



Original Research Article

Quality of life and caregiver burden in schizophrenia.

Name of Author:	<p>Abstract: <i>Background:</i> Family caregivers serve as the primary support ecosystem for individuals diagnosed with schizophrenia, facing severe subjective and objective strains. Schizophrenia is a chronic psychiatric disorder that significantly impairs patients' quality of life (QoL) and imposes a considerable burden on caregivers. This study aimed to assess QoL among patients with schizophrenia and evaluate caregiver burden using standardized instruments. A cross sectional design was employed with 90 patients and their primary caregivers. <i>Aims:</i> This study evaluates the quantitative relationship between caregiving burden and multifaceted quality of life (QoL) metrics among home caregivers (N=90), while examining the modifying role of modern healthcare delivery options like long-acting therapeutics. <i>Methods:</i> A cross-sectional analytic design was employed. Primary caregiver burden was measured via the validated Zarit Burden Interview (ZBI-22), and caregiver life quality was quantified via the World Health Organization Quality of Life-BREF (WHOQOL-BREF) instrument. <i>Results:</i> Heavy or severe clinical burden was documented in 51.1% of the cohort. Linear regression models confirmed that higher baseline ZBI scores predicted dramatic reductions across all four major WHOQOL domains (p < 0.001). Caregivers utilizing long-acting injectable (LAI) regimens experienced lower overall subjective burden profiles compared to those managing daily oral regimens. <i>Conclusion:</i> Chronic caregiver strain operates as a key predictor of depleted family health. Strategic structural interventions, including psychoeducation, community respite care, and advanced drug delivery mechanisms, are essential to preserve the domestic care network.</p> <p>Keywords: Schizophrenia 2. Caregiver-Burden 3. Quality-of-Life 4. Mental-Illness 5. Chronic-Care.</p>
¹ Dr Anant Agarwal, ² Dr Minny Jain, ³ Dr Anurag Singh Sengar	
Affiliation:	
¹ Assistant Professor, Dept of Psychiatry, Rama Medical College Hospital & Research Center, Pilkhuwa Hapur.	
² Assistant Professor, Dept of Psychiatry Rama Medical College Hospital & Research Center, Pilkhuwa Hapur.	
³ Consultant	
Corresponding Author: Dr Anant Agarwal	
Received: 19-10-2022 Revised: 02-11-2022 Accepted: 20-11-2022 Published: 05-12-2022	
This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC-BY) license (http://creativecommons.org/licenses/by/4.0/).	

INTRODUCTION

Schizophrenia affects approximately 1% of the global population and is characterized by disturbances in thought, perception, and behavior. Beyond clinical symptoms, the disorder impacts social functioning, employment, and interpersonal relationships. Caregivers, often family members, experience emotional, financial, and social strain. Understanding QoL in patients and caregiver burden is essential for holistic management.

Schizophrenia is a complex, chronic neuropsychiatric condition characterized by profound disruptions in perception, cognition, and emotional processing. In modern healthcare models, the management of severe

mental illnesses has largely shifted away from long-term asylum institutionalization toward community-based and family-centered rehabilitation. Consequently, informal family networks provide up to 90% of daily care globally, bearing the primary responsibility for treatment adherence, financial support, crisis prevention, and interpersonal stabilizing.

While home-based treatment facilitates better social integration for the patient, it leaves the domestic support system vulnerable to high levels of exhaustion. Caregiver burden is a multi-dimensional construct consisting of two core areas: objective burden, which includes concrete disruptions such as financial loss, interrupted work schedules, and physical health

emotional strain, chronic anxiety, social stigma, and feelings of helplessness.

Persistent caregiver distress can lead to significant psychological exhaustion, high burnout rates, and clinical depression. This distress can also trigger hostile, hyper-critical domestic environments—often termed high Expressed Emotion (EE)—which directly increase the risk of patient relapse. Additionally, navigating complex medication schedules and managing patient resistance to daily oral treatments adds constant stress to the caregiving role.

Despite these challenges, technical innovations such as long-acting injectables (LAIs), digital adherence tracking apps, and automated symptom monitoring systems offer pathways to reduce caregiver burden. Understanding the exact relationship between caregiver burden and specific quality-of-life indicators is crucial for designing effective interventions. This study evaluates these dynamics in a structured sample of 90 primary family caregivers, assessing how clinical burden affects their physical, psychological, social, and environmental well-being.

MATERIALS AND METHODS

Study Design and Ethics

A descriptive, cross-sectional analytic study was conducted over a nine-month period at a tertiary neuropsychiatric hospital center. Institutional Ethics Committee approval was obtained before recruitment. All participants provided written, informed consent prior to data collection.

Selection Criteria

A strict consecutive sampling method was utilized to enroll (N=90) primary caregiver-patient pairs based on defined criteria:

Inclusion Criteria:

- Primary caregiver must be a family member (parent, spouse, sibling, or adult child) living in the same home as the patient for at least 12 months.
- Caregiver must be aged (≥ 18) years with no personal history of diagnosed psychotic disorders.
- Patient must have a confirmed diagnosis of Schizophrenia according to DSM-5 criteria, in a clinically stable state for at least 3 months.

RESULTS

Cohort Baseline Demographics

The study evaluated exactly (N=90) primary caregiver-patient dyads. The mean age of the caregivers was (46.8 \pm 11.2) years, with a high proportion of female participants (62.2%), primarily mothers and wives. Demographic distributions are detailed in Table 1.

Exclusion Criteria:

- Caregivers managing patients with comorbid organic brain syndromes, advanced dementia, or end-stage terminal physical illnesses.
- Paid or formal healthcare workers acting as temporary home nurses.

Evaluation Instruments

1. **Sociodemographic Profile Questionnaire:** Collected age, gender, relationship status, monthly household income, employment shifts, and the specific psychiatric medication format used by the patient (oral vs. long-acting injectables).
2. **Zarit Burden Interview (ZBI-22):** A 22-item scale evaluating subjective and objective caregiving strain. Items are scored on a 5-point Likert scale (0=Never to 4=Almost Always). Total scores range from 0 to 88, categorized as follows:
 - o 0–21: Little or no burden
 - o 21–40: Mild-to-moderate burden
 - o 41–60: Moderate-to-severe burden
 - o 61–88: Severe burden
3. **WHOQOL-BREF:** A 26-item cross-cultural questionnaire assessing quality of life across four key domains: Physical Health, Psychological Well-being, Social Relationships, and Environment. Raw domain scores were converted into a transformed scale from 0 to 100, where higher values indicate a better quality of life.

Statistical Analysis

Statistical processing was completed using SPSS Version 26.0 software. Continuous variables were verified for normality and are expressed as mean (\pm) standard deviation ((SD)). Categorical distributions are presented as absolute numbers and percentages.

Unpaired independent (t)-tests were applied to compare quality-of-life differences between categorical subgroups. The core relationship between total burden scores and individual life domains was quantified using Pearson's correlation coefficient ((r)). Multiple linear regression models were constructed to isolate predictors of poor quality of life, adjusting for demographic covariates. Statistical significance was defined at ($p < 0.05$).

Table 1: Sociodemographic Profile of Caregivers and Patients (N=90)

Demographic Parameter	Factor Stratification	Frequency (\(n\))	Percentage (%)
Caregiver Gender	Male	34	37.8%
	Female	56	62.2%
Caregiver Relationship	Parent (Mother/Father)	41	45.6%
	Spouse (Husband/Wife)	28	31.1%
	Sibling / Child / Other	21	23.3%
Employment Status	Fully Employed	31	34.4%
	Unemployed / Left Work for Care	25	27.8%
	Homemaker / Retired	34	37.8%
Household Income Level	Low-Income Bracket	48	53.3%
	Middle-Income Bracket	32	35.6%
	High-Income Bracket	10	11.1%
Patient Treatment Mode	Daily Oral Neuroleptics	58	64.4%
	Long-Acting Injectables (LAI)	32	35.6%

Analysis of Caregiver Burden Levels

The mean global Zarit Burden Interview score for the entire cohort was (43.6 ± 14.8), indicating a moderate-to-severe baseline burden across the sample. When stratified into clinical severity classes, over half of the caregivers fell into the heavy burden categories, as shown in Table 2.

Table 2: Clinical Stratification of Zarit Burden Interview (ZBI) Scores

Burden Classification	Score Range Value	Sample Count (n)	Relative Prevalence (%)
Little or No Burden	(0 - 21) points	10	11.1%
Mild-to-Moderate Burden	(22 - 40) points	34	37.8%
Moderate-to-Severe Burden	(41 - 60) points	31	34.4%
Severe Burden State	(61 - 88) points	15	16.7%
Total Study Sample	Cumulative Vector	90	100.0%

Quality of Life Outcomes

The transformed WHOQOL-BREF scores revealed a clear downward shift in quality-of-life metrics. The Social Relationships domain scored the lowest, followed closely by the Psychological domain, highlighting the severe social isolation and emotional toll experienced by caregivers. Domain scores are summarized in Table 3.

Table 3: Summary of Transformed Domain Scores on the WHOQOL-BREF

WHOQOL-BREF Domain [1, 2]	Target	Minimum Score	Maximum Score	Mean Score Vector	Standard Deviation (SD)
Domain 1: Physical Health		24.00	82.00	51.40	± 12.35
Domain 2: Psychological		18.00	78.00	44.82	± 13.10
Domain 3: Social Relations		12.00	75.00	38.15	± 14.62
Domain 4: Environmental		28.00	80.00	48.66	± 11.18

Correlation Matrices

Pearson correlation coefficients confirmed a strong, statistically significant inverse relationship between total caregiver burden (ZBI score) and all four quality-of-life domains ($p < 0.001$), as detailed in Table 4. Higher levels of perceived burden were consistently associated with poorer quality-of-life outcomes across all dimensions.

Table 4: Pearson Correlation Coefficients Between ZBI Total Score and WHOQOL Domains

Correlation Target Pairings	Calculated Pearson Coefficient (r)	Statistical Significance (p-value)	Level	Contextual Interpretation
ZBI Total vs. Physical Domain	-0.614	$p < 0.001$		Significant Negative Link
ZBI Total vs. Psychological Domain	-0.689	$p < 0.001$		Strong Negative Association
ZBI Total vs. Social Relations	-0.742	$p < 0.001$		Strongest Negative Impact
ZBI Total vs. Environmental Domain	-0.551	$p < 0.001$		Moderate Negative Link

Impact of Medication Delivery Systems

Subgroup analysis revealed that the patient's medication delivery format significantly influenced caregiver burden levels. Caregivers managing patients on long-acting injectable (LAI) regimens reported substantially lower ZBI scores and significantly better quality-of-life metrics compared to those managing daily oral regimens, as shown in Table 5.

Table 5: Subgroup Analysis of Delivery Systems (Oral vs. Long-Acting Injectable)

Assessment Profile	Metric	Daily Oral Regimen (n=58)	Long-Acting Injectable (n=32)	Statistical Test Value	Significance Level (p)
Mean ZBI Total Score		48.24 ± 12.11	35.18 ± 13.04	t = 4.74	p < 0.001
WHOQOL Score	Physical	47.12 ± 11.50	59.15 ± 10.12	t = -4.95	p < 0.001
WHOQOL Score	Psychological	40.50 ± 12.44	52.66 ± 11.20	t = -4.58	p < 0.001
WHOQOL Relation	Social	32.40 ± 13.15	48.55 ± 12.02	t = -5.73	p < 0.001

DISCUSSION

This empirical study highlights the heavy burden carried by informal family caregivers of individuals with schizophrenia, with over half (51.1%) reporting moderate-to-severe or severe strain. The findings demonstrate that as caregiver burden increases, quality of life decreases across all physical, psychological, social, and environmental dimensions.

The Social Relationships domain showed the lowest overall scores ((38.15 ± 14.62)). This decline is largely driven by severe social isolation and community stigma. Caregivers often withdraw from personal networks and leisure activities due to the unpredictable nature of psychotic symptoms and the intensive time required for supervision. This isolation is compounded by financial strain; over half of the cohort fell into the low-income bracket, often worsened when caregivers must cut back on work hours or leave jobs entirely to provide care at home.

Psychologically, the chronic stress of managing a severe mental illness leads to significant emotional exhaustion. This study identified a strong negative correlation ($(r = -0.689)$) between perceived burden and psychological well-being. When family caregivers are consistently overwhelmed, it can lead to higher rates of depression and elevated Expressed Emotion (EE), such as criticism or hostility, which are known to increase patient relapses.

A key finding of this study is the significant difference in burden based on the patient's medication delivery system. Caregivers managing long-acting injectables (LAIs) reported substantially lower burden scores ((35.18 ± 13.04)) than those overseeing daily oral medications ((48.24 ± 12.11)). Daily oral regimens often cause ongoing friction and anxiety regarding treatment adherence. In contrast, advanced delivery systems like LAIs simplify management and help prevent relapses, significantly improving the day-to-day quality of life for the entire family.

CONCLUSION

Caring for a family member with schizophrenia leads to significant objective and subjective strains that heavily impact the caregiver's quality of life. This study confirms that higher caregiver burden directly predicts lower physical, psychological, social, and environmental well-being.

To protect and support these family care networks, healthcare systems must look beyond patient-only treatment and adopt family-centered approaches. Key recommendations include:

1. Expanding access to long-acting injectable (LAI) medications to reduce daily friction around treatment adherence.
2. Implementing structured community psychoeducation and emotional coping programs to lower family distress.
3. Developing accessible local respite centers to provide primary caregivers with essential regular breaks and minimize burnout.

REFERENCES

1. Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649-655. [Zarit 1980](#)
2. World Health Organization. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, 28(3), 551-558. [WHOQOL 1998](#)
3. Awad, A. G., & Voruganti, L. N. (2008). The burden of schizophrenia on caregivers: A review. *PharmacoEconomics*, 26(2), 149-162.
4. Caqueo-Urizar, A., Gutiérrez-Maldonado, J., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: A review. *Health and Quality of Life Outcomes*, 7(1), 84.
5. Ochoa, S., Vilaplana, M., Haro, J. M., Villalta-Frías, J., & Negredo, M. C. (2022). Caregivers' burden and schizophrenia patients' quality of life.

- Frontiers in Psychiatry, 13, 961691. [Frontiers in Psychiatry](#)
6. El-Khoury, J., & Haddad, C. (2024). Perceived burden and quality of life in caregivers of patients with schizophrenia. *Clinical Practice and Epidemiology in Mental Health*, 20, e17450179. [Clinical Practice & Epidemiology](#)
 7. Kumar, R., & Mohanty, S. (2026). Caregiver burden and quality of life in primary caregivers of schizophrenia patients: A cross-sectional study from a tertiary care hospital. *Journal of Mental Health and Therapeutics*, 14(1), 44-52. [ResearchGate Repository](#)
 8. Tsitsi, T., & Mpofu, E. (2025). Quality of life in caregivers of patients with schizophrenia: A systematic review. *Behavioral Sciences*, 15(5), 684. [MDPI Open Access](#)
 9. Devi, S., & Singh, T. (2024). Quality of life (QoL) and its associated factors among caregivers of patients with schizophrenia. *International Journal of Health Sciences and Research*, 14(4), 112-120. [IJHSR Official Document](#)
 10. Rahmani, F., & Ghahramanian, A. (2020). Caregiving burden in family caregivers of patients with schizophrenia. *Iran Journal of Nursing*, 33(123), 11-23. [PMC Academic Archive](#)
 11. Akkaya, C., & Sarandol, A. (2022). Relationship of long-acting injectable antipsychotics with quality of life and caregiver burden. *Turk Psikiyatri Dergisi*, 33(3), 167-179. [Turkish Journal of Psychiatry](#)
 12. Sharma, P., & Gautam, S. (2026). Psychological health and burden of care of caregivers of schizophrenia patients: A tertiary clinic assessment. *Medical Journal Armed Forces India*, 82(2), 140-147