

A Cross-Sectional Comparative Study of Caregiving Burden, Coping, and Psychological Distress Among Caregivers of Patients with Schizophrenia Based on Illness Chronicity.

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Page | 1

Abstract

Background:

Schizophrenia imposes substantial caregiving demands on families. These demands may vary with illness chronicity, influencing caregiver burden, coping, and psychological distress.

Objective:

To compare caregiver burden, coping, and psychological distress between caregivers of patients with recent-onset and chronic schizophrenia.

Methods:

This hospital-based, cross-sectional, comparative study included 96 caregiver-patient dyads (48 per group) at Dr. S. N. Medical College, Jodhpur. Patients were grouped by illness duration: less than two years (Group B) and more than two years (Group A). Assessments included the Positive and Negative Syndrome Scale (PANSS), Family Burden Interview Schedule (FBIS), Brief COPE, and 12-item General Health Questionnaire (GHQ-12).

Results:

Caregivers were predominantly female (66.7%). Mean caregiving duration was 13.19 ± 9.62 years in Group A and 1.05 ± 0.47 years in Group B. Total PANSS scores were comparable (91.02 ± 6.45 vs. 88.63 ± 5.00), although positive symptoms were higher in Group B (29.81 vs. 23.85), whereas negative symptoms (22.80 vs. 19.80) and general psychopathology (44.90 vs. 39.00) were higher in Group A. Mean GHQ-12 scores were significantly higher in Group B than Group A (28.88 vs. 24.75); both indicated severe psychological distress. Total FBIS scores were significantly higher in Group A (25.85 vs. 19.15), particularly for financial burden (6.71 vs. 5.46), routine disruption (7.31 vs. 4.44), and mental-health impact (2.06 vs. 1.35). Brief COPE scores were higher in Group A (56.44 vs. 52.92). PANSS scores correlated significantly with psychological distress, whereas Brief COPE scores did not correlate significantly with GHQ-12 scores.

Conclusion and Recommendation:

Caregiver burden increased with illness chronicity, while psychological distress was greater in the recent-onset group. Routine caregiver screening, psychoeducation, coping-skills training, and appropriate psychosocial and financial support should be provided irrespective of illness duration.

Keywords: Schizophrenia; caregiver burden; coping; psychological distress; chronicity; Family Burden Interview Schedule; 12-item General Health Questionnaire (GHQ-12).

Submitted: October 5, 2025

Accepted: November 3, 2025

Published: December 30, 2025

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1. Introduction

Schizophrenia is a debilitating psychiatric disorder that affects not only the individuals diagnosed with it but also their families. Its typically chronic course leads to social and occupational impairment, posing lasting obstacles to independent living [1]. The World Health Organization estimates that more than 21 million people worldwide are affected by schizophrenia, and the disorder ranks among the leading causes of disability-adjusted life years, imposing substantial costs on patients, families, and society at large. Over the past five decades, psychiatric care has shifted worldwide from hospital-based to community-based management, with families now providing most day-to-day care and bearing the bulk of the caregiving burden [2]. Families are usually the first to recognise symptoms and seek treatment, and it is they who go on to supervise medication, manage finances, maintain contact with mental health services, and absorb the emotional and social consequences of stigma. This caregiving role often brings distress, worry, guilt, and shame, alongside occasional positive experiences such as a sense of reward [3]. Financial strain frequently follows, as caregivers may reduce working hours, give up employment, or sell assets to fund treatment and support an adult dependent at home.

Relatively little is known about how these burdens, and the strategies caregivers use to cope with them, evolve as an illness moves from recent onset to a chronic course. As schizophrenia becomes more chronic, positive symptoms often give way to more persistent negative symptoms, and the demands placed on caregivers may shift accordingly [4]. Whether caregiver burden, coping style, and psychological distress differ meaningfully between caregivers of recently diagnosed patients and those caring for patients with long-standing illness remains poorly characterised, particularly in Indian tertiary-care settings where the family — rather than institutional care — remains the primary source of support. This study was therefore designed to compare caregiver burden, coping, and psychological distress between caregivers of chronic (>2 years) and recent-onset (<2 years) schizophrenia patients, and to examine associations with sociodemographic and clinical variables.

1.1 Aim

To compare caregiver burden, coping, and psychological distress among caregivers of outpatient/inpatient schizophrenia patients based on illness chronicity.

1.2 Objectives

Primary objectives:

- To assess caregiver burden among caregivers of schizophrenia patients.
- To assess coping mechanisms used by caregivers.

- To assess psychological distress among caregivers.
- To compare the above parameters based on illness chronicity.

Secondary objectives:

- To correlate the sociodemographic profile of caregivers with caregiver burden.
- To correlate patients' symptomatology with caregiving burden.
- To examine the association between caregiving burden and coping style.
- To correlate caregiving burden with severity of symptoms.
- To assess the effect of patients' demographic profile on caregiver distress.

2.1 Study design and setting

This was a hospital-based, cross-sectional, comparative study conducted in the Department of Psychiatry, Dr. S.N. Medical College and associated group of hospitals, Jodhpur, Rajasthan, over a period of six months, following approval from the Institutional Ethics Committee.

2.2 Study population and grouping

Patients diagnosed with schizophrenia as per ICD-10 criteria (diagnosis independently confirmed by a second psychiatrist) were classified into two groups based on chronicity:

- Group A: total duration of illness more than 2 years (chronic).
- Group B: total duration of illness less than 2 years (recent-onset).

The primary caregiver of each patient — defined as the person responsible for the patient's daily needs, supervision of medication, hospital visits, and liaison with hospital staff — was recruited as per the eligibility criteria below.

2.3 Sampling and sample size

Caregivers were recruited using purposive and convenience sampling. Sample size was calculated using a one-sided test with $\alpha = 0.05$ and power = 0.80, yielding a requirement of approximately 42 caregivers per group; 48 caregivers per group (96 in total) were enrolled to provide an adequate margin.

2.4 Eligibility criteria

Inclusion criteria

Patients: Clinically diagnosed with schizophrenia according to ICD-10 criteria, with diagnosis independently confirmed by a second psychiatrist.

Caregivers: caregiver of an officially diagnosed schizophrenia patient; age above 18 years; residing with and providing continuous care to the patient for at least the preceding 6 months; able to read Hindi; and functioning as the patient's principal caregiver (daily needs, medication supervision, hospital visits, liaison with staff).

Exclusion criteria

Organic or chronic medical illness in the caregiver; substance use disorder other than nicotine dependence (per ICD-10); and diagnosed psychiatric illness in the caregiver.

2.5 Procedure

Institutional ethics committee approval and administrative permission were obtained prior to the study. Written informed consent was obtained from both patients and caregivers after the aim and objectives of the study were explained. A semi-structured proforma was used to record sociodemographic details of the patient and caregiver (age, sex, education, occupation, socioeconomic status, religion, duration of illness, duration of untreated psychosis, duration of caregiving, relationship to the patient, and distance of the treating hospital from home). Confidentiality of identity and personal information was maintained throughout. Data were collected by the principal investigator.

2.6 Assessment instruments

Positive and Negative Syndrome Scale (PANSS): An examiner-administered, 30-item scale assessing symptom severity in patients, comprising a 7-item Positive scale (range 7–49), a 7-item Negative scale (range 7–49), and a 16-item General Psychopathology scale (range 16–112). Test–retest reliability of the total score and subscales has been reported at 0.77–0.89 [5,6].

Stress Coping Behaviour Scale (SCBS) — Hindi adaptation of the Brief COPE: A 28-item scale assessing adaptive (15 items) and maladaptive (8 items) coping

behaviours, further categorised into three overarching coping styles — problem-focused coping (active coping, informational support, planning, positive reframing), emotion-focused coping (venting, emotional support, humour, acceptance, self-blame, religion), and avoidant coping (self-distraction, denial, substance use, behavioural disengagement). Reported reliability for the Brief COPE subscales ranges from 0.75–0.90 [7,8].

General Health Questionnaire (GHQ-12): A 12-item self-administered screening instrument for common mental disorders, scored 0–36. A score above 15 indicates evidence of distress and a score above 20 suggests severe distress [9].

Family Burden Interview Schedule (FBIS): A 24-item interviewer-administered scale (Pai and Kapur, 1981) rated on a 3-point scale (0 = no burden, 1 = moderate burden, 2 = severe burden), covering six domains — disruption of family finance, routine, leisure, and interactions, and impact on the physical and mental health of family members. A mean item score ≥ 1 denotes moderate-to-severe burden. Reported internal reliability ranges from 0.87–0.99 [10].

2.7 Statistical analysis

Data were analysed using SPSS version 20. Categorical variables were compared between groups using the chi-square test; continuous variables were compared using means and standard deviations. Correlations between scale scores were examined using appropriate correlation coefficients. A p-value < 0.05 was considered statistically significant.

2.8 Ethical considerations

The study was approved by the Institutional Ethics Committee (IEC), Dr. S. N. Medical College, Jodhpur, Rajasthan, India (Ethical Approval No.: SNMC/IEC/2022/1800–1801, dated 03 June 2022). Written informed consent was obtained from all participants. Confidentiality was maintained, and no additional benefits were offered for participation.

3. Results

A total of 96 caregivers were studied (48 in each group). Key findings are summarised below and in Tables 1–4.

3.1 Sociodemographic profile

Table 1 Sociodemographic Characteristics of Caregivers by Group

Characteristic	Group A (n = 48)	Group B (n = 48)	p value
Mean age (years)	53.96 ± 8.89	51.98 ± 11.34	.504
Female sex, n (%)	34 (70.83)	30 (62.50)	.516
Married, n (%)	48 (100.00)	47 (97.92)	1.000
Rural domicile, n (%)	40 (83.33)	36 (75.00)	.451
Homemaker, n (%)	18 (37.50)	28 (58.33)	—

Note. Group A = illness duration greater than 2 years; Group B = illness duration less than 2 years. Values are presented as mean ± standard deviation or frequency (percentage), as appropriate.

Caregivers' mean age was 53.96 ± 8.89 years in Group A and 51.98 ± 11.34 years in Group B ($p = .504$). Most caregivers were female, married, and from rural areas. Homemakers were more common in Group B (58.33%) than Group A (37.50%). Most caregivers were parents, and illiteracy was common. No significant between-group differences were observed in sociodemographic characteristics.

3.2 Clinical profile of patients

By definition, mean duration of caregiving differed markedly between groups (Group A: 13.19 ± 9.62 years;

Group B: 1.05 ± 0.47 years). Age of onset of illness was significantly higher in Group A (32.83 years) than in Group B (22.88 ± 5.52 years). Most patients were male in both groups (Group A 68.75%, Group B 64.58%; not significant) and married. On the PANSS, total scores did not differ significantly between groups (Group A: 91.02 ± 6.45; Group B: 88.63 ± 5.0). However, subscale scores diverged: positive-symptom scores were significantly higher in Group B (29.81) than in Group A (23.85), whereas negative-symptom scores (Group A 22.8 vs Group B 19.8) and General Psychopathology scores (Group A 44.9 vs Group B 39.0) were significantly higher in Group A.

Table 2. PANSS scores by group

PANSS domain	Group A (>2 yr)	Group B (<2 yr)	Comparison
Positive symptoms	23.85	29.81	Significantly higher in B
Negative symptoms	22.80	19.80	Significantly higher in A
General psychopathology	44.90	39.00	Significantly higher in A
Total PANSS	91.02 ± 6.45	88.63 ± 5.00	Not significant

3.3 Psychological distress (GHQ-12)

Mean GHQ-12 scores were 24.75 in Group A and 28.88 in Group B; both means exceeded the cut-off of 20, denoting severe distress, and the between-group difference was statistically significant, with caregivers of recent-onset patients (Group B) reporting greater distress than those caring for chronic patients. Overall, 51.1% of caregivers scored above the GHQ cut-off for psychological distress. Mothers reported the highest distress of all caregiver-relationship categories, although this difference did not reach statistical significance. A significant positive correlation was observed between PANSS total score and GHQ score, indicating that greater illness severity was associated with greater caregiver distress.

3.4 Coping (Brief COPE / SCBS)

Total Brief COPE scores were significantly higher in Group A (56.44) than in Group B (52.92). Problem-focused and emotion-focused coping were the predominant styles used by caregivers in both groups, while avoidant coping was comparatively less common. In Group B, male caregivers showed significantly higher avoidant coping than female caregivers; no other gender-based differences in coping emerged. Mothers and wives showed the highest emotion-focused coping, husbands scored highest on avoidance-based coping, and parents overall showed the highest problem-focused coping. Coping style did not differ significantly by caregiver relationship to the patient,

patient's education, or duration of illness, and no significant correlation was found between Brief COPE and GHQ scores.

3.5 Caregiver burden (FBIS)

The total FBIS score was significantly higher in Group A (25.85) than in Group B (19.15), indicating greater overall burden with increasing chronicity. Among FBIS subdomains, financial burden (Group A 6.71 vs Group B 5.46), disruption of routine (7.31 vs 4.44) were all significantly higher in Group A; disruption of family leisure was marginally higher in Group A (3.29 vs 3.15). No significant between-group difference was observed for impact on

caregiver physical health. Female caregivers of chronic patients (Group A) experienced significantly greater disruption of routine than male caregivers; in Group B, male caregivers reported significantly greater impact on physical and mental health than female caregivers. Urban caregivers in both groups reported significantly greater impact on physical health than rural caregivers, while in Group B, rural caregivers reported significantly higher financial burden than urban caregivers. No significant difference in FBIS was found by caregiver relationship to the patient, except that caregiver physical health was better preserved among mothers than other relationships. Within Group A, a significant correlation was found between negative symptoms and disruption of family leisure.

Table 3. Family Burden Interview Schedule (FBIS) scores by group

FBIS domain	Group A (>2 yr)	Group B (<2 yr)	Significance
Financial burden	6.71	5.46	Significant
Disruption of routine	7.31	4.44	Significant
Disruption of family leisure	3.29	3.15	Significant
Impact on mental health	2.06	1.35	Significant
Impact on physical health	—	—	Not significant
Total FBIS score	25.85	19.15	Significant

3.6 Summary of key comparisons

Table 4. Summary of principal outcome measures by chronicity group

Measure	Group A (>2 yr)	Group B (<2 yr)	Significance
Mean caregiving duration (years)	13.19 ± 9.62	1.05 ± 0.47	By design
GHQ-12 (psychological distress)	24.75	28.88	Significant (B > A)
Brief COPE (overall coping)	56.44	52.92	Significant (A > B)
FBIS (total burden)	25.85	19.15	Significant (A > B)

4. Discussion

This hospital-based cross-sectional comparative study evaluated caregiver burden, coping strategies, and psychological distress among 96 caregivers of patients with schizophrenia, categorized according to illness duration. The findings highlight differences in clinical presentation, caregiver distress, coping patterns, and perceived burden between caregivers of patients with recent-onset and chronic schizophrenia.

The sociodemographic profile of caregivers was characterized predominantly by middle-aged women, married individuals, rural residents, and parents, particularly mothers. These findings are consistent with Montero et al. [11], who examined family interventions in schizophrenia and highlighted the importance of family involvement in

patient care. The predominance of female caregivers underscores the substantial caregiving responsibilities frequently undertaken by women in families affected by schizophrenia.

Regarding clinical characteristics, patients in the recent-onset group had significantly higher positive symptom scores, whereas those in the chronic-illness group had higher negative symptom and general psychopathology scores. However, the difference in total PANSS scores between groups was not statistically significant. These findings are broadly consistent with the clinical course of schizophrenia described by Tandon et al. [12], in which symptom profiles may vary across illness stages. Nevertheless, differences in symptom domains should be interpreted cautiously, as the

cross-sectional design does not establish longitudinal changes in symptom severity.

Psychological distress was substantial in both caregiver groups, with higher mean GHQ-12 scores among caregivers of patients with recent-onset illness. This finding suggests that the early phase of schizophrenia may be particularly distressing because of diagnostic uncertainty, difficulties understanding the illness, and challenges adapting to treatment and caregiving responsibilities. Tennakoon et al. [13] explored the experiences of relatives caring for individuals experiencing a first episode of psychosis, emphasizing the importance of understanding family experiences during this period. The higher distress observed in the recent-onset group, despite lower overall caregiver burden, suggests that psychological distress and perceived caregiving burden may represent related but distinct dimensions of the caregiving experience. The significant positive correlation between PANSS and GHQ-12 scores in the present study further suggests an association between greater symptom severity and caregiver distress.

Regarding coping strategies, problem-focused and emotion-focused approaches were more prominent than avoidant coping in both groups. Walke et al. [14] examined caregiver burden and coping mechanisms among caregivers of individuals with mental illness, providing a relevant Indian context for interpreting these findings. In the present study, female caregivers tended to report greater use of problem-focused, support-seeking, and emotional coping strategies than male caregivers. However, coping strategies were not significantly associated with caregiver distress. This finding suggests that the relationship between coping and psychological well-being may depend on factors beyond illness duration alone, including available support, family resources, and individual coping preferences.

Caregiver burden, measured using the Family Burden Interview Schedule (FBIS), was greater in the chronic-illness group, particularly in the domains of financial burden, disruption of routine family activities, and impact on mental health. These findings are consistent with the broader literature documenting the practical and psychological challenges experienced by families caring for individuals with schizophrenia. Lasebikan and Ayinde [13] examined the prevalence and sociodemographic correlates of family burden among caregivers of patients with schizophrenia, while Mehra et al. [16] investigated caregiver burden and its correlates in a similar population. Rebecca and Kumar et al. [17] also examined family burden and associated factors among caregivers of patients with schizophrenia. Collectively, these studies provide a relevant context for understanding the multiple dimensions of family burden. Onwumere et al. [15] discussed family interventions

in early psychosis, highlighting the relevance of family-focused support during the early stages of illness. In the present study, female caregivers tended to report greater use of problem-focused, support-seeking, and emotional coping strategies than male caregivers. However, coping strategies were not significantly associated with caregiver distress. These findings highlight the importance of assessing individual coping patterns and providing appropriate psychoeducation and family support throughout the course of schizophrenia.

The greater burden in the chronic-illness group may reflect prolonged caregiving responsibilities, cumulative financial demands, and sustained disruption of daily routines. However, because the study was cross-sectional, the findings cannot establish that burden necessarily increases over time in individual caregivers. The absence of a significant difference in physical-health burden between groups, alongside observed urban-rural differences in physical-health impact and financial strain, suggests that socioeconomic and contextual factors may also influence caregiving experiences. These findings highlight the importance of considering both illness-related and family-related factors when assessing caregiver needs.

Overall, the study demonstrates that caregiver distress and caregiver burden may follow different patterns across illness chronicity. Caregivers of patients with recent-onset schizophrenia may require early psychological support, psychoeducation, and guidance regarding treatment and illness management. In contrast, caregivers of patients with chronic schizophrenia may benefit particularly from interventions addressing financial strain, routine disruption, and sustained caregiving demands. Family psychoeducation, coping-skills training, psychosocial support, and appropriate referral for financial assistance may help address these needs. Routine screening for psychological distress and caregiver burden should therefore be considered regardless of illness duration.

The findings should be interpreted in light of certain limitations. The single-centre, cross-sectional design limits generalizability and prevents causal conclusions. The relatively small sample and potential influence of unmeasured socioeconomic and family factors may also have affected the observed differences. Longitudinal, multicentre studies with larger samples are needed to clarify how caregiver burden, coping, and psychological distress evolve over the course of schizophrenia and to evaluate the effectiveness of targeted family interventions.

Generalizability

The findings may apply to similar tertiary-care psychiatric settings. However, the single-centre design, convenience

sampling, and cross-sectional nature limit generalizability. Multicentre and longitudinal studies are needed to validate these findings.

5. Conclusion

Caregivers of schizophrenia patients experience substantial burden, coping demands, and psychological distress irrespective of how long they have been providing care. Overall burden — particularly its financial, routine-disruption, and mental-health components — rises with the chronicity of the patient's illness, consistent with a cumulative caregiving load. Psychological distress, however, was severe in both groups and was, if anything, more pronounced among caregivers of recently diagnosed patients, and correlated significantly with the severity of the patient's symptoms rather than with illness duration alone. These findings support the need for routine screening of caregivers for burden and distress at all stages of a patient's illness — not only after the illness becomes chronic — coupled with structured psychoeducation, coping-skills training, and social and financial support to help families sustain their caregiving role. Longitudinal studies following the same caregiver–patient dyads over time would help clarify how burden, coping, and distress evolve together as schizophrenia progresses.

5.1 Strengths

- Use of validated instruments (PANSS, FBIS, Brief COPE/SCBS Hindi adaptation, GHQ-12) with established psychometric properties, including validated Hindi adaptations suited to the study population.
- Direct clinical assessment of patients by trained mental health professionals rather than reliance on caregiver report alone.
- Comparative design stratified explicitly by chronicity, addressing a relatively understudied question in the caregiving literature.
- Balanced sample across both genders and adequate power based on a priori sample-size calculation.

5.2 Limitations

- Purposive and convenience sampling limits generalisability.
- Possible under-reporting or concealment by caregivers due to stigma associated with psychiatric illness.
- Cross-sectional design precludes conclusions about the trajectory of burden and distress over time within the same caregivers.

- Caregiver health status, quality of life, and the pre-illness caregiver–patient relationship were not assessed and may confound the findings.
- Recruitment from a single tertiary-care centre limits applicability to community samples.

6. Recommendations

Routine screening for caregiver burden and psychological distress, along with psychoeducation, coping-skills training, and psychosocial and financial support, is recommended for caregivers irrespective of illness duration.

7. Acknowledgement

The authors thank the Department of Psychiatry, Dr. S. N. Medical College, Jodhpur, the participating patients and caregivers, and the hospital staff for their support.

8. Funding

The study received no specific external funding.

9. Conflict of Interest

The authors declare no conflict of interest.

10. List of Abbreviations

- **Brief COPE:** Brief Coping Orientation to Problems Experienced
- **FBIS:** Family Burden Interview Schedule
- **GHQ-12:** 12-item General Health Questionnaire
- **ICD-10:** International Classification of Diseases, Tenth Revision
- **PANSS:** Positive and Negative Syndrome Scale
- **SCBS:** Stress Coping Behaviour Scale
- **SPSS:** Statistical Package for the Social Sciences

11. Data Availability

The data are available from the corresponding author upon reasonable request, subject to ethical requirements and participant confidentiality.

12. Author Contributions

Dr. JKS: Conceptualization, methodology, data collection, and drafting.
Dr. NK: Data interpretation and manuscript editing.
Dr. HS: Critical review and revision of the manuscript.
Dr. SG: Supervision and critical revision of the manuscript.

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PUBLISHER DETAILS:



Student's Journal of Health Research Africa
e-ISSN: 2709-9997, p-ISSN: 3006-1059
Vol.6 No. 12 (2025): December 2025 Issue
<https://doi.org/10.51168/wcbjy377>
Original Article

Student's Journal of Health Research (SJHR)

(ISSN 2709-9997) Online

(ISSN 3006-1059) Print

Category: Non-Governmental & Non-profit Organization

Email: studentsjournal2020@gmail.com

WhatsApp: +256 775 434 261

**Location: Scholar's Summit Nakigalala, P. O. Box 701432,
Entebbe Uganda, East Africa**

