Impact of Care Dependency on the Quality of Life of Caregivers of Children with Special Needs, Jaffna, Sri Lanka

S. Sasrubi[1]*, L.B.T.C. Lokubalasuriya[2], S. Kumaran[1]

[1]*Department of Community & Family Medicine, Faculty of Medicine, University of Jaffna, Jaffna, 40000, Sri Lanka*
[2]*Department of Disability Studies, Faculty of Medicine, University of Kelaniya, Ragama, 11010, Sri Lanka*
**sasrubi@univ.jfn.ac.lk*

Caring for children with special needs place physical, psychological, social, and financial demands on caregivers, which may negatively affect their quality of life. This study aimed to assess the impact of care dependency of children with special needs on the quality of life of their caregivers. A cross sectional study was carried out among caregivers of students studying in special education units in thirty three Government schools of Jaffna, Sri Lanka. Information regarding children's dependency on mobility support, medication use, and assistive devices was collected. Quality of life of physical health, psychological health, social relationships, and environment of caregivers was assessed using the WHOQOL-BREF questionnaire, which is cross culturally validated in Tamil Language also. Data were analyzed using SPSS (V27.0). One-way ANOVA and independent sample *t* test were used to identify the mean differences in quality of life. A p-value of <0.050 was considered statistically significant. Three hundred and fifty-four caregivers participated in the study. Mean age of caregivers was 42.6 years (±6.95). Most caregivers were aged between 41-60 years (57.9%), mothers (72.0%), and received support from spouses in caregiving (94.4%). Mean age of students was 11.55 years (±3.09), and the majority were males (65.3%). Major clinical diagnoses were Down syndrome (18.4%), autism spectrum disorder (18.1%), specific learning disability (13.8%), and global developmental delay (10.5%). Overall mean quality of life score among caregivers was 12.01 ± 1.2 out of 20. Among the four domains, the highest mean score was observed in the physical domain (12.2 ± 1.2), followed by the psychological domain (12.2 ± 1.5), the environmental domain (12.1 ± 1.2), and the social domain (11.5 ± 1.9). Poorer quality of life across all domains was observed among caregivers of children who were dependent on medication and assistive devices, with statistically significant associations identified ($p < 0.050$). In addition, caregivers of children requiring mobility support demonstrated significantly lower scores in the physical health domain. However, age, gender, and type of disability of the students were not significantly associated with the caregivers' quality of life. These findings highlight the need for family centered interventions focusing on reducing caregiving burden of caregivers of children with special needs.

Keywords: quality of life, caregivers, special education, WHOQOL-BREF, Sri Lanka