ORIGINAL ARTICLE

QUALITY OF LIFE IN CAREGIVERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITY IN A TERTIARY CARE HOSPITAL OF LAHORE, PAKISTAN.

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ABSTRACT

Background: Caring about an intellectually disabled (ID) person can significantly transform the emotional, physical, and social life of the caregiver as it is a life-long obligation. ID diagnosis at birth or later in life is likely to alter family dynamics and bring about grieving responses in addition to generating the ongoing financial and emotional strain.

Objectives: To measure the quality of life (QoL) among caregivers of individuals with intellectual disability (ID) and to identify sociodemographic factors that may aeffect caregiver well-being.

Methods: It is cross-sectional study conducted at Outpatient and Inpatient Psychiatry Departments, Services Hospital, Lahore, from June-2025 to November-2025. Sixty primary caregivers of individuals diagnosed with intellectual disability according to DSM-5 criteria were recruited using non-probability consecutive sampling. Data was collected using a structured socio demographic questionnaire and the Urdu version of the World Health Organization Quality of Life-BREF (WHOQOL-BREF), which identifies physical, psychological, social, and environmental domains. Descriptive statistics were calculated and Chi-square test was used to examine associations between QoL and sociodemographic variables. Independent t tests, oneway ANOVA, and multiple linear regression were applied to find out potential predictors of overall QoL.

Results: The average age of caregivers in this study was 41.23 ± 11.35 years, and on average, they had been providing care for about 7–8 years (89.68 ± 50.63 months). Overall, caregivers reported a moderate level of quality of life, with a mean score of 57.52 ± 6.19. When looking at different areas of life, scores were fairly similar: physical health (58.46 ± 9.08), psychological well-being (57.96 ± 11.32), social relationships (56.11 ± 11.95), and environmental factors (57.56 ± 10.36), though social well-being appeared slightly lower than the others. Most of the caregivers were women (71.7%), and more than half were mothers of individuals with intellectual disability (55.0%), highlighting the central caregiving role of mothers in our setting.

Conclusion: Overall caregivers of individuals with intellectual disability were found to have a moderate quality of life with relatively lower satisfaction in social and environmental aspects. These findings suggest a need to shift greater attention toward caregiver support, particularly through psychosocial interventions and community based programs, to improve their overall well-being.

Keywords: Intellectual disability, Caregiver, Quality of life, WHOQOL-BREF, Pakistan.

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INTRODUCTION

Caring about an intellectually disabled (ID) person can significantly transform the emotional, physical, and social life of the caregiver as it is a life-long obligation. ID diagnosis at birth or later in life is likely to alter family dynamics and bring about grieving responses in addition to generating the ongoing financial and emotional strain. As per the Hellenized conceptualization of the subjective concept of the well-being [physical, psychological, social

and environmental], quality of life (QoL) is subjectively defined as an indicator of well-being of all individuals undergoing physical, psychological, social and environmental issues on a long-term basis [a long-term condition that is chronic and lifelong], and the concept of quality of life, thus, seems to be a beneficial framework to analyze the experience of caregivers who are exposed to long-term issues.[1,3] In accordance with ever growing literature, the quality of life of a person with ID can be significantly diminished in case they are left unattended. Constant exhaustion, emotional tiredness and isolation are frequent complaints made by the caregivers and are most of the time worsened by the inability to have strong social support networks.[6] In this regard, Hassanein et al. established that caregivers QoL is significantly low because of the absence of a strong social support.[7]

Not only individual condition defines the caregiving burden but also socioeconomic and cultural surrounding do it. There is some evidence of lower QoL in caregivers in low- and middle-income nations (including Pakistan, India, and Ethiopia) because of less access to healthcare services due to financial limitations and disability-related stigma.

The COVID-19 pandemic also covered the world and put an even more significant burden on caregivers. Mental health rehabilitation, problems related to the access to healthcare services, and other ge-caring demands caused the worsening of mental health and QoL within families of developmentally disabled children.[14,15] The case was explained as chronic lockdown among caregivers residing in the United Kingdom and South Korea as intensive isolation and burnout. However, there are a few types of protection that have been identified to have a positive role in the well being of the care giver including the religious coping, good family relationships and social connectedness; which could be particularly true in collectivist cultures like Pakistan.[18] Still, more intensive local investigations in defining the multidimensional QoL of caregivers basing on verified tools like the WHOQOL-BREF is deficient.[4] Very little research has been done that analyzes QoL in tertiary care units, examining the concept of psychometric nuisance or psychiatric pathology.[12] To address this gap, this study will be used to establish the quality of life among the caregivers of the intellectually disabled who were admitted in a tertiary care psychiatric unit in Lahore, Pakistan. This is because using the process of determining caregiver well-being determinants can be applied to add certain intervention, support and ultimately offer better care-givers and individuals with ID results.

METHODS

This cross-sectional study was conducted in the outpatient and inpatient Psychiatry Departments of Services Hospital Lahore between June and November 2025 after taking approval from the Institutional Ethical Review Committee of the Services Institute of Medical Sciences (SIMS) Lahore.The study includes primary caregivers of people diagnosed with intellectual disability (ID) based on the DSM-5 criteria. Caregivers were defined as family members who provided regular emotional, physical or supervisory support to individuals with ID.

A non-probability consecutive sampling technique was used to recruit participants presenting to the psychiatry department during the study period. A total of 60 caregivers meeting the eligibility criteria were included in the study.

Caregivers aged 18–65 years who had been providing care for at least six months and had a minimum primary level of education sufficient to understand the questionnaire were eligible to participate. Caregivers with a known major psychiatric illness (such as schizophrenia, bipolar disorder, or major depressive disorder), paid professional caregivers (e.g., attendants or nurses), and those responsible for more than one dependent with a disability were excluded to minimize confounding influences on quality of life.The data were gathered through structured interviews, which were conducted in person in a private setting within the psychiatry department.

Each interview took about 20–30 minutes to complete. A structured sociodemographic questionnaire was used to gather basic information about the caregivers. This included details such as age, gender, marital status, education, occupation, place of residence, family structure, and their relationship with the individual with intellectual disability (ID). We also asked about the number of other children in the household and how long they had been in a caregiving role.

Quality of life was assessed using the Urdu version of the World Health Organization Quality of Life-BREF (WHOQOL-BREF). This is a well-established 26-item tool that looks at four main areas of life: physical health, psychological well-being, social relationships, and environmental conditions. Each item is rated on a five-point scale, with higher scores indicating a better perceived quality of life. Domain scores were calculated following WHO guidelines and then converted to a 0–100 scale to make interpretation and comparison easier.

The data were analyzed using SPSS version 27. Initially, descriptive statistics were computed, with means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Differences in overall quality of life between two groups were examined using independent samples t-tests, while comparisons involving more than two groups were carried out using one way ANOVA.The relationship between categorized quality of life levels and sociodemographic factors was assessed using the Chi-square test or Fishers exact test where needed. In addition, multiple linear regression analysis was performed to identify factors that independently predicted caregivers quality of life. A p value of less than 0.05 was considered statistically significant.

All participants give written informed consent before taking part in the study. Their privacy was carefully maintained, and all data were kept confidential and

anonymous. Participants were also informed that they could withdraw from the study at any time without any consequences. The study was conducted in line with the ethical principles outlined in the Declaration of Helsinki (2013 revision).

RESULTS

A total of 60 caregivers of individuals with intellectual disability were included in the study. The mean age of the caregivers was 41.23 ± 11.35 years (range: 18–65 years). The mean duration of caregiving was 89.68 ± 50.63 months. The mean overall quality of life (QoL) score calculated from the WHOQOL domains was 57.52 ± 6.19.

Most caregivers were female (71.7%), while 28.3% were male. The majority resided in urban areas (66.7%), and 33.3% were from rural areas. Regarding family structure, 55.0% belonged to joint families, followed by 30.0% from nuclear families and 15.0% from extended families. Half of the caregivers had secondary education (50.0%), while 26.7% had primary education and 23.3% had university-level education. Most caregivers were married (80.0%), and the majority were mothers of the patient (55.0%).

The mean scores of the WHOQOL domains were as follows: physical domain 58.46 ± 9.08, psychological domain 57.96 ± 11.32, social domain 56.11 ± 11.95, and environmental domain 57.56 ± 10.36.

Table 1: Baseline Demographic Characteristics of Caregivers (n = 60)

Variable	n (%)
Gender	
Female	43 (71.7)
Male	17 (28.3)
Place of Residence	
Urban	40 (66.7)
Rural	20 (33.3)
Family Type	
Joint	33 (55.0)
Nuclear	18 (30.0)
Extended	9 (15.0)
Educational Level	
Primary	16 (26.7)
Secondary	30 (50.0)
University	14 (23.3)
Marital Status	
Married	48 (80.0)
Single	11 (18.3)
Widowed	1 (1.7)
Relationship with Patient	
Mother	33 (55.0)
Father	18 (30.0)
Other relative	7 (11.7)
Sibling	2 (3.3)

Table 2: Descriptive Statistics of Caregiver and WHOQOL Variables

Variable	Mean ± SD	Minimum	Maximum
Caregiver age (years)	41.23 ± 11.35	18	65
Caregiving duration (months)	89.68 ± 50.63	6	176
WHOQOL Physical	58.46 ± 9.08	40.4	78.5
WHOQOL Psychological	57.96 ± 11.32	26.6	87.6
WHOQOL Social	56.11 ± 11.95	35.7	87.6
WHOQOL Environmental	57.56 ± 10.36	36.7	95.5
Overall QoL score	57.52 ± 6.19	41.5	72.5

Comparisons of QoL categories across demographic variables using Chi-square or Fisher's exact tests showed no statistically significant association with gender ($p = 0.504$), place of residence ($p = 0.361$), family type ($p = 0.352$), educational level ($p = 0.765$), occupation ($p = 0.742$), or marital status ($p = 0.435$).

Table 3: Association of Demographic Variables with Quality of Life Category

Variable	χ^2	p-value
Gender	0.447	0.504
Residence	0.833	0.361
Family type	2.088	0.352
Educational level	0.536	0.765
Occupation	1.246	0.742
Marital status	1.667	0.435

A multiple linear regression analysis was conducted to examine predictors of overall caregiver QoL. The model included caregiver age, caregiving duration, education level, occupation, place of residence, and family type. The regression model explained 9.4% of the variance in QoL ($R^2 = 0.094$) but was not statistically significant ($F = 0.918$, $p = 0.490$). None of the independent variables significantly predicted caregiver QoL. However, family type demonstrated a borderline association ($\beta = -0.246$, $p = 0.071$).

Table 4: Multiple Linear Regression Predicting Caregiver Quality of Life

Predictor	B	β	p-value
Caregiver age	0.025	0.046	0.728
Caregiving duration	0.016	0.129	0.355
Educational level	−1.264	−0.146	0.296
Occupation	−0.391	−0.032	0.824
Residence	0.320	0.025	0.854
Family type	−2.312	−0.246	0.071

Overall, demographic and caregiving variables did not significantly predict the quality of life of caregivers of individuals with intellectual disability in the present study.

DISCUSSION

This study aims to assess the quality of life of caregivers of intellectually disabled patients attending a tertiary care psychiatric facility in Lahore. Overall caregiver quality of life is moderate. The mean is 57.52 ± 6.19. The physical domain showed the highest quality of life scores, while the social domain showed the least quality of life scores. It indicates that the caregivers are able to maintain both physical and psychological well-being but are having difficulties when it comes to social well-being.

Caregiver demographic characteristics are similar to the general demographic characteristics of caregivers reported by previous studies. Most caregivers are female (71.7%), and the majority of the caregivers are mothers of intellectually disabled patients (55.0%). It indicates the significant role of women, especially mothers, in the care of intellectually disabled patients. It is consistent with the previous reports of female caregivers of intellectually disabled patients being mostly mothers. Caregiving of patients with developmental disabilities is mostly done by female caregivers.[1,2] Despite the dominant female caregivers of intellectually disabled patients being mostly mothers, no significant relationship was found between the quality of life of caregivers and the genders of the caregivers. It may be due to the fact that the cultural setting of the study is collectivist-oriented. In collectivist-oriented societies, the whole family plays an important supportive role.[19]

Domain-specific quality of life scores of the caregivers are consistent with the quality-of-life scores of caregivers reported by previous regional studies. Similar quality of life scores of the physical and psychological domains of the caregivers of intellectually disabled patients were reported by previous studies conducted in Pakistan.[8] It indicates that even the caregivers of intellectually disabled patients from low- and middle-income countries are maintaining moderate quality of life despite the lack of supportive care services.

However, it is interesting to note that none of the sociodemographic variables, including age, gender, marital status, residence, occupation, family structure, or relationship with the ID person, were found to have a significant association with QoL. This result concurs with previous studies that have found that well-being in caregivers is influenced by a multitude of psychosocial and contextual factors.[3,5] Although the result did not reach statistical significance, it can be noted that there was a clear trend towards a better QoL in caregivers who were more educated. This might be because education plays a vital role in providing access to more resources that can lead to a better adjustment in life.[5,11] The lower scores in social and environmental domains also highlight some of the major concerns that are associated with the QoL of caregivers in this study. These domains include concerns related to social support availability, financial resources, etc. Such concerns have also been noted in qualitative studies done in Pakistan in which it was found that stigma and support systems were major concerns that led to a high level of stress in caregivers.[9] In addition to that, studies done in various nations during the pandemic have also noted that a lack of support systems in the community and rehabilitation facilities have led to a high level of burden in caregivers.[14,15]

The regression analysis done in the study also supported the findings in that it showed that none of the sociodemographic variables, including age, duration of caregiving, education level of caregivers, occupation of caregivers, residence of caregivers, or family type of caregivers, had a significant association with QoL. This might be because well-being in caregivers depends on more intangible aspects like resilience and support systems.

In the context of Pakistan, it is possible that culture and religion can also play an important role in providing protection. Religion and spirituality, and strong family ties, are often considered a source of coping for caregivers. Previous research has indicated that these can be useful in alleviating emotional problems for caregivers of individuals with ID.[18] These findings suggest that caregivers are managing a moderate quality of life. All of these findings suggest that a focus on supporting caregivers is warranted. Interventions such as providing psychoeducation and counseling, and community-based support programs for caregivers, can be useful in supporting caregivers. Strengthening social support for caregivers is a priority and should be accessible for caregivers.[16]

Limitations that need to be considered in interpreting these findings. First, the cross-sectional nature of the study does not allow for causal inferences. Second, the relatively small sample size of 60 caregivers and the fact that the caregivers were recruited from a single tertiary care center limit the findings. Third, the self-report nature of the data makes response bias a potential threat. Fourth, the focus of the study was limited to sociodemographic variables and did not explore other important variables such as caregiver stress, coping styles, severity of ID, and levels of social support.

CONCLUSION

Caregivers of intellectually disabled persons in this study have a moderate quality of life, wherein they have better physical and psychological well-being but lesser satisfaction in terms of social and environmental factors. Since none of the sociodemographic factors significantly predicted QoL, it is likely that factors influencing caregiver QoL might be more complex and include a range of psychosocial factors. These results emphasize the need for developing structured interventions for caregivers of intellectually disabled persons, which include psychoeducation and counseling programs. Improving caregiver support in psychiatric and rehabilitation services will likely have a positive impact on caregiver QoL and quality of care provided to intellectually disabled persons.

Informed Consent: Consent has been obtained in the form of all the participants who were involved in the research.

ETHICAL APPROVAL

Ethical approval of article was granted by the Institutional Review Board of Services Institute of Medical Sciences Lahore, vide reference No. IRB/2025/1637/SIMS. Dated 11/07/2025

AUTHOR'S CONTRIBUTIONS

ZA: Conceived idea, study design, supervision of data collection, statistical analysis, critical review
DAJ: Data collection, literature review; manuscript writing, data analysis; critical review
AUHB: Data collection, data analysis, manuscript review
QH: Data entry, references, manuscript writing
MNSK, SAB: Supervision, interpretation,major revision
All Authors: Approval of the final version of the manuscript to be published

CONFLICT OF INTEREST

Authors declare no conflict of interest.

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