

A Study to Assess the Quality of Life and Lived-in Experiences Among Caregivers of Differently Abled Persons in Selected Special Schools in Kannur District

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Abstract: **Background:** Caregivers of differently abled persons play a crucial role in providing continuous physical, emotional, and social support. However, the burden of caregiving often affects their quality of life (QoL) and overall well-being. Assessing QoL and lived-in experiences is essential to understand their challenges and provide appropriate interventions. **Aim:** To assess the quality of life and lived in experiences among caregivers of differently abled persons and to determine the factors associated with quality of life. **Methodology:** Mixed methodology a study to scrutinize the research subject. Purposive sampling technique was used for the data collection. 30 samples were taken. 15 samples from Buds Special School, Chundayil and 15 samples from Snehatheeram Buds School, Dharmasala. Out of 30 samples, 5 samples taken for qualitative research. Baseline data was elicited using sociodemographic tool and informed consent was obtained from the samples. Data collection was done by providing WHO Quality of life questionnaire to the samples. Lived in experience was collected by using structured interview questionnaire through audio recordings from the samples. **Results:** The results reveals that social domain has highest mean score of 51.67 ± 32.53 , followed by psychological domain 50.41 ± 35.48 , environmental domain 48.23 ± 4.98 and physical domain 48.21 ± 32.53 . Majority of the caregivers scored moderate quality of life. Significant association was found between marital status, relation with child and socioeconomic status in physical domain, in psychological domain there is significant association between religion, relation with child, number of children, socio economic status, in social domain there is significant association between type of family and marital status, and in environmental domain there is significant association between age and relation with child. **Conclusion:** Through this study we find out that majority of the caregivers have moderate quality of life. Our study indicates that caregivers of differently abled children in Kannur's Buds schools experience a moderate quality of life, highlighting both the resilience of these individuals and the significant challenges they face. These findings underscore an urgent need for targeted support systems and respite care programs to alleviate their caregiving burden and enhance their overall well-being. The findings suggest that the caregivers also need emotional and psychological support to strengthen up their mental health.

Keywords: *Quality of life, Lived in Experience, Differently Abled Person, Caregivers.*

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I. INTRODUCTION

Caregivers of differently abled persons are essential contributors to the health and well-being of individuals with disabilities. They provide continuous care, including assistance with daily activities, medical care, emotional support, and social integration.

Despite their vital role, caregiving often leads to physical exhaustion, emotional stress, financial burden, and social isolation. The long-term nature of caregiving responsibilities significantly impacts the caregiver's quality of life (QoL), which includes physical health, psychological well-being, social relationships, and environmental factors.

In India, disability remains associated with stigma and limited access to support systems, increasing caregiver burden. Therefore, understanding the quality of life and lived experiences of caregivers is important for developing effective support strategies.

II. REVIEW OF LITERATURE

A mixed study was conducted by Swathi V Koramboor and Rajasi (2025) among 115 primary caregivers in Kozhikode, Kerala, using a mixed-methods approach to evaluate their quality of life (QOL). The quantitative analysis utilizing the WHOQOL-BREF scale revealed that caregivers of differently abled children scored significantly lower across all domains compared to caregivers of typically developing children. Specifically, the psychological domain was the most severely impacted with a mean score of 59.86 ± 19.45 .

A mixed-method study conducted by Karni-Visel Y, Roth D, Lev S, and Werbeloff N in 2025 in Israel investigated the quality of life and mental health in families of 408 parents caring for children with developmental disabilities during wartime, using an online survey that included standardized quantitative measures and qualitative responses to evaluate family quality of life (FQoL). Overall, the study concluded that wartime conditions are significantly associated with adverse impacts on both mental health and quality of life for families raising children with developmental disabilities, emphasizing the importance of resource availability and support systems in mitigating these effects.

III. METHODOLOGY

- Research Approach: Mixed method approach
- Research Design: Qualitative strand: Phenomenological
- Quantitative strand: Descriptive cross sectional design
- Setting: Snehatheeram Buds School, Dharmasala
- Buds Special School, Chunda
- Population: Caregivers of differently abled persons
- Sample Size: 30 samples (30 quantitative, 5 qualitative)
- Sampling Technique: Purposive sampling
- Data Collection Tools: Demographic tool, WHOQOL-BREF Questionnaire, Semi Structured interview
- Data Analysis:
 - Descriptive Statistics: Frequency, percentage, mean, standard deviation
 - Inferential Statistics: chi-square test
- Qualitative data: Thematic analysis

- Ethical Consideration: Ethical clearance and formal permission were obtained from the administrative authority of both schools.

IV. FINDINGS AND ANALYSIS

A. Socio-Demographic Findings

- Majority of caregivers were mothers
- Most were married
- Many belonged to upper lower class
- Majority of the caregivers belongs to the age group of 41-50 years

B. Quality of Life Findings

- Majority of the caregivers had moderate quality of life

Table 1 Quality of Life Findings

DOMAIN	MEAN	SD
Physical	48.213	32.53
Psychological	50.416	35.48
Social	51.667	47.63
Environmental	48.231	4.98

C. Association Findings

There is a significant association between marital status, relation with the child and socioeconomic status with quality of life among caregivers in physical domain. There is a significant association between religion, relation with the child, no of children and socioeconomic status with quality of life among caregivers in psychological domain. There is a significant association between marital status and type of family with quality of life among caregivers in social domain. There is a significant association between age in years and relation with the child with quality of life among caregivers in environmental domain.

D. Lived-in Experiences

Themes identified: After data analysis 5 themes were extracted physical domain, psychological domain, social domain, financial domain and environmental domain. Majority of the participants reported physical strain, ineffective role performance, low self-esteem, emotional distress, disturbed social life, job related issues safety concerns, dependency, poor living condition, decreased accessibility of healthcare services, lack of support and increased cost of treatment. They reported of going through a lot of psychological distress.

The first theme was physical domain. They expressed feelings of lack of sleep, worries about health, caregiving burden, physical exhaustion, self neglect. The second theme was psychological domain. The caregivers expressed hopelessness, helplessness, unable to cope, sadness, anxiousness, worries, blame, criticism and isolation. The third theme was social domain. The caregivers expressed feelings of being socially discriminated, facing socially embarrassed situations because of the child, constant supervision and voluntary resignation of job. Fourth theme was environmental domain. The caregivers felt difficulties in transportation, long distance to therapy centers and poor

living conditions. The fifth domain was financial domain. The caregivers expressed no financial help and increased treatment cost.

V. DISCUSSION

The study findings indicate that caregivers experience moderate quality of life, with significant challenges in physical and psychological domains. The psychological burden and social stigma remain major concerns. Caregivers require emotional support, counseling, and better access to healthcare services. National studies also supported the present findings. A mixed study conducted by Swathi Koramboor and Rajasi (2025) among 115 primary caregivers in Kozhikode, Kerala revealed that the main themes abstracted from the focussed group discussion were of psychological issues, physical health issues, child related issues, social issues, financial issues and government and scheme related issues.

VI. CONCLUSION

The study concludes that caregivers of differently abled persons face multiple challenges affecting their quality of life. Most caregivers experience moderate QoL, with significant emotional, social, and financial difficulties.

Improving caregiver well-being requires:

- Psychological support programs
- Financial assistance
- Community awareness
- Strengthening healthcare services

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