Navigating the Dual Realities of Caregiving: A Cross-Sectional Analysis of Parental Stress and Caregiver Burden in Families of Children with Down Syndrome

Dr. Chhaya Akshay Divecha
Associate Professor (Pediatrics), College of Medicine and Health Sciences, National University, Oman

Miriam Simon
College of Medicine and Health Sciences, National University, Oman

Wajud Al-Shibli
College of Medicine and Health Sciences, National University, Oman

Jenan Al-Omrani
College of Medicine and Health Sciences, National University, Oman

Abstract:

Background: The long-term management of children with Down syndrome requires significant parental involvement, often impacting the psychological well-being of the primary caregivers. This study evaluates the relationship between parental stress and caregiver burden to inform pediatric healthcare strategies.

Methods: A cross-sectional study was conducted with 250 parents (Mean age: 45.65 years) of children with Down syndrome (Mean age: 6.81 years). Validated instruments, including the Parental Stress Scale (PSS) and the Zarit Caregiver Burden Assessment, were utilized to quantify experiences. Data were analyzed using non-parametric tests (Kolmogorov-Smirnov, Spearman's correlation, and Kruskal-Wallis) due to non-normal distribution

Results: The study results revealed a unique psychological landscape where participants experienced moderate levels of parental stress (Mean = 56.18, SD = 3.23) alongside notably mild levels of caregiver burden (Mean = 13.01, SD = 11.95). A significant negative correlation between these variables (r_s = -.209, $p < .001$) suggests a "psychological paradox" wherein parents feel overwhelmed by the responsibilities and time demands of their role without necessarily perceiving the child as a personal burden. Nearest neighbor analysis further clarified these experiences, identifying that parenting stress is primarily driven by emotional discomfort and a lack of personal time, while caregiver burden is more closely tied to parenting satisfaction and the physical energy demands of care. Interestingly, demographic factors such as parent gender, employment status, and the child's gender did not significantly influence these outcomes. However, satisfaction with multidisciplinary rehabilitative services—specifically physical, speech, and occupational therapies—emerged as a critical factor in the caregiving experience.

Conclusion: The findings highlight a unique scenario where high parental stress coexists with mild caregiver burden, likely mediated by parental resilience and cultural coping mechanisms. Effective

pediatric healthcare must move beyond clinical treatment to include robust social support and accessible multidisciplinary therapies to mitigate parental stress and foster positive adaptation in families.

Keywords:
Pediatrics, Down Syndrome, Parental Stress, Caregiver Burden, Child Health, Rehabilitative Services.