

Family Caregiver Burden and Quality of Life among Families Caring for Individuals with Schizophrenia at Mutiara Sukma Mental Hospital, Indonesia: A Cross-Sectional Study

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Abstract: Family caregivers play an essential role in supporting individuals with schizophrenia, particularly in outpatient settings. However, prolonged caregiving responsibilities may produce emotional, physical, social, and financial strain that can affect caregivers' quality of life. This study examined the relationship between caregiver burden and quality of life among family caregivers of individuals with schizophrenia. A descriptive correlational cross-sectional study was conducted at the outpatient clinic of Mutiara Sukma Mental Hospital, West Nusa Tenggara, Indonesia. The study included 89 family caregivers selected using purposive sampling. The sample size was based on a reported outpatient population of 849 individuals and the Slovin formula with a 10% error tolerance. Caregiver burden was assessed using a questionnaire based on the Zarit Burden Interview, while quality of life was assessed using the Schizophrenia Caregiver Quality of Life Questionnaire. We analyzed the relationship between caregiver burden and quality of life using Spearman's rank correlation. Among the 89 caregivers, 45 were women (50.6%) and 44 were men (49.4%). Most participants were aged 36–50 years (62, 69.7%), had university-level education (39, 43.8%), and were homemakers or not working (35, 39.3%). Caregiver burden was categorized as none to little in 19 participants (21.3%), mild to moderate in 43 participants (48.3%), and moderate to severe in 27 participants (30.3%). All participants were classified as having moderate quality of life. Caregiver burden was significantly and negatively correlated with quality of life ($\rho = -0.309$, $p = 0.003$, $n = 89$). Higher caregiver burden was associated with lower quality of life among family caregivers of individuals with schizophrenia. Nurses should routinely assess caregiver burden and provide family-centered education, emotional support, referral, and community-based interventions. Because of the cross-sectional design, interpret the findings as an association rather than a causal relationship.

Keywords: caregiver burden; quality of life; schizophrenia; family caregiver; mental health nursing

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Introduction

Schizophrenia is a severe and often chronic mental disorder associated with disturbances in perception, thinking, behavior, emotional regulation, and social functioning (American Psychiatric Association, 2022). Although treatment is commonly

initiated in hospitals or mental health facilities, many individuals with schizophrenia return to their families and continue treatment through outpatient services. Consequently, family members frequently become responsible for medication supervision, transportation to health services, monitoring of symptoms, assistance

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with daily activities, and management of behavioral changes.

The caregiving role may generate considerable burden. Caregiver burden refers to the physical, psychological, social, and financial difficulties experienced as a consequence of caring for a person with a chronic illness. In schizophrenia, the burden may be intensified by recurrent symptoms, impaired functioning, treatment nonadherence, stigma, and the long duration of care. A systematic review found that caregivers of individuals with psychotic disorders have a substantial prevalence of caregiver burden, particularly when burden is assessed using the Zarit Burden Interview (Cham et al., 2022). Family caregivers may also experience emotional exhaustion, restricted social participation, financial difficulties, and disruption of employment or family roles (Shiraishi & Reilly, 2018; Sustrami et al., 2023).

Quality of life is a multidimensional construct involving psychological and physical well-being, daily functioning, family relationships, social relationships, interaction with health professionals, and material circumstances. The Schizophrenia Caregiver Quality of Life Questionnaire was specifically developed to assess these domains among caregivers of individuals with schizophrenia (Richieri et al., 2011). Unlike generic quality-of-life instruments, the S-CGQoL addresses caregiving-related experiences, including psychological burden, daily life, relationships with family members and friends, interactions with psychiatric services, and material burden.

Previous studies have consistently suggested an inverse relationship between caregiver burden and quality of life. In Indonesia, Tristiana et al. (2019) found a significant negative correlation between caregiver burden and quality of life among 222 caregivers of individuals with schizophrenia in Malang, with a correlation coefficient of -0.434 . Similarly, Winahyu et al. (2015) reported that caregiver burden negatively affected quality of life, whereas employment and perceived social support were positively associated with quality of life. International evidence also indicates that caregiver burden, financial difficulties, unemployment, depression, anxiety, and limited social support are associated with poorer caregiver quality of life (Gagiu et al., 2025; Ribé et al., 2018).

The rationale for the present study is not that the relationship between caregiver burden and quality of life is entirely unknown in Indonesia. Rather, evidence from West Nusa Tenggara and from the outpatient context of Mutiara Sukma Mental Hospital remains limited. Local data are relevant because mental health service organization, family involvement, transportation demands, socioeconomic conditions, and access to

community support may differ across Indonesian regions. This study therefore provides a local description of caregiver burden and quality of life and a baseline association that may inform family-centered mental health nursing services in West Nusa Tenggara. Therefore, this study aimed to determine the relationship between caregiver burden and quality of life among family caregivers of individuals with schizophrenia receiving outpatient.

Method

Study Design and Setting

This study used a descriptive correlational cross-sectional design. Data were collected at the outpatient clinic of Mutiara Sukma Mental Hospital, West Nusa Tenggara, Indonesia, on 25 February 2025.

Participants and Sampling

The study population consisted of family caregivers accompanying individuals with schizophrenia for outpatient care. The reported outpatient population was 849 individuals. The sample size was calculated using the Slovin formula with a 10% error tolerance, resulting in a target sample of 89 participants. Using the Slovin formula, the calculation was $n = N/[1 + N(e^2)] = 849/[1 + 849(0.10^2)] = 89$ participants.

Participants were recruited using purposive sampling. Eligible participants were family members who were directly involved in caring for an individual with schizophrenia and who agreed to participate in the study. Participants who were unable to complete the questionnaire or did not provide consent were not included in the analysis.

Instruments

Caregiver Burden

The previous wording, "questionnaire based on the Zarit Burden Interview," was insufficiently precise. The available manuscript does not establish whether the study used the original validated Zarit Burden Interview, an Indonesian-adapted version, or a researcher-developed instrument based on the ZBI.

The original Zarit Burden Interview is commonly described as a 22-item instrument assessing subjective caregiver burden. The instrument evaluates the subjective burden experienced by caregivers in relation to their caregiving responsibilities. The resulting burden categories were reported as none to little, mild to moderate, and moderate to severe.

Caregiver Quality of Life

Caregiver quality of life was assessed using the Schizophrenia Caregiver Quality of Life Questionnaire. The S-CGQoL was developed specifically for caregivers of individuals with schizophrenia and includes domains related to psychological and physical well-being,

psychological burden and daily life, relationships with family and friends, relationships with the psychiatric team, relationships with a spouse, and material burden (Richieri et al., 2011).

The original S-CGQoL contains 25 items across seven domains: psychological and physical well-being, psychological burden and daily life, relationships with a spouse, relationships with the psychiatric team, relationships with family, relationships with friends, and material burden. The classified quality of life as very poor, 0–20; poor, 21–40; moderate, 41–60; good, 61–80; and very good, 81–100.

Data Collection

Researchers approached potential participants at the outpatient clinic and provided information about the study's purpose and procedures. Written informed consent was obtained from all participants before questionnaire completion. Participants completed the caregiver burden and quality-of-life instruments during the data-collection process. The collected information was analyzed in aggregate without identifying individual participants.

Data Analysis

Descriptive analysis was used to summarize participant characteristics, caregiver burden, and quality-of-life categories using frequencies and percentages. The association analysis was performed using the total continuous caregiver-burden score and total continuous quality-of-life score rather than the categorical labels alone. Spearman's rank correlation was selected because the analysis examined the monotonic relationship between questionnaire-based scores that may be ordinal or non-normally distributed. This method does not require bivariate normality and is appropriate for estimating the direction and strength of a monotonic association. Spearman's rank correlation was used to examine the relationship between caregiver burden and quality-of-life scores. Statistical significance was set at $p < 0.05$.

Result and Discussion

Participant characteristics

A total of 89 family caregivers participated. Women represented 50.6% of the sample, while men represented 49.4%. Most participants were 36–50 years old (69.7%), followed by 20–35 years (18.0%) and 51–70 years (12.4%). University graduates accounted for 43.8%, followed by senior high school graduates (41.6%). The largest occupational group was homemakers or participants not working (39.3%).

Table 1. Participant characteristics (n=89)

Characteristic	n	%
Sex:		
male	44	49.4
female	45	50.6
Age:		
20–35 years	16	18.0
36–50 years	62	69.7
51–70 years	11	12.4
Education:		
elementary school	1	1.1
junior high school	12	13.5
senior high school	37	41.6
university	39	43.8
Occupation		
homemaker/not working	35	39.3
self-employed	26	29.2
laborer	14	15.7
trader	12	13.5
farmer	2	2.2

Caregiver burden and quality of life

The most common caregiver-burden category was mild to moderate burden, reported by 43 participants (48.3%). A moderate to severe burden was reported by 27 participants (30.3%), while 19 participants (21.3%) reported none to little burden. No participant was reported in the very severe category.

Table 2. Caregiver burden and quality of life (n=89)

Caregiver-burden category	n	%
None to little	19	21.3
Mild to moderate	43	48.3
Moderate to severe	27	30.3
Total	89	100.0

All 89 participants were classified as having moderate quality of life based on the reported score range of 41–60. No participant was classified as having very poor, poor, good, or very good quality of life.

Table 3. Quality of life category (n=89)

Quality-of-life category	n	%
Very poor	0	0.0
Poor	0	0.0
Moderate	89	100.0
Good	0	0.0
Very good	0	0.0
Total	89	100.0

Relationship between caregiver burden and quality of life

Spearman's rank correlation showed a statistically significant negative relationship between caregiver burden and quality of life ($\rho = -0.309$, $p = 0.003$, $n =$

89). The negative direction indicates that participants reporting higher caregiver burden tended to report lower quality of life. The magnitude of the coefficient indicates a small-to-moderate monotonic association and does not establish causality.

Table 4. Relationship between caregiver burden and quality of life (n=89)

Variable	Spearman's rho	p-value	n
Caregiver burden and quality of life	-0.309	0.003	89

Discussions

This study found a statistically significant negative relationship between caregiver burden and quality of life among family caregivers of individuals with schizophrenia. The correlation coefficient was -0.309 , indicating that greater caregiver burden was associated with lower quality of life. Although the association was statistically significant, its magnitude was not large. Therefore, caregiver burden should be understood as one contributor to quality of life rather than the sole determinant.

The finding is consistent with previous Indonesian research. Tristiana et al. (2019) reported a stronger inverse correlation between caregiver burden and quality of life among 222 caregivers in Malang, Indonesia. Winahyu et al. (2015) similarly found that caregiver burden negatively affected quality of life, while perceived social support and employment were positively associated with quality of life. The consistency of these findings across Indonesian settings suggests that the caregiving experience may influence multiple dimensions of family well-being, including psychological health, social participation, financial circumstances, and daily functioning.

The current correlation was weaker than the coefficient reported by Tristiana et al. (2019). Several methodological and contextual factors may explain this difference. The present study included a smaller sample of 89 participants and was conducted at a single outpatient clinic. The participants may also have differed in terms of family relationship, duration of caregiving, patient symptom severity, household income, treatment adherence, and access to social support. These variables were not analyzed in the current study and may influence the strength of the relationship between burden and quality of life.

A notable finding was that all participants were categorized as having moderate quality of life. This restricted categorical variation should be considered when interpreting the result. The significant correlation was based on the underlying questionnaire scores, which may still vary within the moderate category.

Nevertheless, the limited spread of the grouped outcome may have affected the strength and precision of the correlation. Future studies should report the full score distribution, mean, standard deviation, median, interquartile range, and domain-specific results.

The proportion of caregivers experiencing mild to moderate or moderate to severe burden was substantial. This pattern is consistent with systematic reviews showing that caregivers of individuals with psychotic disorders experience clinically relevant burden (Cham et al., 2022). Caregiving responsibilities may involve supervising treatment, managing behavioral changes, accompanying patients to health services, addressing stigma, and providing continuous emotional support. These responsibilities may become particularly demanding when formal mental health services are limited or when caregivers have insufficient knowledge and social support. However, the present study cannot determine which specific caregiving demands produced the reported burden because those mechanisms were not measured.

The relationship between burden and quality of life is likely multidimensional. Caregiver burden may interfere with sleep, employment, social relationships, and emotional well-being. At the same time, reduced quality of life may limit a caregiver's coping resources and make caregiving responsibilities feel more demanding. Thus, the relationship may be reciprocal rather than unidirectional. A recent systematic review identified caregiver burden, depression, anxiety, financial difficulties, unemployment, lower education, and limited social support as important factors associated with caregiver quality of life (Gagiu et al., 2025).

The results also support the need to assess caregivers as part of routine outpatient mental health care. Family caregivers are not merely companions who transport patients to the hospital. They are active participants in treatment continuity, symptom monitoring, medication support, and relapse prevention. However, their needs may remain invisible if services focus exclusively on the patient. Nurses are well positioned to identify caregiver distress, provide psychoeducation, facilitate communication with the psychiatric team, and connect families with social and community resources.

The findings should not be interpreted causally. Because the study was cross-sectional, caregiver burden and quality of life were measured at the same time. The study therefore cannot establish whether burden causes reduced quality of life, whether reduced quality of life increases perceived burden, or whether both are influenced by other factors. Longitudinal and intervention studies are needed to examine changes over

time and determine whether reducing caregiver burden improves quality of life.

Implications for Nursing

The findings have several implications for mental health nursing practice. First, caregiver burden and quality of life should be included in routine outpatient assessment. A brief screening process can identify caregivers who experience moderate to severe burden and may require additional support. Caregivers with moderate to severe burden should receive further assessment of psychological distress, sleep, safety concerns, social support, financial strain, and their ability to continue caregiving.

Second, nurses should provide structured psychoeducation about schizophrenia, medication adherence, early warning signs, relapse prevention, crisis management, and communication strategies. Psychoeducation may improve caregiver knowledge and confidence while reducing uncertainty about the caregiving role. Evidence from intervention research indicates that psychoeducational programs can reduce caregiver burden, particularly when they are delivered in a structured and continuing format (Okafor & Monahan, 2023; Sin et al., 2017).

Third, outpatient services should consider caregiver support groups. Group-based support can reduce social isolation, normalize caregiving experiences, and allow families to exchange practical strategies. Support groups may be particularly important for caregivers who are homemakers or not working because they may have fewer opportunities for social participation outside the home.

Fourth, nurses should assess practical stressors, including transportation costs, treatment expenses, employment disruption, family conflict, and access to social support. The quality of life of family caregivers is not determined only by psychological factors. Financial and social circumstances also shape the caregiver's ability to sustain long-term care.

Finally, caregiver interventions should be integrated into family-centered mental health services. Nurses can coordinate referrals to psychiatrists, psychologists, social workers, community mental health teams, and social assistance programs. The goal is not to transfer all responsibility to the family but to strengthen the family's capacity while ensuring that caregivers also receive appropriate care.

Limitations

This study has several limitations. First, the cross-sectional design prevents causal interpretation. The findings demonstrate an association between caregiver burden and quality of life but do not establish temporal direction.

Second, the study used purposive sampling at a single outpatient clinic, which may limit generalizability to caregivers in other hospitals, community settings, rural areas, or regions of Indonesia. The sample size was also relatively small.

Third, the data were based on self-reported questionnaires and may have been affected by recall bias, response bias, or participants' desire to provide socially acceptable answers.

Finally, the quality-of-life results showed that all participants were categorized as having moderate quality of life. This restricted categorical variation limits interpretation and may reduce the ability to distinguish caregivers with relatively better or poorer quality of life. Future studies should analyze continuous scores and each quality-of-life domain separately.

Conclusion

Caregiver burden was significantly and negatively associated with quality of life among family members caring for individuals with schizophrenia at the outpatient clinic of Mutiara Sukma Mental Hospital ($\rho = -0.309$, $p = 0.003$). Higher burden tended to accompany lower quality of life. Nurses should incorporate caregiver-burden screening, family psychoeducation, coping support, and psychosocial referral into outpatient mental health services. Future studies should use larger multisite samples, longitudinal designs, and multivariable models that include patient clinical status, caregiving duration, social support, stigma, and economic conditions.

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Author Contributions

Conceptualization, SKD. and E.P.R.; methodology, SKD. and E.P.R.; software, E.P.R.; validation, SKD., E.P.R., and N.M.S.; formal analysis, E.P.R.; investigation, E.P.R.; resources, S. and N.M.S.; data curation, E.P.R.; writing—original draft preparation, E.P.R.; writing—review and editing, S. and N.M.S.; visualization, E.P.R.; supervision, SKD. and N.M.S.; project administration, E.P.R.; funding acquisition, none. All authors have read and approved the final manuscript.

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Conflicts of Interest

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