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Research Article

Quality of Life and Relapse Prevention Behaviors among Family Caregivers of Individuals with Schizophrenia: The Mediating Role of Psychological Distress

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Abstract

Background: Caring for individuals with schizophrenia presents major emotional and psychological challenges, particularly in low-resource settings like Indonesia. Family caregivers often face high levels of burden and stress due to the lack of professional support and cultural expectations. ***Objective***: To examine whether psychological distress mediates the relationship between caregivers' quality of life (QoL) and relapse prevention behaviors with caregiver burden in the context of schizophrenia care. ***Methods***: A cross-sectional study was conducted among 104 primary family caregivers at Puskesmas Sempor 1, Central Java. Data were collected through structured face-to-face interviews using validated instruments: WHOQOL-BREF for QoL, a self-developed 10-item relapse prevention behavior scale, the Perceived Stress Scale, and the Zarit Burden Interview (ZBI). Data were analyzed using ANOVA, multiple linear regression, and Hayes' PROCESS Macro Model 4 with 5,000 bootstrap samples to test for mediation. ***Results***: Most participants were female (78.8%), aged 36–55 (57.7%) and lived with the patient (92.3%). Mean scores reflected moderate levels across QoL (M=2.59), relapse prevention behavior (M=2.34), psychological distress (M=1.88), and caregiver burden (M=2.06). ANOVA indicated significant differences in psychological distress by QoL and relapse prevention levels ($p < 0.001$). Regression indicated that higher QoL and relapse prevention predicted lower distress, with distress partially mediating their effects on caregiver burden. ***Conclusions***: Psychological distress partially mediates the association between quality of life, relapse prevention, and caregiver burden.

Keywords: Caregiver burden; Quality of life; Mediation; Psychological distress; Relapse prevention; Schizophrenia.

سلوكيات جودة الحياة والوقاية من الانتكاس بين مقدمي الرعاية الأسرية للأفراد المصابين بالفصام: الدور الوسيط للضيق النفسي

الخلاصة

الخلفية: رعاية المصابين بالفصام تمثل تحديات عاطفية ونفسية كبيرة، خاصة في البيئات ذات الموارد المنخفضة مثل إندونيسيا. غالبا ما يواجه مقدمو الرعاية العائلية مستويات عالية من العبء والتوتر بسبب نقص الدعم المهني والتوقعات الثقافية. **الهدف**: دراسة ما إذا كان الضيق النفسي يتوسط في العلاقة بين جودة حياة مقدمي الرعاية (QoL) وسلوكيات الوقاية من الانتكاس مع عبء مقدم الرعاية في سياق رعاية الفصام. **الطرائق**: أجريت دراسة مقطعية بين 104 مقدمي رعاية أساسيين في مركز بوسكيسماس سيمبور 1، جاوة الوسطى. تم جمع البيانات من خلال مقابلات منظمة وجها لوجه باستخدام أدوات موثقة: WHOQOL-BREF لجودة الحياة، مقياس سلوك الوقاية من الانتكاس مكون من 10 بنود مطور ذاتيا، مقياس التوتر المدرك، ومقابلة عبء زاريت (ZBI). تم تحليل البيانات باستخدام ANOVA، والانحدار الخطي المتعدد، ونموذج هايز الماكرو PROCESS 4 مع 5,000 عينة تمهيد لاختبار الوساطة. **النتائج**: كان معظم المشاركين من الإناث (78.8٪)، وتتراوح أعمارهم بين 36–55 عاما (57.7٪) وعاشوا مع المريض (92.3٪). عكست الدرجات المتوسطة مستويات متوسطة عبر جودة الحياة (M=2.59)، وسلوك الوقاية من الانتكاس (M=2.34)، والضيق النفسي (M=1.88)، وعبء مقدم الرعاية (M=2.06). أشارت ANOVA إلى فروق كبيرة في الضيق النفسي حسب جودة الحياة ومستويات الوقاية من الانتكاس ($p<0.001$). أشارت النتيجة إلى أن جودة الحياة الأعلى والوقاية من الانتكاس تنبأ بانخفاض الضيق، مع أن الضيق يتوسط جزئيا في تأثيرها على عبء مقدمي الرعاية. **الاستنتاجات**: يلعب الضيق النفسي دورا وسيطا مهما في العلاقة بين جودة حياة مقدمي الرعاية، وسلوكيات الوقاية من الانتكاس، وعبء مقدم المرض.

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INTRODUCTION

Schizophrenia is a chronic, severe mental disorder that affects approximately 20 million people worldwide, often leading to significant impairments in cognition, emotion regulation, and social functioning [1]. In the Indonesian context, mental health infrastructure is often underdeveloped, and there is a scarcity of specialized healthcare professionals such as psychiatrists and mental health nurses [2]. As a result, caregiving responsibilities, including symptom management, medication supervision, and emotional and financial support, are predominantly shouldered by families, who frequently lack professional training [3]. This informal caregiving model, while culturally rooted in familial responsibility, may increase the risk of emotional strain and psychological distress among caregivers [4]. Prolonged caregiving under stressful conditions can deteriorate caregivers' physical and mental health, compromise their quality of life (QoL), and contribute to caregiver burnout [5]. In turn, this distress may negatively influence the caregiver's ability to perform relapse prevention behaviors, such as ensuring treatment adherence and recognizing early warning signs of psychotic episodes [6]. For instance, Awad and Voruganti reported that caregivers of individuals with schizophrenia often experience depression, anxiety, and a reduced sense of well-being [7]. Furthermore, research suggests that heightened caregiver burden may contribute to increased relapse rates among patients due to inconsistent or ineffective caregiving practices. However, most of these studies are concentrated in high-income countries, and there remains a significant research gap in low- and middle-income countries (LMICs), including Indonesia, where sociocultural dynamics and resource limitations present unique challenges [8]. A study emphasized the need for culturally sensitive, evidence-based interventions in LMICs to enhance family caregivers' capacity and resilience. Drawing on the Stress Process Model, this study conceptualizes QoL and relapse prevention behaviors as protective resources that may buffer the effects of caregiving stressors [9]. Psychological distress is hypothesized to serve as a mediating factor, shaping how these protective variables influence caregiver burden. By exploring these pathways, this study aims to provide a comprehensive understanding of the psychological mechanisms underlying caregiver experiences, particularly in low-resource settings like Indonesia. Therefore, the objective of this study is to examine the relationship between quality of life (QoL) and relapse prevention behaviors and caregiver burden and to determine whether psychological distress mediates these relationships.

METHODS

Study design and setting

This study employed a quantitative, cross-sectional design conducted between May and June 2024 in the service area of *Puskesmas Sempor 1*, Central Java, Indonesia. The region encompasses both rural and semi-urban populations, offering a representative context of caregiving environments for individuals with schizophrenia in Indonesia.

Participants and sampling technique

Participants were selected using a purposive sampling method. Inclusion criteria were 1) being the primary caregiver of an individual diagnosed with schizophrenia for a minimum duration of six months, 2) being aged 18 years or older, 3) actively providing care for patients undergoing outpatient treatment, and 4) being fluent in Bahasa Indonesia. Exclusion criteria included caregivers who had been diagnosed with any psychiatric disorders or those currently undergoing psychiatric treatment. Sample size estimation was calculated using Cochran's formula for finite populations. A minimum of 96 participants was deemed adequate; however, 104 caregivers were ultimately recruited to increase the statistical power and account for potential nonresponse.

Data collection procedures

Data were collected through structured, face-to-face interviews conducted by trained enumerators [10]. Each session lasted approximately 30–45 minutes, during which informed consent was obtained prior to participation. Respondents were assured of confidentiality, and anonymity was preserved throughout the study.

Instrument

This study used several standardized and validated instruments to measure key variables. Quality of life (QoL) was measured using the Indonesian version of the WHOQOL-BREF, a 26-item instrument covering four main domains: physical health, psychological well-being, social relationships, and environment. Each item is answered on a 5-point Likert scale (1 = very poor to 5 = very good), where higher scores indicate better quality of life [11]. Relapse prevention behavior (RRB) was measured using a self-developed 10-item questionnaire, adapted to the context of caregiving in Indonesia [12]. This instrument assesses caregiver involvement in relapse prevention activities such as monitoring medication adherence, following up on appointments, and early detection of advanced symptoms. Each item is rated on a 3-point Likert Scale (1 = rarely, 2 = sometimes, 3 = always), with higher scores indicating greater involvement in relapse prevention. Psychological distress was measured using the Perceived Stress Scale [13]. Consisting of 10 items that measure an individual's perception of stress towards life situations during the past month. Items are rated using a 5-point Likert Scale (0 = never to 4 = very often), with a total score ranging from 0 to 40; the higher the score, the higher the level of perceived stress. Meanwhile, caregiver burden was measured using the Zarit Burden Interview (ZBI), a widely used tool to assess caregivers' perceived burden related to time, financial costs, emotional distress, and social isolation. This instrument consists of 22 items with a 5-point Likert scale (0 = never to 4 = almost always), where higher scores indicate greater levels of burden [14].

Ethical considerations

The study was conducted following ethical approval from the Research Ethics Committee of Mahardika number KEP. 108/KEPK.ITEKESMA/III/2024 All procedures adhered to the principles outlined in the Declaration of Helsinki.

Data analysis

The data analysis in this study encompassed several statistical procedures to ensure comprehensive interpretation of the research findings [15]. Descriptive statistics were first computed to summarize demographic characteristics and key study variables, including means, standard deviations, frequencies, and percentages [16]. To investigate group differences, Analysis of Variance (ANOVA) was employed to examine variations in psychological distress across different categories of quality of life (QoL) and relapse prevention behavior. Furthermore, multiple linear regression analysis was used to identify significant predictors of caregiver burden, with QoL and relapse prevention behavior as the primary independent variables. To explore the underlying mechanism of the relationships, mediation analysis was conducted using Hayes' PROCESS Macro Model 4 with 5,000 bootstrap samples. This approach tested whether psychological distress served as a mediator between (a) QoL and caregiver burden and (b) relapse prevention behavior and caregiver burden, with the significance of the indirect effects assessed through bias-corrected 95% bootstrap confidence intervals [17].

RESULTS

In Table 1, among the 104 respondents, the majority were female (78.8%) and aged between 36 and 55 years (57.7%). Most had an education level below high school (63.5%) and a monthly income of less than IDR 500,000 (50.0%).

Table 1: Sociodemographic profile of respondents (n = 104)

Variable	Category	Frequency (%)
Gender	Female	82(78.8)
Age	36–55 years	60(57.7)
Education Level	< High School	66(63.5)
Monthly Income	< IDR 500,000	52(50)
Living with Patient	Yes	96 (92.3)

Nearly all participants (92.3%) lived with the individual they were caring for, indicating close daily contact and caregiving involvement. Table 2 shows the mean score for perceived stress was 1.88±0.64, suggesting a moderate level of stress among caregivers. The mean quality of life (QoL) score was 2.59±0.6, while the relapse prevention behavior score averaged 2.34±0.72, indicating a moderate engagement in both aspects.

Table 2: Mean scores of study variables

Variable	Mean±SD	Range	Maximum
Perceived Stress (PSS-10)	1.88±0.64	1.0-3.0	3.00
Quality of Life (QoL)	2.59±1.0	1.0-4.0	4.00
Relapse Prevention	2.34±1.0	1.0-3.0	3.00

Analysis of variance (ANOVA) in Table 3 showed that both quality of life ($p< 0.001$) and relapse prevention behavior ($p< 0.001$) had statistically significant effects on caregiver stress levels.

Table 3: ANOVA on Stress by QoL and relapse prevention levels

Source	F	*p*-value
QoL and Stress	26.587	< 0.001
Relapse Behavior and Stress	11.012	< 0.001

This suggests that variations in QoL and relapse prevention behavior are strongly associated with different levels of perceived stress. Table 4 shows the regression model significantly predicted perceived stress ($R^2= 0.525$, $p< 0.001$), with quality of life ($\beta= -0.470$, $p< 0.001$) and relapse prevention behavior ($\beta= -0.387$, $p< 0.001$) both showing significant negative associations. This means higher QoL and better relapse prevention behavior are significantly linked to lower caregiver stress.

Table 4: Multiple linear regression predicting stress

Predictor	B	SE	β	*p*-value
Constant	3.961	0.203	-	<0.0001
Quality of Life	-0.490	0.079	-0.470	<0.0001
Relapse Behavior	-0.346	0.068	-0.387	<0.0001
Model Summary: $R^2 = 0.525$; F(2,101) = 55.963; $p< 0.001$				

Relationship between quality of life and stress in Table 5. The direct effect of QoL on stress remained significant ($\beta = -0.490$, $p< 0.001$), while the indirect effect through relapse prevention behavior was also significant ($\beta = -0.169$, 95% CI: [-0.252, -0.092]). The total effect was $\beta = -0.659$ ($p< 0.001$), confirming that improved QoL reduces stress both directly and indirectly via better relapse prevention behavior.

Table 5: Mediation results: QoL → stress via relapsed behavior

Effect Type	β	95% CI	*p*-value
Direct Effect	-0.490	[-0.621, -0.359]	< 0.001
Indirect Effect	-0.169	[-0.252, -0.092]	< 0.001
Total Effect	-0.659	[-0.778, -0.540]	< 0.001

DISCUSSION

This study shows a strong link between caregivers' quality of life (QoL) and their involvement in relapse prevention for individuals with schizophrenia. Caregivers with higher QoL are better able to ensure medication adherence, recognize early warning signs, and manage stress triggers. Conversely, poor physical and emotional health reduces their ability to intervene effectively [9]. High QoL also enhances caregivers' social functioning, self-efficacy, and problem-solving skills, enabling more adaptive responses to caregiving challenges [18]. These findings highlight the interdependence of caregiver well-being and patient outcomes, reinforcing the importance of a family-centered approach in schizophrenia care [19]. This study confirmed that psychological distress partially mediates the link between caregivers' QoL and relapse prevention behaviors. Even with good QoL, high levels of anxiety, depression, or emotional strain can limit caregiving effectiveness, supporting Lazarus and Folkman's Stress and Coping Theory [20, 21]. The findings emphasize that QoL and psychological functioning are distinct; improving QoL alone is insufficient without addressing distress. Evidence-based interventions such as psychoeducation, CBT, mindfulness, and peer support can reduce distress and enhance caregiving performance. Integrating these into family-centered care plans is essential to strengthen both caregiver well-being and patient outcomes [22,23]. In Indonesia's collectivist culture, caregiving is seen as a moral obligation, fostering family solidarity but often masking caregiver distress. While shared responsibility can provide meaning and resilience, it may also suppress emotional expression, leading to shame, guilt, or depression when caregiving outcomes such as relapse are unfavorable. These cultural dynamics highlight the need for interventions that are not only family-centered but also culturally sensitive, addressing stigma and promoting help-seeking. Community education, tailored psychoeducation, and collaboration with religious or local leaders can reduce caregiver burden and create more supportive environments [24–26]. The findings highlight the need for integrated, caregiver-inclusive mental health services. Routine screening for caregiver distress (e.g., using DASS, Zarit Burden Interview, or Caregiver Strain Index) should complement patient monitoring. Structured caregiver training in relapse prevention covering medication management, symptom recognition, stress reduction, and emergency response can enhance competence and engagement. Support groups and coping-skills programs should be expanded to reduce isolation and build resilience, facilitated by professionals, peer mentors, or community health workers. Policymakers and hospital administrators must allocate resources for respite care, counseling, and caregiver education, recognizing caregivers as key stakeholders. Shifting toward holistic, family-based care models such as family therapy, caregiver inclusion in discharge planning, and caregiver helplines can improve outcomes by lowering relapse rates and hospital stays.

Conclusion

This study confirms that higher quality of life among family caregivers is associated with greater engagement in relapse prevention behaviors for individuals with schizophrenia. However, psychological distress significantly mediates this relationship, reducing the effectiveness of caregiving even when QoL is high. These findings underscore the importance of integrated support programs that both enhance caregiver well-being and address emotional burden. Culturally sensitive interventions are essential to improve outcomes for both caregivers and care recipients, especially in collectivist settings such as Indonesia.

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Conflict of interests

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Data sharing statement

Supplementary data can be shared with the corresponding author upon reasonable request.

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