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

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Abstract

During the COVID-19 outbreak, parents of children with developmental disabilities were forced to suspend institutional rehabilitation sessions, exacerbating caregiver burden and adversely affecting mental health. The Caregiver Health Self-Assessment Questionnaire can help identify psychological distress and health risks among these caregivers. This study aimed to examine the impact of COVID-19 on parents of children with developmental delays and to compare caregiver burden, stress, and health status across parent gender and child age groups. From October 2020 to March 2021, we conducted telephonic interviews with 30 caregivers whose children were enrolled in developmental therapy at the Child Development Center, Saveetha Medical College and Hospital. We assessed caregiver burden, stress, and health status using standardized questionnaire scores. Overall, parents of female children reported higher mean stress (8.00) and health-status (7.18) scores than parents of male children (stress = 5.73; health status = 4.52). When stratified by child age, caregivers of preschool-aged children exhibited the highest burden (mean = 10.00) and stress (mean = 7.37). Those caring for school-aged (burden = 8.75; stress = 6.28) and toddler-aged children (burden = 6.57; stress = 7.00) reported intermediate scores, while caregivers of infants experienced the lowest burden. These findings confirm that caring for children with developmental disabilities during the pandemic imposes significant psychological and physical strain. Because these children rely entirely on their caregivers for activities of daily living, declines in child health are mirrored by deteriorations in caregiver well-being. To mitigate these impacts, our team has developed a home-based exercise program delivered via teleconsultation and supplemented with instructional handouts.

Keywords

Family caregiver, Developmental therapy, Burden, Caregiver

Introduction

Due to the COVID-19 pandemic, all individuals were affected physically and mentally, with caregivers being the ones 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). The COVID-19 pandemic

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leads to reduced transport facilities, and other causes lead parents of differently abled children to quit their institutional rehabilitation sessions as a result.

Developmental delay refers to a delay in developmental milestones (gross motor, fine motor, language, and social-cognitive) compared to that of the prior group. These occur 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 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 milestones for age and independence in ADL (Agarwal & Sharma, 2002). Many factors lead to a depressing experience on the caregiver's mental stress, burden, and health status. A major factor is delayed developmental milestones in children, and also a decline in their health, which inversely affects the health status of the caregivers (Yue et al., 2018). In addition to this, COVID-19 increased the stress level in all individuals (Russell et al., 2020). The 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 that assesses caregivers' 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). The caregiver self-assessment questionnaire is a self-reporting instrument with high internal consistency and a reliability coefficient value of alpha 0.78 (American Medical Association, 2011).

The present study aims 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 whose children were receiving institutional rehabilitation were included in this study. Ethical approval was obtained from the institutional ethics committee. Between October 2020 and March 2021, a total of 30 caregivers of 30 differently abled children undergoing developmental therapy at the Child Development Center, Saveetha Medical College and Hospital, Chennai, India, were invited to participate. Data collection was conducted through telephonic interviews. Informed consent was obtained from all participants after explaining the purpose and procedure of the study.

Inclusion criteria included:

- Primary caregivers (male or female) of differently abled children aged 0–12 years
- Caregivers whose children were receiving institutional rehabilitation
- Caregivers who were willing to participate in the study

Exclusion criteria included:

- Caregivers who were under home quarantine due to COVID-19
- Caregivers of children with traumatic brain injury or any type of fracture

Procedure

All 30 caregivers were briefed on the Caregiver Self-Assessment Questionnaire (CSAQ), and telephonic interviews were conducted accordingly. Scoring was performed based on the guidelines provided in the CSAQ. The CSAQ consists of 18 yes/no items and is a valid and reliable tool used to measure mental health status, caregiver burden, and stress among caregivers of differently abled children.

Data were analyzed by comparing the burden, stress, and health status of caregivers based on the child's gender and age group.

Results

A total of 30 caregivers of 30 differently abled children receiving institutional rehabilitation were included. Among them, 26 were parents, and 4 were grandparents serving as primary caregivers. Demographic characteristics, caregiver CSAQ scores, and child age groups are presented in Table 1. The CSAQ responses were analyzed to determine the caregivers' stress, burden, and health status in relation to the COVID-19 pandemic. Comparisons were made based on the gender of the children (Figure 1) and age groups (Figure 2).

Table 1. Demographics of the included caregivers with mean CSAQ and their children's 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

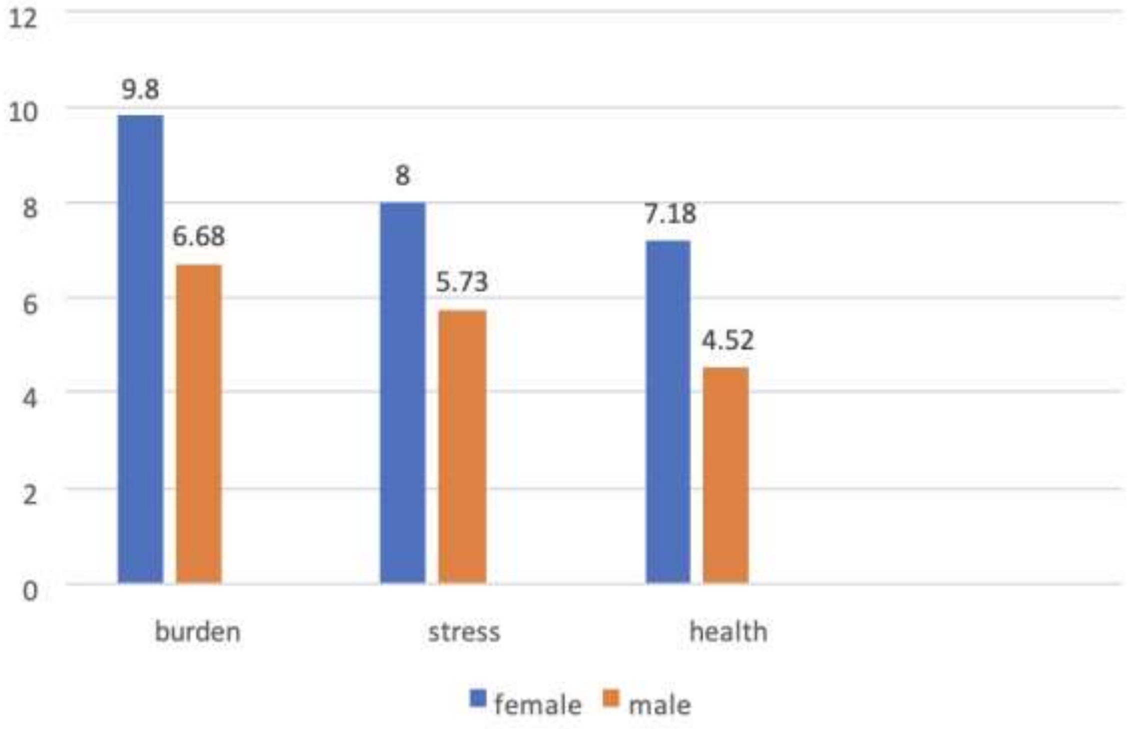

Figure 1. Comparing the burden, stress, and health of parents during COVID-19 of male and female children.

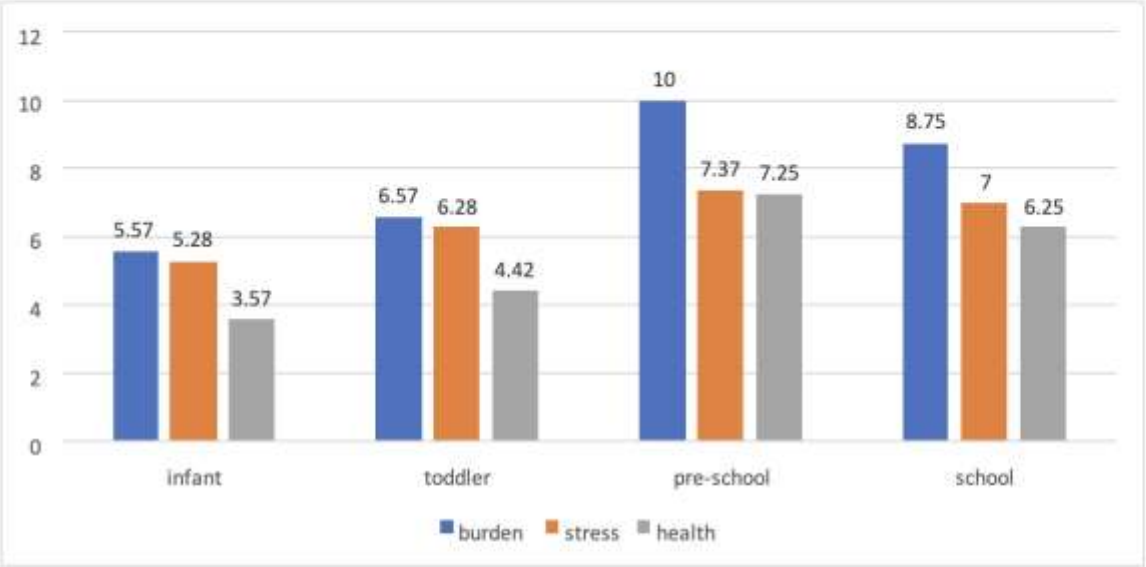

Figure 2. Comparing the mean values of the post-lockdown CSAQ score of different age groups.

The results indicated that caregiver burden significantly varied across different age groups of children. Parents of female children reported higher levels of burden than those of male children, potentially due to heightened concerns around child protection. Among the age groups, parents of preschool-aged children (3–5 years) experienced the highest burden (M = 10.00), largely due to the physical demands of transporting and assisting children who were partially or fully dependent for mobility. Parents of school-aged children (M = 8.75) and toddlers (M = 6.57) also reported elevated levels of burden, primarily due to decision-making challenges, physical demands, and reduced personal time. Caregivers of infants experienced the lowest burden (M = 5.57).

Stress and health status were measured using the Likert-scale format of the CSAQ. Parents of female children reported higher mean stress scores (M = 8.00) compared to parents of male children (M = 5.73). Similarly, health status scores were higher among parents of female children (M = 7.18) than male children (M = 4.52), indicating greater psychological strain and poorer self-care among caregivers of girls.

When analyzed by child age group, caregivers of preschool-aged children reported the highest stress (M = 7.37) and poorest health status (M = 7.25). School-aged children's caregivers experienced moderate stress (M = 7.00) and health status scores (M = 6.25). Toddler caregivers reported stress and health status scores of M = 6.28 and M = 4.42, respectively. Infant caregivers had the lowest scores for both stress (M = 5.28) and health status (M = 3.57), suggesting less impact relative to caregivers of older children.

Discussions

The impact of COVID-19 on caregiver burden must be assessed alongside patient outcomes, as parents are the only members of the rehabilitation team who remain consistently involved in a child's care, particularly during early intervention (Chandolias et al., 2020). With limited access to external support, children with developmental disabilities became entirely dependent on their parents for personal and healthcare needs (Hassall et al., 2005). This study serves as an initial attempt to explore caregiver burden, stress, and health status among parents of differently abled children across various age groups.

The results revealed significant differences in caregiver burden, stress, and health status based on the gender of the child. While stress levels were relatively consistent across participants indicating that stress is a common symptom among all caregivers parents of female children reported significantly higher burden and poorer health status compared to those of male children. This increased burden may be attributed to additional physical demands, heightened concerns about child abuse, emotional distress, and neglect of self-care. These findings align with previous research by Govindshenoy and Spencer (2007).

When comparing caregiver responses across age groups, parents of preschool-aged children exhibited the highest levels of burden and stress. This may be due to the demands of social integration, transportation challenges, the caregivers' own physiological limitations, and the lag in the child's motor development relative to peers (Dabrowska & Pisula, 2010). Similarly, parents of school-aged children reported elevated stress and health issues, likely due to the pressure of managing academic expectations, reduced personal time, lack of decision-making support, and difficulties balancing family responsibilities and employment (Kuhlthau et al., 2010). In contrast, caregivers of infants reported the lowest levels of burden, stress, and health issues, possibly due to more optimistic perceptions of the child's growth potential and the ease of physically handling infants (Shonkoff et al., 1992). However, even this group was not free from caregiving challenges.

Consistent with prior studies (e.g., Amirkhanyan & Wolf, 2003), caregivers of children with intellectual disabilities often experience poor self-care, reduced personal and professional time, and anxiety about the child’s future. The COVID-19 pandemic has intensified these concerns, as caregivers frequently neglected their own health while focusing on the needs of their children (Masefield et al., 2020). Kim et al. (2020) further emphasized the dual stress experienced by both caregivers and children, highlighting the need for social, familial, and financial support (Leonard et al., 1992). Mothers, in particular, tend to experience more stress than other family members, likely due to cultural norms and caregiving expectations in the Indian context. Regardless of these challenges, parents play a central role in both assessment and rehabilitation, and the number of caregiving hours is closely associated with levels of burden, stress, and health deterioration (Plant & Sanders, 2007).

This study underscores the critical role of caregiver well-being in the rehabilitation process. Interventions that address caregiver stress, burden, and health must be prioritized. Limitations of the current study include a small sample size, single-center design, and unequal distribution by gender and age groups. As the first study of its kind in India to explore these variables, future research should aim to include larger, more diverse samples across multiple centers, with a focus on parental needs and quality of life.

Conclusions

Parents of differently abled children commonly experience high levels of burden, stress, and health-related challenges. However, these symptoms vary notably by the gender and age group of the child. Parents of female children, in particular, face greater stress and poorer health outcomes than those of male children. Similarly, caregivers of preschool-aged children report a higher burden than those caring for infants or toddlers.

Given the complete dependency of differently abled children on their caregivers for daily functional and physiological needs, the health status of the parent is directly linked to the child’s rehabilitation progress. Parental well-being plays a pivotal role in treatment adherence and outcomes.

To mitigate the effects of the COVID-19 pandemic, our team has introduced home-based exercise programs, supported through teleconsultation and educational handouts, aimed at reducing caregiver burden and supporting the developmental progress of these children.

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