

Original Research Article

QUALITY OF LIFE AMONG CAREGIVERS OF DISABLED CHILDREN ATTENDING DISTRICT EARLY INTERVENTION CENTRE IN A TERTIARY CARE HOSPITAL, THIRUVALLUR : A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Caregivers of children with disabilities attending District Early Intervention Centers (DEICs) often bear substantial physical, psychological, social, and financial burdens that may compromise their quality of life (QoL). The objective is to assess the Quality of life (QoL) of caregivers of children with disabilities attending DEIC.

Materials and Methods: A cross-sectional study was conducted among 194 primary caregivers of children attending the DEIC in a tertiary care Hospital. QoL was assessed using the interviewer-administered WHOQOL-BREF questionnaire. Data were collected using a semi-structured proforma capturing sociodemographic and financial-burden variables.

Results: The mean age of caregivers was 32.12 ± 6.66 years; 89.7% were female and most were housewives. The commonest disabilities were Autism Spectrum Disorder (12.9%), Developmental Delay (11.9%), and ADHD (11.3%). Mean WHOQOL-BREF domain scores were: Physical Health 49.69 ± 9.21 , Psychological Health 47.23 ± 11.96 , Social Relationships 44.37 ± 14.58 , and Environment 44.39 ± 9.96 , with an overall QoL score of 46.42 ± 8.86 . All four domains correlated positively with overall QoL (Spearman's rho 0.730–0.873, $p < 0.001$), most strongly the Environment domain. Male caregivers reported significantly higher scores than female caregivers across all domains ($p < 0.05$), caregivers aged >30 years scored higher on the Environment domain ($p = 0.013$), and Social Relationship scores varied significantly by educational status ($p = 0.007$). 64.3% reported reduced work hours, job change, or unemployment due to caregiving.

Conclusion: Caregivers of children attending the DEIC experienced moderate overall QoL, with the greatest impairment in the social and environmental domains, and considerable financial strain.

Keywords: Quality of life, Children with disabilities, WHOQOL-BREF, DEIC.

INTRODUCTION

The Centers for Disease Control and Prevention define disability as any impairment of body or mind that makes it more difficult for a person to perform certain activities and to interact with the world around them.^[1] In children, long-term cognitive, mobility, visual, auditory, and behavioural impairments may arise from genetic disorders,

perinatal or acquired brain and spinal cord injury, nutritional deficiencies, infections, and environmental exposures, with additional psychological morbidity precipitated by associated stressful life events.^[1]

The World Health Organization defines Quality of life (QoL) as an individual's perception of their position in life in the context of the culture and value systems in which they live, in relation to their goals,

expectations, standards, and concerns — a construct shaped by physical and psychological health, personal beliefs, social relationships, and the environment. Raising a child with a lifelong disability imposes sustained financial, emotional, and physical demands that can substantially erode this perceived QoL among caregivers.^[1]

Disability is a major public health concern globally. An estimated one in four adults (26%) in the United States lives with a disability, and more than one billion people — approximately 15% of the world's population — live with some form of disability. The World Health Survey estimates roughly 785 million adults above 15 years live with a disability, while the Global Burden of Disease study, the only source of comparable childhood (0–14 years) estimates, suggests that around 13 million of 95 million children (5.1%) live with severe impairment. Given demographic shifts and the rising burden of chronic illness, the impact of childhood disability — and consequently on caregivers — is expected to grow.^[1] Caregiving for a child with disability is consistently associated with psychological and physical strain that lowers caregiver QoL. In an early study among parents of children with disabilities, Leung and Li-Tsang reported that parents of children with more severe disabilities scored significantly worse on the social relationships and environmental domains of QoL, with the physical demands of caregiving proposed as a key contributor to this burden; because caregiver well-being can, in turn, influence the care a child receives, supporting caregivers has been framed as integral to supporting the child.^[2]

District Early Intervention Centers (DEICs), established under the Rashtriya Bal SwasthyaKaryakram (RBSK) in India, provide medical, therapeutic, and educational support aimed at improving developmental outcomes for children with disabilities. However, despite access to these services, the caregivers who bring children to DEICs for repeated visits and long-term follow-up may themselves carry a substantial and under-recognized burden. Understanding the magnitude and correlates of this burden among DEIC caregivers is essential to inform caregiver-directed policies and support systems, yet Indian data specific to DEIC settings remain sparse.^[3,4] This study was therefore conducted to assess the QoL of caregivers of children with disabilities attending a DEIC in Tamil Nadu and to identify the major physical, emotional, financial, and social burdens they face.

Objectives

1. To assess the quality of life of caregivers of disabled children attending the DEIC.
2. To identify the major physical, emotional, financial, and social burdens faced by these caregivers.

MATERIALS AND METHODS

Study design and setting: This was a cross-sectional observational study conducted at the District Early

Intervention Center (DEIC) attached to the Government Medical College Hospital, Thiruvallur, Tamil Nadu, India over a period of one year.

Study population: Primary caregivers (parents, guardians, or other family members) of children with disabilities attending the DEIC who fulfilled the eligibility criteria below were enrolled after obtaining Institutional Ethics Committee approval and written informed consent.

Inclusion Criteria

1. Primary caregivers (parents, guardians, or family members) of children with disabilities attending the DEIC.
2. Caregivers who had been providing care for at least six months.
3. Caregivers aged 18 years and above.
4. Caregivers willing to participate and provide informed consent.

Exclusion Criteria

1. Professional caregivers (e.g., paid nurses or institutional staff).
2. Individuals with severe cognitive impairment or mental health conditions that could interfere with participation.
3. Caregivers who had recently participated in similar studies, to avoid survey fatigue.

Eligible caregivers presenting to the DEIC during the study period were enrolled [using a purposivesampling technique] until the study period ended.

Study tool: QoL was assessed using the WHOQOL-BREF instrument, a 26-item abbreviated version of the WHOQOL-100 covering four domains — Physical Health, Psychological Health, Social Relationships, and Environment.^[5] Items are rated on a 5-point Likert scale (1 = very dissatisfied/very poor to 5 = very satisfied/very good). Raw domain scores (possible ranges: Physical Health 7–35 from 7 items, Psychological Health 6–30, Social Relationships 3–15, Environment 8–40) were transformed to a standardized 0–100 scale using the WHO-recommended conversion formula, with higher scores indicating better QoL. A semi-structured questionnaire was additionally used to capture sociodemographic characteristics, the child's primary medical condition, and financial-burden indicators related to caregiving.

Statistical analysis: Data were entered in MS Excel 2019 and validated by checking for infeasible values and typographical errors before analysis in IBM-SPSS version 16.0. Categorical variables were summarised as frequencies and percentages, and continuous variables as mean $\pm$ standard deviation (normally distributed) or median with interquartile range (non-normally distributed). The internal consistency of the WHOQOL-BREF domains was assessed using Cronbach's alpha. Normality of domain scores was assessed using the Shapiro–Wilk test; as none of the four domains were normally distributed, non-parametric tests were used throughout — the Mann–Whitney U test for two-group comparisons (sex, age group), the Kruskal–

Wallis test for comparisons across more than two groups (educational status), and Spearman's rank correlation to assess the association between each domain score and overall QoL. A two-tailed p-value <0.05 was considered statistically significant throughout.

RESULTS

Sociodemographic profile of study participants: A total of 194 caregivers were included in the study. The mean age of participants was 32.12 ± 6.66 years,

and more than half (54.6%) were aged 30 years or older. The overwhelming majority of caregivers were female (89.7%), and most were housewives by occupation. Regarding educational status, the largest proportion had completed secondary school (59.8%), while 3.6% had no formal education [Table 1].

Primary medical condition of children: Autism spectrum disorder was the commonest primary condition among the children of enrolled caregivers (12.9%), followed by Developmental delay (11.9%), Attention-deficit/Hyperactivity disorder (11.3%), Growth disorders (8.8%), and Cerebral palsy (6.7%) [Table 2].

Table 1: Sociodemographic characteristics of caregivers (N = 194)

Characteristic	Frequency (n)	Percentage (%)
Age group		
<30 years	88	45.4
≥30 years	106	54.6
Sex		
Male	20	10.3
Female	174	89.7
Marital status		
Married	191	98.5
Living as married	2	1.0
Widowed	1	0.5
Educational status		
No formal education	7	3.6
Primary school	18	9.3
Secondary school	116	59.8
Undergraduate	28	14.4
Diploma	10	5.2
Tertiary	8	4.1
Postgraduate	7	3.6

Table 2: Primary medical condition of the children (N = 194)

Primary medical condition	Frequency (n)	Percentage (%)
Autism spectrum disorder	25	12.89
Developmental delay (incl. GDD)	23	11.86
Growth disorders	17	8.76
Attention-deficit/hyperactivity disorder	22	11.34
Cerebral palsy	13	6.70
Speech and language delay	8	4.12
Congenital heart disease/cardiac disorders	12	6.19
Dental disorders	10	5.15
Visual disorders	9	4.64
Hearing disorders	8	4.12
Down syndrome	4	2.06
Malnutrition/underweight/SAM	5	2.58
Hemophilia	3	1.55
Endocrine disorders	4	2.06
Muscular dystrophy	3	1.55
Learning disability	2	1.03
Thalassemia	1	0.52
Others	7	3.61

Overall quality of life and general health satisfaction: The mean overall quality of life score

was 46.42 ± 8.86 , and the mean general health satisfaction score was 47.49 ± 13.62 [Table 3].

Table 3: Overall quality of life and general health satisfaction

Variable	Mean ± SD
Overall quality of life	46.42 ± 8.86
General health satisfaction	47.49 ± 13.62

Correlation between WHOQOL-BREF domains and overall quality of life: All four WHOQOL-BREF domain scores showed positive, statistically significant correlations with overall QoL ($p < 0.001$ for all). The Environment domain demonstrated the strongest correlation with overall QoL (Spearman's

$\rho = 0.873$), followed by Psychological Health ($\rho = 0.771$), Social Relationships ($\rho = 0.742$), and Physical Health ($\rho = 0.730$), indicating that higher domain scores were consistently associated with better perceived overall QoL [Table 4].

Table 4: Correlation between WHOQOL-BREF domains and overall quality of life

Domain	Spearman's rho	p-value
Physical	0.730	<0.001
Psychological	0.771	<0.001
Social	0.742	<0.001
Environment	0.873	<0.001

Comparison of WHOQOL-BREF domain scores by sex: On Mann–Whitney U testing, male caregivers reported significantly higher WHOQOL-BREF scores than female caregivers across all four domains: Physical Health ($U = 860.0$, $p < 0.001$), Psychological Health ($U = 1097.0$, $p = 0.006$), Social Relationships ($U = 1197.5$, $p = 0.019$), and Environment ($U = 776.0$, $p < 0.001$)

Comparison of WHOQOL-BREF domain scores by age group: Caregivers aged >30 years had numerically higher mean scores than those ≤ 30 years across all four domains; this difference reached statistical significance only for the Environment domain (46.02 vs. 42.44; $U = 5623$, $p = 0.013$). No significant age-group differences were observed for Physical Health ($U = 5107$, $p = 0.250$), Psychological Health ($U = 5328$, $p = 0.085$), or Social Relationships ($U = 5103$, $p = 0.245$)

Comparison of WHOQOL-BREF domain scores by educational status: On Kruskal–Wallis testing across the seven educational categories, transformed Social Relationships scores differed significantly by educational status ($\chi^2 = 17.64$, $df = 6$, $p = 0.007$). No significant differences by educational status were observed for the Physical Health ($\chi^2 = 10.70$, $df = 6$, $p = 0.098$), Psychological Health ($\chi^2 = 8.915$, $df = 6$, $p = 0.178$), or Environment ($\chi^2 = 10.23$, $df = 6$, $p = 0.115$) domains.

Financial burden of caregiving: Financial strain associated with caregiving was substantial. Nearly two-thirds of caregivers (64.3%) reported that caregiving had led to reduced work hours, a job change, or unemployment.

DISCUSSION

In this cross-sectional study of 194 caregivers attending a DEIC in Thiruvallur, overall QoL was moderate (46.42 ± 8.86 on a 0–100 scale), with the Physical Health domain scoring highest and the Social Relationships domain scoring lowest. This pattern — relative preservation of physical health perception alongside disproportionate erosion of social participation — mirrors earlier findings among parents of children with disabilities, where social relationships and environmental domains were most affected, particularly among caregivers of children with more severe disability.^[2] The predominance of female caregivers in this sample (89.7%) is consistent with the broader caregiving literature, in which mothers typically assume the principal day-to-day caregiving role and, correspondingly, bear the greater share of its psychosocial cost.^[2,6]

The finding that male caregivers reported significantly higher WHOQOL-BREF scores than

female caregivers across all four domains is consistent with reports that caregiving responsibilities, and their attendant restriction of personal time, employment, and social participation, fall disproportionately on women, predisposing them to greater psychological morbidity and poorer QoL.^[7,8]

Older caregivers (>30 years) scored higher on the Environment domain than younger caregivers, while other domains did not differ significantly by age. Environment-domain items in the WHOQOL-BREF capture financial resources, home environment, and access to services and information; older caregivers may have accumulated greater financial stability, household resources, or familiarity with navigating health and social services over a longer caregiving trajectory, which could plausibly explain this selective difference.

Educational status was significantly associated with the Social Relationships domain but not with the other three domains. Caregivers with higher educational attainment may have greater access to social networks, workplace flexibility, and community resources that support social participation despite caregiving demands, a pattern broadly consistent with the socioeconomic gradients described in caregiver QoL research from other Indian and international settings.^[4,9]

All four WHOQOL-BREF domains correlated positively with overall QoL, with the Environment domain showing the strongest association, followed by Psychological Health, Social Relationships, and Physical Health. This ordering suggests that, in this population, perceived overall QoL is most closely tied to material and environmental circumstances — financial security, home environment, and access to services — rather than to physical health alone, a pattern that resonates with the substantial financial burden identified in this study and reported previously among caregivers of children with disability.^[4,9,10]

Limitations: The cross-sectional, single-centre design limits causal inference and generalizability to other settings. The marked predominance of female caregivers restricted the reliability of sex-based comparisons.

CONCLUSION

Caregivers of children with disabilities attending this DEIC experienced moderate overall quality of life, with the most pronounced impairment in the social relationships and environmental domains, and reported substantial caregiving-related financial strain. Female caregivers, younger caregivers, and

those with lower educational attainment appeared particularly vulnerable to poorer QoL. These findings support the integration of routine caregiver QoL screening, psychosocial support, and facilitated access to financial assistance schemes within DEIC/RBSK service delivery, alongside the existing referral pathway to psychiatric counselling for caregivers identified as having low QoL.

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