groups the pre-school group (3 - 5years) parents had shown to have increased burden (mean= 10) due to additional physical effort taken during transport and they were partially are completely dependent for ambulation, however the school (mean= 8.75) and toddler (mean= 6.57) age group parents faced difficulties in decision making, additional physical efforts, or reduced personal time and finally, the infant (mean= 5.57) age group parents scored the lowest scores in facing burden when compared with other age group parents.

The stress status and health status were measured in a Likert scale format as mentioned in CSAQ. The mean stress scores among parents of female children (8) were much higher than parents of male children (5.73), however the mean health status scores among parents of female children (7.18) were also significantly higher than parents of male children (4.52) indicating increased stress and poor self-health care among parents of female children. Based on the age groups the pre-school group had shown to have increased stress scores (mean= 7.37) and poor health status (mean= 7.25), the school group experienced moderate stress (mean= 7) and health status (mean= 6.25), the toddler group had stress scores of (mean= 6.28) and health status of (mean= 4.42), and the infant age group scored the lowest scores in stress (mean= 5.28) as well as health status (mean= 3.57) when compared with other age groups.

## Discussions

Impact of the COVID-19 on caregiver burden must be assessed along with the patient assessment since parents are the only person in childhood rehabilitation team who continuously stays with the children and engaging them to achieve the rehabilitation goal (Chandolias, K et al., 2020). Due to limited external support, the differently abled children were completely depended on the parents for all personal and health needs (Hassall et al., 2005). This study is an initial attempt to understand the caregiver burden, stress and health status among parents of differently abled children of different age group.

The result shows significant difference between parents of male and female children in terms of the caregiver burden, stress, and health status. With the mean scores, it is revealed that most of the parents experience similar stress indicating stress as the common symptom among parents of differently abled children, but the health status and burden among parents of female children were higher than that of parents of male children due to additional physical effort and poor self-health care, risk of child abuse, increased emotional and psychological disturbances, which is similar to the study done by Govindshenoy & Spencer (2007).

While comparing the age groups, the parents of pre-school age group shown to have poor health status and stress due to the process of socialization and transportation their own physiological changes, and decline in their musculoskeletal ability of the child to achieve function which are common among peer age group resulting in increased burden (Dabrowska & Pisula, 2010). The school group also shown

to have increased burden, stress, and poor health status due to parents having lack of social experience, poor decision making, loss of personal time, and difficulty in managing family and job status simultaneously (Kuhlthau et al., 2010). However, the infant age group shown to be lowest in burden, stress, and health status when compared with other age groups, this might be due to the positive attitude of parents towards the growth and development, easy to carry and transport (Shonkoff et al., 1992). Though this age group is shown to be better among the groups compared, they weren't completely rid of burden and experiences burden in certain time.

Similar to previous study (Amirkhanyan & Wolf, 2003) on caregivers of children with intellectual disability the mean scores revealed that caregivers experience poor health care, lack of personal time and work time, and stress about the child's future. Stress level has been increased during COVID19 while taking care of the children with developmental disability parents tend to forget about their health status (Masefield et al., 2020). In contrast to these, a study analyzed the stress level of both caregivers as well as developmentally delayed children (Kim et al., 2020) and also need for the social, family and financial support to raise the developmentally differently abled children (Leonard et al., 1992). Family members of differently abled children face stress in social but the mothers of differently abled children face more stress compared to that of the other members in the family this may be due to difference in taking care of individual, gender and cultural norms of Indian population. Despite the norms, parents take responsibility in taking care of their child and they play a major role during assessment and rehabilitation. Thus, care-giving hours plays a vital role in determining the burden, stress and health status of the parents of differently abled children (Plant & Sanders 2007).

The present research suggests that the caregiver burden, stress, and health status play an important role in rehabilitation of differently abled children and it is essential to plan interventions to tackle them. Small sample size, single center study, and unequal sample distribution between the gender and age groups were considered to be limitations of this study. As this study is the first study to describe the burden among parents of differently abled children in India, future researches focusing on parental needs and their quality of life with large sample size and multicenter involvement will be beneficial for parents of differently abled children.

### **Conclusions**

The parents of differently abled children experiences burden, stress, and health issues in common. However, the burden symptoms vary greatly in different age groups and gender.

Parents of female children were shown to have increased burden, stress, and health issues than parents of male children. Similarly, pre-school age group also experience increased burden. Differently abled children were completely dependent on their parent for every functional and physiological needs; thus, parent's health status is directly associated with the health status of the patients.

Parents play a vital role in rehabilitation and progression of treatment follow up in children with disability; decline in their health also inversely have an impact on health status of the caregivers. Our team is working out with home-based exercises facilitated through tele consultation and handouts to reduce the possible impact of COVID19 on these children and caregivers.

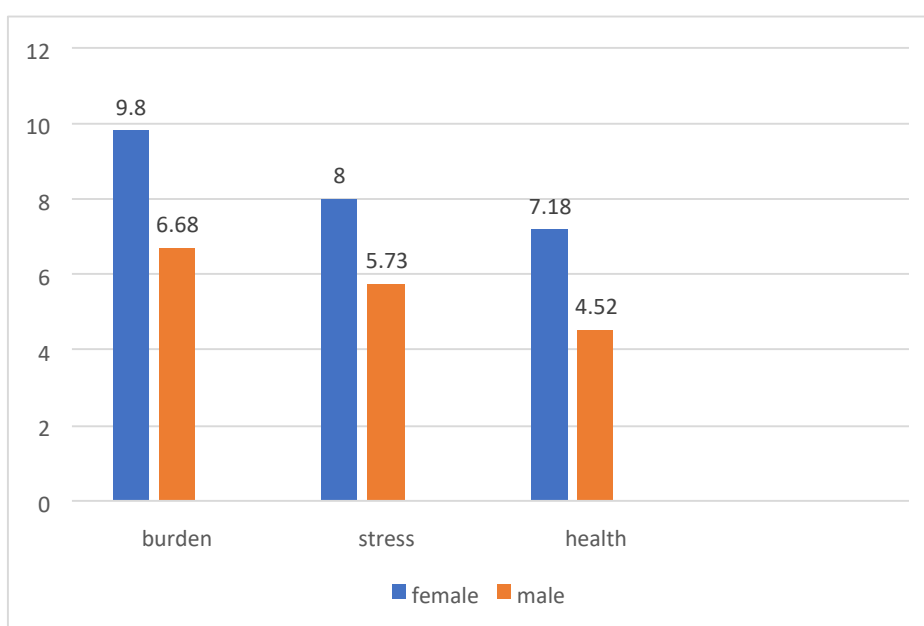
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**Table 1:** Demographic of the included caregivers with mean CSAQ and their children age groups

Age group	Male child	Female child	Mean CSAQ scores	Mean stress scores	Mean health status
Infant	6	1	5.57	5.28	3.57
Toddler	5	2	6.57	6.28	4.42
Pre-school	3	5	10	7.37	7.25
School	5	3	8.75	7	6.25

**Figure 1:** Comparing burden, stress and health of parents during COVID19 of male and female child.



**Figure 2:**

Comparing the mean values of post lockdown CSAQ score of different age groups.

