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Clinical Study on Quality of Life among Caregivers of Patients with Intellectual Disability in a Tertiary Care Hospital

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ABSTRACT

Background: Intellectual disability (ID) is a neurodevelopmental condition that can impose substantial long-term demands on families. Caregivers may experience burden and impaired quality of life due to prolonged caregiving responsibilities and associated socioeconomic challenges.

Methods: A hospital-based cross-sectional study was conducted among 100 participants, comprising 50 caregivers of patients with ID and 50 controls, at a tertiary care centre in Silchar, Assam. Participants were recruited by purposive sampling. Quality of life and caregiver burden were assessed using the WHOQOL-BREF and PAI and KAPUR Burden Interview Schedule, respectively. Data were analysed using non-parametric statistical tests.

Results: Caregivers of cases had significantly poorer quality of life than controls, with median WHOQOL-BREF scores of 59.5 (IQR 18.5) and 79.5 (IQR 15.5), respectively (U = 299, $p < 0.001$). Caregiver burden was significantly higher among cases, with median PAI/KAPUR scores of 15.0 (IQR 6.75) compared with 0.0 (IQR 1.0) among controls (U = 0.00, $p < 0.001$). A strong inverse correlation was observed between caregiver burden and quality of life (Spearman's $\rho = -0.829$, $p < 0.001$).

Conclusion: Caregivers of patients with intellectual disability experienced significantly greater burden and poorer quality of life than controls. The strong inverse association between burden and quality of life highlights the need for caregiver-focused psychosocial support, counselling, and family-centred interventions.

Key-words: Caregiver burden; Family caregivers; Intellectual disability; Quality of life; WHOQOL-BREF

INTRODUCTION

Intellectual disability (ID) is a neurodevelopmental condition characterized by significant impairments in intellectual functioning and adaptive behaviour, with onset during the developmental period.

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These impairments affect an individual's ability to acquire and apply conceptual, social, and practical skills necessary for independent functioning in everyday life. The DSM-5-TR describes intellectual and adaptive functioning across conceptual, social, and practical domains, emphasizing the importance of assessing both cognitive abilities and everyday adaptive skills [1]. Similarly, the ICD-11 defines disorders of intellectual development as significant limitations in intellectual functioning and adaptive behaviour that emerge during the developmental period [2]. The severity and functional consequences of intellectual disability vary considerably among individuals, depending on the extent of

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impairment, associated medical and psychiatric conditions, and the availability of appropriate educational, rehabilitative, and social support services.

Intellectual disability affects approximately 1% of the global population and represents an important cause of long-term disability, often requiring sustained support from family members and caregivers [3]. Beyond its direct effects on affected individuals, intellectual disability can have substantial consequences for family functioning, caregiver well-being, and overall quality of life. Caregivers frequently assume responsibility for daily activities, personal care, behavioural management, medical appointments, educational needs, and long-term rehabilitation. These responsibilities may place considerable physical, emotional, social, and financial demands on caregivers, particularly when professional support services are limited. Consequently, intellectual disability may influence multiple dimensions of caregiver quality of life, including physical health, psychological well-being, social relationships, and perceptions of the home and living environment [4]. Assessment of caregiver quality of life has therefore become an important component of understanding the broader impact of chronic disability and identifying areas in which additional support may be required.

Previous studies have reported reduced quality of life among caregivers of individuals with intellectual disability. Lin et al. found lower scores on the World Health Organization Quality of Life-BREF (WHOQOL-BREF), suggesting that caregiving responsibilities may adversely affect several domains of subjective well-being [5]. Similarly, Isa *et al*. reported poorer quality of life and greater psychological stress among caregivers, highlighting the potential emotional and psychosocial consequences of providing long-term care [6]. These findings indicate that caregiver quality of life is an important consideration in the comprehensive management of intellectual disability. However, the extent of its impact may differ according to caregiver characteristics, family circumstances, the severity of the individual's disability, and the availability of social and institutional support. Understanding these factors may help clinicians identify caregivers, who are particularly vulnerable to reduced well-being and develop appropriate interventions.

In India, caregiving for individuals with intellectual disability frequently occurs within the family, with relatives often providing substantial support over extended periods. The demands of caregiving may be compounded by socioeconomic disadvantage, limited access to specialized healthcare and rehabilitation services, inadequate respite care, and insufficient formal support systems. These challenges may be particularly relevant in resource-constrained settings, where families may experience difficulties balancing caregiving responsibilities with employment, household activities, and other social obligations. Although caregiver burden has received increasing attention, relatively few Indian studies have specifically examined caregiver quality of life and its associated factors. Existing evidence also suggests that socioeconomic circumstances, prolonged caregiving responsibilities, and limited support may influence caregiver well-being [7]. Furthermore, differences in cultural expectations, family structures, healthcare accessibility, and socioeconomic conditions may affect the caregiving experience across geographical regions, limiting the generalizability of findings from one setting to another. Local studies are therefore necessary to better understand caregiver quality of life and identify potentially modifiable factors associated with poorer outcomes.

In this context, the present study aims to assess the quality of life among caregivers of patients with intellectual disability attending a tertiary care hospital and to examine its association with selected sociodemographic and clinical variables. By evaluating caregiver quality of life alongside relevant caregiver and patient characteristics, the study seeks to contribute to the understanding of caregiving experiences in a hospital-based Indian population. The findings may help identify areas of unmet need and provide a basis for developing caregiver-focused psychosocial interventions and support strategies.

MATERIALS AND METHODS

Study design and setting- Hospital based cross sectional study was conducted among the care giver of the patients with intellectual disability in Silchar, Cachar district from 1 June 2025 to 31 May 2026 for a period of 1 year.

Study population- The sampling was purposive sampling of all the caregivers attending the OPD of a tertiary care centre. Sampling size was calculated as 100 samples.

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Caregiver who has lived with the children and was the primary caregiver for the same for over 2 years were considered eligible as a case. Paid and professional caregiver were excluded. And the controls were Adult primary caregivers of children/adolescents without intellectual disability, living with and providing regular care for at least 2 years, and willing to provide informed consent.

Data collection and study tools- The data was collected by the in- person interview using the pretest semi-structured questionnaire. The instruments were translated into the local language (Bengali) using the forward and backward translation by bilingual experts. The interview was conducted by the trained investigators. The questionnaires were consisting of the following parts–the first part have the sociodemographic status of the caregiver and the child. Such as age, gender, education, occupation, family structure and the socio-economic status, which were also recorded as potential confounding variables. The second part consist of the WHOQOL-BREF which assess the quality of life which is the primary outcome variable and the third part consist of the Pai and Kapur Burden interview schedule which assessed the subjective and objective burden of caregiver of the patient with psychiatric illness it is the secondary outcome variable. All the instruments are available for academic and non-commercial research.

Statistical Analysis- Data was entered into the Microsoft excel version 2019 (Microsoft corporation, Redmond, Washington, U.S.) and thoroughly checked for completeness and accuracy. Statistical analysis was performed using IBM SPSS statistics for windows, version 16.0 (SPSS, Inc., Chicago, Illinois, U.S.).

Ethical Consideration- Ethical approval was obtained from the institutional ethical committee of Silchar Medical College (approval number: SMC/14022). Informed written consent were obtained from the participants in the local language (Bengali).

RESULTS

In Table 1, the mean age of patients was higher among cases than controls (13.9 ± 8.28 vs. 6.70 ± 2.89 years), while the mean caregiver age was 41.7 ± 11.4 and 34.3 ± 5.67 years, respectively. Patient sex did not differ significantly between the groups (p = 0.067), caregiver sex did not show a significant difference (p = 0.067). No significant difference was observed in patient religion. Patient education (p < 0.001) and caregiver education (p = 0.003) differed significantly between groups. Disability status also differed significantly (p < 0.001), with 92% of cases having mild and 8% moderate disability, while all controls had no disability. Caregiver marital status was not significantly different (p = 0.172), whereas caregiver relationship with the patient (p < 0.001), occupation (p = 0.001), and family type (p = 0.041) showed significant differences between cases and controls. There was no non- participation or missing data.

Table 1: Socio-demographic data

Variable	Category / Statistic	Cases (n=50)	Controls (n=50)	*p*-value
Patient age (years)	Mean ± SD	13.9 ± 8.28	6.70 ± 2.89	-
	Median	12.5	6.0	
	Range	2–40	2–14	
Caregiver age (years)	Mean ± SD	41.7 ± 11.4	34.3 ± 5.67	-
	Median	42.5	34.0	
	Range	23–70	23–47	
Patient sex	Male	34 (68.0%)	25 (50.0%)	0.067
	Female	16 (32.0%)	25 (50.0%)	
	Male	25 (50.0%)	16 (32.0%)	0.067
	Female	25 (50.0%)	34 (68.0%)	
Patient religion	Christian	1 (2.0%)	1 (2.0%)	0.916
	Hindu	19 (38.0%)	17 (34.0%)	

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	Muslim	30 (60.0%)	32 (64.0%)	
Patient education	No schooling	12 (24.0%)	0 (0%)	<0.001
	Primary school	32 (64.0%)	48 (96.0%)	
	Middle school	5 (10.0%)	1 (2.0%)	
	High school	1 (2.0%)	1 (2.0%)	
Caregiver education	Illiterate	2 (4.0%)	0 (0%)	0.003
	Primary school	12 (24.0%)	0 (0%)	
	Middle school	14 (28.0%)	11 (22.0%)	
	High school	9 (18.0%)	13 (26.0%)	
	Higher secondary	5 (10.0%)	9 (18.0%)	
	Graduate	6 (12.0%)	14 (28.0%)	
	Post-graduate	2 (4.0%)	3 (6.0%)	
Disability status/severity	Nil	0 (0%)	50 (100.0%)	<0.001
	Mild	46 (92.0%)	0 (0%)	
	Moderate	4 (8.0%)	0 (0%)	
Caregiver marital status	Married	44 (88.0%)	50 (100.0%)	0.172
	Divorced	1 (2.0%)	0 (0%)	
	Separated	2 (4.0%)	0 (0%)	
	Unmarried	1 (2.0%)	0 (0%)	
	Widow	2 (4.0%)	0 (0%)	
Caregiver relationship	Father	26 (52.0%)	47 (94.0%)	<0.001
	Mother	18 (36.0%)	3 (6.0%)	
	Brother	4 (8.0%)	0 (0%)	
	Sister	1 (2.0%)	0 (0%)	
	Aunt	1 (2.0%)	0 (0%)	
Caregiver occupation	Clerical	3 (6.0%)	12 (24.0%)	0.001
	Homemaker	16 (32.0%)	2 (4.0%)	
	Professional	12 (24.0%)	9 (18.0%)	
	Skilled worker	11 (22.0%)	18 (36.0%)	
	Unskilled worker	8 (16.0%)	9 (18.0%)	
Family type	Joint	15 (30.0%)	25 (50.0%)	0.041
	Nuclear	35 (70.0%)	25 (50.0%)	

Table 2 shows that caregivers of patients with intellectual disability had significantly lower quality-of-life scores than caregivers in the comparison group, with a median WHOQOL-BREF score of 59.5 (IQR: 18.5; range: 37–80) compared with 79.5 (IQR: 15.5; range: 63–94), respectively (Mann–Whitney U = 299.0, $p < 0.001$).

Table 2: Comparison of WHOQOL-BREF scores between caregivers of cases and controls

Group	Median	IQR	Range	Mann–Whitney U	*p*-value
Cases (n=50)	59.5	18.5	37–80	299.0	<0.001
Controls (n=50)	79.5	15.5	63–94		

Note: Values are presented as median (IQR). A lower WHOQOL-BREF score indicates poorer quality of life.

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In multivariable linear regression analysis, which is shown in Table 3, caregiver group remained significantly associated with WHOQOL-BREF score after adjustment for caregiver age and sex. Compared with caregivers in the case group, caregivers in the comparison group had a 16.59-point higher WHOQOL-BREF score (β = 16.59, 95% CI 12.84–20.34, $p < 0.001$). Caregiver age was also independently associated with WHOQOL-BREF score (β = 0.30, 95% CI 0.10–0.50, $p = 0.003$), whereas caregiver sex (β = 0.80, 95% CI −2.61–4.20, $p = 0.643$) was not significantly associated with WHOQOL-BREF score.

Table 3: Multivariable linear regression analysis of factors associated with WHOQOL-BREF score

Predictor	β (Estimate)	SE	95% CI	*p*-value
Caregiver group: Control vs Case	16.59	1.89	12.84 to 20.34	<0.001
Caregiver age	0.30	0.10	0.10 to 0.50	0.003
Caregiver sex: Male vs Female	0.80	1.71	−2.61 to 4.20	0.643

Conversely, caregiver burden, as assessed by the PAI and KAPUR scales which is shown in Table 4, was significantly higher among caregivers of cases. The median burden score was 15.0 (IQR: 6.75; range: 7–30) in cases compared with 0.0 (IQR: 1.0; range: 0–2) in controls (U = 0.00, p < 0.001).

Table 4: Comparison of PAI and KAPUR scores between caregivers of cases and controls

Group	Median	IQR	Range	Mann–Whitney U	*p*-value
Cases (n=50)	15.0	6.75	7–30	0.00	<0.001
Controls (n=50)	0.0	1.0	0–2		

Note: Values are presented as median (IQR). Higher PAI and KAPUR scores indicate greater caregiver burden.

Spearman's rank correlation demonstrated a very strong negative correlation between caregiver burden (PAI and KAPUR) and WHOQOL-BREF scores (ρ = −0.829, df = 98, p < 0.001) as shown in Table 5, indicating that higher caregiver burden was associated with poorer quality of life. Overall, caregivers of patients in the case group experienced substantially greater caregiver burden and significantly poorer quality of life compared with caregivers in the control group.

Table 5: Correlation between caregiver burden and quality of life

Variables	Spearman's ρ	df	*p*-value
WHOQOL-BREF vs. PAI and KAPUR	−0.829	98	<0.001

Note: Spearman's rank correlation demonstrated a very strong negative correlation, indicating that greater caregiver burden was associated with poorer quality of life.

DISCUSSION

The study comprised 50 cases and 50 controls and identified notable differences between the two groups with respect to socio-demographic characteristics, caregiver burden, and quality of life. The mean age of patients was considerably higher among cases than controls (13.9 ± 8.28 versus 6.70 ± 2.89 years). Although no significant variation was observed in the sex or religious distribution of patients, several caregiver-related characteristics—including educational attainment, occupation, relationship to the patient, and family structure—differed significantly between the groups. Such variations in baseline characteristics should be considered when interpreting caregiver burden and quality-of-life outcomes, as both the patient's age and the caregiver's socio-demographic and familial circumstances may have an independent influence on these measures.

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The variation observed in caregiver characteristics in the present study could be related to differences in the composition of the study population, household structure, and the availability of family members to assume caregiving responsibilities. The relatively lower levels of education noted among both patients and caregivers in the case group may also have important implications for their ability to obtain relevant information, secure employment, and utilize available rehabilitation and social-support services. Supporting this observation, Suresh et al. found that socioeconomic circumstances were significantly related to the extent of burden experienced by caregivers of children with autism spectrum disorder and intellectual disability [8].

Caregiver burden was markedly greater in the case group, with a median PAI/KAPUR score of 15.0 (IQR 6.75), compared with 0.0 (IQR 1.0) in controls (U = 0.00, $p < 0.001$). Similar findings were reported by Bhatia et al., who observed considerable caregiver burden among caregivers of individuals with intellectual disability in Delhi, with 39% experiencing high burden and 46% reporting mild-to-moderate burden [10]. Suresh et al. also reported substantial caregiver burden and highlighted socioeconomic and caregiver-related factors as important determinants [8]. Differences in instruments and populations should, however, be considered when comparing absolute scores.

Caregivers of cases had significantly lower quality-of-life scores, with a median WHOQOL-BREF score of 59.5 (IQR 18.5) compared with 79.5 (IQR 15.5) among controls (U = 299, $p < 0.001$). Similarly, Arasu and Shanbhag found reduced quality of life among caregivers of children with disabilities in rural Karnataka, particularly across the physical, psychological, social, and environmental domains [9]. Their finding that caregiver occupation and disability characteristics influenced quality of life is relevant to the present study, where caregiver occupation and family characteristics also differed significantly.

The present study demonstrated a strong negative association between caregiver burden and quality of life (Spearman's $\rho = -0.829$, $p < 0.001$), suggesting that greater caregiving burden was linked to poorer quality of life. This finding is in agreement with Indian literature indicating that caregiving demands can adversely affect psychological well-being, physical health, social functioning, and family resources [8-11]. Cithambaram *et al*., through a qualitative synthesis of evidence on family caregivers of children with intellectual disabilities in India, identified caregiving dynamics, parental responses, concerns surrounding transitions, advocacy, and resilience as key themes, reflecting the multifaceted challenges experienced by these families [11].

Multivariable analysis showed that caregiver group remained significantly associated with WHOQOL-BREF scores after adjusting for caregiver age and sex. Controls had a 16.59-point higher score than cases (95% CI: 12.84–20.34, $p < 0.001$). Caregiver age was also significantly associated with quality of life, whereas caregiver sex was not. This suggests that the poorer quality of life among caregivers of patients with intellectual disability was not fully explained by differences in age or sex.

Differences in caregiver relationships and occupational status may have influenced the outcomes observed in the present study. Controls were more commonly cared for by fathers, while mothers and other relatives were more frequently represented among cases. Findings from earlier Indian studies have likewise suggested that the caregiver's relationship to the patient and socioeconomic circumstances can affect the level of caregiving burden [8]. Thus, the higher burden and poorer quality of life in the case group likely reflect the combined effects of disability-related demands and caregiver, family, and socioeconomic factors.

LIMITATION

This study was limited by its cross-sectional, single-centre design, small sample, and potential selection bias. Differences between groups in patient and caregiver characteristics may have resulted in residual confounding. Although multivariable analysis was performed, adjustment was limited to caregiver age and sex. Self-reported measures may also have introduced reporting bias.

CONCLUSIONS

The findings are consistent with Indian evidence showing greater caregiver burden and poorer quality of life among caregivers of children with disabilities. In the present study, caregivers of patients with intellectual disability experienced significantly higher burden and poorer quality of life than controls. The median WHOQOL-BREF score was lower among cases (59.5) than

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controls (79.5), while caregiver burden was significantly higher among cases. A strong negative correlation was observed between caregiver burden and quality of life (Spearman's ρ = −0.829, p < 0.001), indicating that increased burden was associated with poorer quality of life. In multivariable analysis, caregiver group and age remained significantly associated with quality-of-life scores, whereas caregiver sex was not. These findings emphasize the importance of addressing caregiver well-being alongside patient care. Routine caregiver assessment, psychoeducation, psychosocial interventions, and family-centred support services may help reduce burden and improve quality of life. Future multicentre studies involving larger, representative samples and adjustment for sociodemographic and clinical confounders are needed to validate these findings and guide targeted interventions.

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