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Quality of Life in Caregivers of Patients with Mental Retardation: A Cross-Sectional Study

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Abstract

Introduction: Mental retardation (MR) is a lifelong condition that significantly impacts not only patients but also their caregivers. The quality of life (QOL) of caregivers can be adversely affected due to continuous caregiving , stress, and socio-economic challenges. This study aimed to assess the QOL of caregivers of patients with MR responsibilities and analyze its relationship with socio-demographic variables of both patients and caregivers, as well as clinical variables related to the severity of MR.

AIMS AND OBJECTIVES:- The study aims to assess the quality of life of caregivers of patients with mental retardation in relation to socio-demographic factors and severity of illness.

Material and Methods: A cross-sectional study was conducted involving 100 patients diagnosed with mental retardation and their respective caregivers. Caregivers' QOL was measured using a standardized QOL questionnaire, and socio-demographic and clinical data of both patients and caregivers were collected. Statistical analyses were performed to determine the correlation between QOL scores and various socio-demographic and clinical factors, with significance tested at $p<0.05$.

Results: Caregivers' QOL scores ranged from 29% to 86%, with a mean score of 52.6% (SD=10.4), indicating a moderate impairment in quality of life. Patients' age showed an inverse relationship with caregivers' QOL; however, other patient variables such as sex, domicile, religion, education, and occupation showed no significant correlation with caregiver QOL. Caregivers' age was also negatively correlated with their QOL, while their education, marital status, type of family, and per capita income showed significant positive associations with better QOL scores. Caregivers' sex, domicile, religion, occupation, and relationship to the patient were not significantly related to their QOL. Severity of MR did not significantly influence caregivers' QOL; however, caregivers of patients with MR and comorbid epilepsy reported significantly poorer QOL scores compared to those without epilepsy.

Conclusion: The study reveals that caregivers of individuals with mental retardation experience moderately impaired quality of life, influenced more by socio-demographic factors than by the severity of the patient's condition. Caregiver support programs and policies need to focus on improving socio-economic conditions and providing psycho-social assistance to enhance caregiver well-being.

Keywords: Mental retardation, caregivers, quality of life, socio-demographic factors, epilepsy, caregiver burden

Introduction:-

Children are universally cherished as blessings, bringing joy, hope, and a sense of purpose to their families. However, when a child is diagnosed with an intellectual disability (ID), it can be a deeply distressing experience for parents, marked by emotional, social, and psychological challenges (1). Intellectual disability, previously termed "mental retardation," is characterized by limitations in intellectual functioning (IQ below approximately 70) and significant deficits in adaptive behavior, with onset before 18 years of age (2).

The global prevalence of intellectual disabilities is estimated to be around 1–3%, with developing countries showing higher rates due to increased exposure to risk factors such as birth injuries, malnutrition, and inadequate healthcare (3). In India, surveys indicate a prevalence of approximately 2%, with mild intellectual disability being the most common subtype (4).

Children with ID often exhibit delayed developmental milestones, difficulties with language acquisition, poor social and adaptive skills, and a lifelong need for support. These functional impairments place a continuous caregiving demand on parents, primarily mothers, who serve as the primary caregivers. This prolonged caregiving is associated with emotional strain, physical fatigue, social isolation, and financial hardship (5).

A caregiver is defined as an individual who provides ongoing, unpaid assistance to someone unable to perform daily living activities independently (6). In families with a child with developmental disabilities, caregiving goes beyond normal parenting and involves round-the-clock supervision, medical management, behavior control, and educational support (7).

Several studies have shown that caregivers of children with intellectual and developmental disabilities (IDD) are at increased risk for mental health issues such as depression, anxiety, and poor quality of life (QOL) (8,9). This burden is magnified in low- and middle-income countries due to limited access to professional support, societal stigma, and lack of institutional care systems (10).

In the Indian socio-cultural context, where family bonds are deeply rooted and expectations are high, the presence of a child with ID often leads to social marginalization and a significant disruption in family functioning. Parents frequently report stress, helplessness, marital strain, and concerns about the child’s future (11). While caregiving is often seen as a familial responsibility, the lack of formal support systems makes the burden unsustainable in many cases.

Despite this, there is limited empirical research on the quality of life of caregivers of children with intellectual disabilities in India. Quality of Life (QOL) is a broad multidimensional concept that includes subjective evaluations of physical health, psychological well-being, social relationships, and environmental factors (12). Assessing the QOL of caregivers is crucial for designing effective interventions, promoting caregiver health, and ultimately improving the care provided to children with disabilities.

Therefore, the present study aims to assess the quality of life among caregivers of children with intellectual disabilities, exploring the emotional, physical, social, and economic impacts of caregiving, and identifying areas where targeted support may be most beneficial.

Aim and Objectives;-

Aim:

To comprehensively assess the quality of life of caregivers of patients with mental retardation and to identify factors influencing it.

Objectives:

1. To study the overall quality of life among caregivers of patients with mental retardation.

2. To evaluate the association between the quality of life of caregivers and the socio-demographic characteristics of the patients.

3. To evaluate the association between the quality of life of caregivers and their own socio-demographic characteristics.

4. To examine the impact of severity of mental retardation on the quality of life of caregivers.

Materials and Methods

This cross-sectional observational study was conducted in a clinical setting at the Department of Psychiatry, P.D.U. Hospital, Rajkot—a tertiary care center affiliated with P.D.U. Medical College. The study was carried out between July 2013 and June 2014. A total of 100 patients diagnosed with intellectual disability (ID) and their respective primary caregivers were recruited from the psychiatry outpatient department. Patients were brought to the OPD either for certification purposes or for management of behavioral issues associated with ID.

Participants were selected based on specific inclusion and exclusion criteria. Patients aged 5 years or older and diagnosed with intellectual disability as per DSM-IV-TR criteria were included. Patients with comorbid Axis-I psychiatric disorders or those under the age of 5 were excluded. Caregivers included in the study were aged between 18 and 65 years and were identified as primary caregivers using the Pollak and Perlick method, which defines the primary caregiver as one who fulfills at least three out of five criteria: being a parent/spouse/spouse equivalent, having the most frequent contact with the patient, supporting the patient financially, being the main collateral informant in treatment, and acting as the emergency contact. Caregivers who could not communicate in Gujarati, Hindi, or English, who were mentally unfit to participate, or who did not provide informed consent were excluded.

An initial pilot study with 10 caregiver-patient dyads was conducted to test the feasibility of the data collection tools, and these participants were subsequently included in the final analysis. Each patient underwent detailed clinical evaluation, including history taking, mental status examination, and IQ testing by a trained clinical psychologist using age-appropriate standardized instruments. After obtaining informed consent, caregivers were interviewed privately to maintain confidentiality.

Socio-demographic data of both patients and caregivers were collected using standardized proformas (Annexure I and II). The severity of intellectual disability was classified based on IQ scores. Caregiver quality of life was assessed using the **Quality of Life Enjoyment and Satisfaction Questionnaire - Short Form (Q-LES-Q-SF)** This is a self-administered tool developed by Endicott et al., consisting of 16 items rated on a 5-point Likert scale, covering domains such as physical health, mood, work, social relationships, and overall life satisfaction. The Gujarati language version of the scale was used in this study to ensure cultural appropriateness(13).

All collected data were analyzed using **SPSS version 21.0**. Descriptive statistics were employed for socio-demographic data, while inferential analysis was done using t-tests and ANOVA to assess differences in QOL scores. Pearson's correlation coefficient was calculated to determine the relationship between QOL and variables such as patient age, caregiver age, per capita income, and severity of intellectual disability. Statistical significance was set at $p < 0.05$, with correlations considered significant at the 0.01 level (2-tailed). The study was conducted following ethical approval from the Institutional Ethics Committee, and informed written consent was obtained from all participants.

RESULT:- Total 100 patients of mental retardation and their 100 caregivers (one caregiver for each patient) were studied.

Table 1: Quality of Life in Caregivers

	Range	Mean	SD
% Maximum QOL score	29-86	52.6	10.4

The caregivers' QOL scores ranged from 29% to 86%, with a mean of 52.6% (SD = 10.4), indicating moderate impairment in overall quality of life.

Table 2: Caregivers' QOL in Relation to Patients' Socio-demographic Variables

Patient's Variables		Mean QOL score (SD)	Test of significance
Age (years)			
Range	5-48	_	_
Mean	17.6		
SD	10.2		
Age (years)	**N (%)**		
≤20	66 (66)	54.0 (10.7)	_
21-39	33 (33)	50.0 (9.5)	
≥40	1 (1)	46.0	
Sex	**N (%)**		t=0.806,
Male	71 (71)	53.1 (10.6)	p=0.422,
Female	29 (29)	51.3 (10.0)	Not Significant
Domicile	**N (%)**		
Urban	64 (64)	53.2 (11.2)	F=0.685,
Semi-urban	15 (15)	51.3 (9.3)	p=0.851,
Rural	21 (21)	51.8 (8.6)	Not Significant
Religion	**N (%)**		t=1.574,
Hindu	87 (87)	53.2 (10.7)	p=0.119,
Muslim	13 (13)	48.4 (7.3)	Not Significant
Education	**N (%)**		
Illiterate	43 (43)	50.7 (10.0)	F=0.489,
Primary education	48 (48)	54.1 (10.3)	p=0.974,
Secondary education	9 (9)	53.8 (10.1)	Not Significant
Occupation	**N (%)**		t=0.062,
Unemployed	94 (94)	52.6 (10.5)	p=0.951,
Employed	6 (6)	52.3 (8.8)	Not Significant

Patients' age ranged from 5 to 48 years (mean = 17.6, SD = 10.2), with most (66%) under 20 years. No significant association was found between caregivers' QOL and patients' sex, domicile, religion, education, or occupation.

Table 3: Caregivers' Quality of Life in Relation to Caregivers' Socio-demographic Variables

Caregiver's Variables		Mean QOL score (SD)	Test of Significance
Age (years)			
Range	23-64	_	_
Mean	42.6		
SD	10.8		

Age (years)	**N (%)**		
≤20	0 (0)	—	—
21-39	45 (45)	55.3 (8.6)	
≥40	55 (55)	50.3 (11.3)	
Sex	**N (%)**		
Male	53 (53)	53.5 (11.8)	t=0.918, p=0.361
Female	47 (47)	51.6 (8.6)	Not Significant
Domicile	**N (%)**		
Urban	64 (64)	53.2 (11.2)	F=0.685,
Semi-urban	15 (15)	51.3 (9.3)	p=0.851,
Rural	21 (21)	51.8 (8.6)	Not Significant
Religion	**N (%)**		
Hindu	87 (87)	53.2 (10.7)	t=1.574, p=0.119
Muslim	13 (13)	48.4 (7.3)	Not Significant
Education	**N (%)**		
Illiterate	12 (12)	45.2 (9.6)	
Primary education	40 (40)	48.7 (8.7)	F=2.791,
Secondary/Higher secondary education	41 (41)	57.3 (9.8)	**p=0.001,**
Graduate	5 (5)	62.0 (12.5)	**Significant****
Postgraduate	2 (2)	55.5 (2.1)	
Occupation	**N (%)**		
Labourers	44 (44)	50.4 (10.8)	F=0.990,
Housewives	42 (42)	52.0 (8.3)	p=0.489,
Others	14 (14)	61.4 (10.3)	Not Significant
Marital Status	**N (%)**		
Married	93 (93)	53.8 (9.7)	F=2.463,
Separated	1 (1)	30.0	**p=0.002**,
Widow/Widower	6 (6)	38.3 (7.6)	**Significant**
Relationship with Patient	**N (%)**		
Father	42 (42)	54.6 (11.8)	t=1.948,
Mother	48 (48)	50.3 (9.4)	p=0.055,
Others	10 (10)	55.0 (6.6)	Not Significant
Type of Family	**N (%)**		
Nuclear	79 (79)	51.0 (10.2)	t=3.062, **p=0.003**
Joint	21 (21)	58.5 (8.8)	**Significant**
Per Capita Income # (In Rupees /Month)	**N (%)**		
Class 1 (≥5181)	5 (5)	68.4 (11.2)	
Class 2 (2585-5180)	12 (12)	58.8 (10.1)	F=9.315,
Class 3 (1554-2584)	28 (28)	55.4 (6.8)	**p=0.001,**
Class 4 (777-1553)	38 (38)	49.3 (9.4)	**Significant****
Class 5 (≤776)	17 (17)	46.4 (9.8)	

** Indicates highly significant

According to modified Prasad's Classification

Caregivers' age ranged from 23 to 64 years (mean = 42.6, SD = 10.8). QOL was significantly associated with caregivers' education, marital status, type of family, and per capita income, but not with sex, domicile, religion, occupation, or relationship with the patient.

Table 4: Caregivers' Quality of Life in Relation to Severity of Mental Retardation

Patient's Clinical Variables		**Mean QOL score (SD)**	**Test of significance**
Category of MR	**N (%)**		
Mild	57 (57)	53.7 (9.6)	F=1.027,
Moderate	32 (32)	52.3 (11.4)	p=0.084,
Severe	8 (8)	45.4 (9.7)	Not significant
Profound	3 (3)	54.0 (13.9)	
Comorbid Medical Illness	**N (%)**		
Epilepsy			t=2.480*,
Cerebral Palsy	15 (15)	46.6 (8.8)	**p=0.015*,**
Down's syndrome	3 (3)		**Significant***
None	1 (1)	53.6 (10.3)	
	81 (81)		

[*] Here, 2 groups i.e. patients of MR with epilepsy (15) and without epilepsy (85) were taken into account and t-test was applied

Majority of patients had mild to moderate MR (89%), and severity of MR did not significantly affect caregivers' QOL. However, presence of comorbid epilepsy was significantly associated with poorer QOL among caregivers.

Discussion

The present study revealed a moderately impaired quality of life (QOL) among caregivers of patients with mental retardation, with a mean QOL score of 52.6%. This aligns with earlier studies showing that caregivers of individuals with intellectual disabilities often face substantial challenges affecting their physical, emotional, and social well-being. Previous findings have highlighted compromised life satisfaction, higher stress, and reduced psychological health in these caregivers compared to those caring for individuals without disabilities (14–17).

Patient-related factors showed that caregivers' QOL was significantly lower when caring for older patients, indicating that care demands tend to increase with patient age. Similar associations were reported by Awerdalla et al. and Mbugua et al., suggesting that the complexity and intensity of care responsibilities may rise over time, leading to increased burden (18–20). However, variables like patients' sex, religion, education, occupation, and residence showed no statistically significant relationship with caregivers' QOL, which is consistent with other Indian and international studies (21–24).

Among caregiver-related factors, older caregivers showed significantly poorer QOL, possibly due to age-related physical health issues and prolonged emotional strain. This has been supported by studies by Chou et al. and Walker et al., who emphasized age as a crucial determinant of caregiver stress (25, 26). Contrary to some earlier studies, caregiver gender was not significantly associated with QOL in our sample, diverging from research such as Purkayastha et al., which suggested women are often more affected due to traditional caregiving roles (27).

Education was found to be positively correlated with caregivers' QOL, which aligns with previous findings that better-educated caregivers may have more coping skills, awareness of resources, and access to support (15, 21). Caregivers' occupation, on the other hand, did not show a significant effect on QOL, indicating that employment status alone may not capture the nuances of caregiving stress (22).

Marital status and type of family showed significant associations: married caregivers and those living in joint families reported better QOL, possibly due to stronger emotional and logistical support systems. These findings are in line with those of John et al. and Upadhyaya et al., who highlighted the role of family structure in buffering caregiving stress (23, 24). Higher per capita income was also associated with better caregiver QOL, supporting previous research indicating that financial security can ease caregiving burdens and improve access to healthcare services (27, 28).

Interestingly, the severity of mental retardation did not significantly affect caregiver QOL, which contradicts findings by Greenberg et al. This may be due to sample characteristics or cultural resilience factors. However, the presence of co-morbid epilepsy in patients was significantly associated with reduced caregiver QOL, a finding echoed in a study by Nuhu et al., which highlighted the added challenges in managing multiple conditions (29).

In summary, the QOL of caregivers is influenced by multiple interrelated factors, with caregiver age, marital status, education, income, family structure, and patient comorbidities playing significant roles. These insights emphasize the need for multi-dimensional and culturally sensitive support systems for caregivers.

Conclusion

This study indicates that caregivers of individuals with Mental Retardation experience a moderately impaired quality of life. Caregiver QOL is inversely related to both the patient's and caregiver's age, while not significantly affected by the severity of mental retardation. These findings highlight the need for targeted psychosocial support, financial aid, and community-based interventions. Policy measures aimed at supporting caregivers could substantially enhance both caregiver well-being and patient outcomes.

Limitations

The cross-sectional design limits conclusions about changes in QOL over time. As the study was conducted on caregivers of outpatients, results may not be generalizable to all caregivers, especially those without access to health services. The relatively small sample size (n=100) and the presence of comorbidities like epilepsy in some patients may also influence findings.

Suggestions for Future Research

Future studies should employ longitudinal designs with larger, more diverse samples, including rural and underserved populations, to better understand the dynamic nature of caregiver burden and QOL over time.

Conflict of Interest

The authors declare no conflict of interest related to this study.

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