Original Article

The Caregiver Burden and Family Coping in Families with Schizophrenia: Cross-sectional Study

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Abstract

Background: Schizophrenia causes social conflict because it brings a burden of care for family caregivers. Thus, effective handling and management strategies are needed. This study aims to identify the relationship between family caregiver burden and family coping in schizophrenia patients. **Materials and Methods:** This cross sectional study design was conducted on 73 family caregivers of schizophrenia patients in Lamongan Regency, Indonesia, in 2023 through a purposive sampling technique. The Burden Scale for Family Caregivers (BSFC-s) was used to measure the burden of care, and the Brief-COPE scale was used to measure family coping felt by families of schizophrenia patients. Data were analyzed using univariate and bivariate analysis, including the Spearman rank test, using Microsoft Excel and IBM Corp SPSS Statistics 24 applications. **Results:** There was a significant negative relationship between the emotional support dimension in the family coping variable and the burden of family caregivers (r = −0.71, p = <0.001), and a significant negative relationship between the acceptance dimension in the family coping variable and the burden of family caregivers (r = −0.80, p = <0.001). Overall, the Spearman rank test results showed a significant negative relationship between family coping and family caregiver burden (r = −0.82, p = <0.001). **Conclusions:** There is a significant negative correlation between caregiving burden and family coping in schizophrenia patients. This requires increased reciprocal cooperation to reduce the burden on families in providing care for schizophrenia patients.

Keywords: *Burden, caregiver, coping, family, schizophrenia*

Introduction

Patients with schizophrenia impose a significant burden on their family members[1] due to their dependence on others and unpredictability.[2] This is the main reason why individuals with schizophrenia are often late in seeking treatment.[3] Research indicates the central role of families as informal caregivers in continuing care at home.[4] Additionally, the family bears a moral responsibility to provide a comfortable home atmosphere so that patients with schizophrenia can adapt to the new psychological environment and conduct cognitive and behavioral reconstruction to achieve stable emotions. This can be attained if family members interact, understand, and help each other.[5] However, the presence of a patient with schizophrenia renders the family atmosphere stressful, and constant supervision places a significant burden on the family members.[6]

According to the World Mental Health Report, the global population of patients with schizophrenia at the end of 2019 was 24 million people—approximately 1 in 200 adults (aged 20 years and over).[7] In addition to emotional problems such as irritability,[8] individuals with schizophrenia experience many other challenges. These include abnormalities related to motivation and behavior, lack of willpower, disturbed or unstable verbal/emotional responses, etc. These issues exacerbate the burden on the family.[9] Furthermore, society stigmatizes patients with schizophrenia as individuals who have failed morally, always depend on others, endanger the environment, and exhibit unproductive behavior. This stigma can be traced back to the family, further aggravating their burden.[10] Additionally, the social stigma that patients with schizophrenia are cursed and atoning for past sins augments the family's suffering.[11]

The burden of care is also a predictor of psychological stress experienced by the family. It adversely impacts the family's motivation, leading to withdrawal from

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maximum involvement in the healing process.[12] The family's inability to adapt to these changes can negatively impact the home atmosphere, inducing the exploration of alternative coping mechanisms.[13] Scientific evidence indicates that adaptive coping strategies can be employed to minimize the burden on the family.[14] Therefore, family caregivers must possess the necessary skills to choose effective coping strategies to reduce the burden of caring for patients with schizophrenia. These coping strategies include instrumental support, emotional support, active coping, planning, acceptance, distraction, denial, humor, self-blame, behavioral disengagement, venting, positive reframing, substance use, and religious approaches. Among these strategies, instrumental support and religious approaches are the most frequently applied, although drug abuse is also common.[15] Family-based psychiatric nursing practice through psychoeducational therapy can provide families with the necessary experience to determine effective coping strategies to help individuals with schizophrenia recover.[16] Additionally, exploring personal resources and family environments can foster resilience in caring for patients with schizophrenia.[17] Family-based interventions are extremely effective in reducing both negative and positive symptoms in patients with schizophrenia.[2] Therefore, families as caregivers need to apply several coping strategies.[18] Thus, this study aims to determine the relationship between caregiver burden and family coping in families of schizophrenia patients.

Materials and Methods

This study was conducted from March 13 to April 28, 2023. A descriptive correlational research design was used in this study to determine the relationship between family caregiving burden and coping in families of schizophrenia patients. Participants in this study numbered 100, and based on the sample size from the table list that had been calculated by Krejcie and Morgan using power analysis, namely X2 = 3.841, N = 100, P = 50, and d = 0.05, the sample size in this study was 80 respondents. Because six refused to participate, 73 participants were included in this study. Purposive sampling was used to recruit samples with the following inclusion criteria: (1) Families of schizophrenia patients who are undergoing treatment or care; (2) living in the same house as schizophrenia patients; and (3) first-degree relatives who care for schizophrenia patients. Samples were excluded if family members refused to participate. Family caregiver burden was measured using the Burden Scale for Family Caregivers (BSFC-s), tested on dementia patients, and produced high internal consistency, indicated by a Cronbach's alpha value of 0.92.[19] Furthermore, the BSFC-s was tested on 20 family caregivers of schizophrenia patients before being used by researchers to measure the burden of caregiving to see the validity of the instrument, containing 10 statement items with four possible answer categories (1 = disagree; 2 = neutral; 3 = agree; 4 = strongly agree). The results of the instrument validity test showed a Cronbach's alpha value of 0.880. In addition, the Brief-COPE Scale, which was developed in Chile in a population aged 11–86 years who were exposed to various stressful events, was used to measure the Family Coping Scale for Schizophrenia, where the results of the model 1 test showed a value of $\chi 2$ = 1079.42, df = 259, $\chi 2$/df = 4.17, CFI = 0.94, NFI = 0.92, TLI = 0.91, PNFI = 0.59, AIC = 1429.42, RMSEA = 0.04, 90% CI = 0.04–0.05 with P value < 0.001.[15] Furthermore, Brief-COPE was tested on 20 family caregivers of schizophrenia patients before being used by researchers to measure the coping scale, containing 14 factors with 28 statement items with four possible answer categories (1 = disagree; 2 = neutral; 3 = agree; 4 = strongly agree). The results of the instrument validity test showed a Cronbach's alpha value of 0.945.

This study used the Indonesian version of the questionnaire after obtaining permission to use it from each instrument developer. Furthermore, researchers conducted back-translation from English to Indonesian with the help of a translation agency.

Demographic data, including age, gender, education, occupation, and kinship with schizophrenia patients, have been carefully identified. The questionnaire link was distributed to participants with the help of a mental health clinic nurse, after obtaining consent from the respondents. Researchers verified the data and obtained appropriate and complete data. The collected data were then analyzed by researchers using univariate and bivariate analysis. In the univariate analysis, data on the burden of families with schizophrenia and coping instruments were presented by researchers in the form of percentages. Bivariate analysis involving a correlation test using the Spearman rank test was used by researchers to ensure the existence of a relationship between the two variables. Both variables are ordinal data: the family care burden variable and the family coping variable, and a comprehensive analysis was carried out with a significance value of $p < 0.05$.

Ethical considerations

The study was approved by the Muhammadiyah Lamongan University Research Ethics Committee with reference number 273/EC/KEPK-S1/05/2023 (March 2, 2023). Respondents were informed about the research purpose and estimated participation duration. Confidentiality of identity and personal data was ensured. Participants were informed about the voluntary nature of participation. All participants received transportation assistance of Rp. 50,000. The questionnaire was designed to avoid causing any harm to the respondents during completion.

Results

Respondents' characteristics

The respondent characteristics were reported according to age, gender, education level, occupation, and relationship to the patient [Table 1].

Statistical description based on research variables

The results of the statistical description test showed that caregiver burden was most significantly felt in caregiving, with a mean value and standard deviation of 2.8493 ± 0.63838. Meanwhile, family coping attributed to patients with schizophrenia was found in religion, with a mean value and standard deviation of 3.1027 ± 0.57710. The overall results are presented in Table 2.

Description of the relationship between variable dimensions

Regarding the results of the correlation test between variable dimensions of family coping and caregiver burden, four dimensions of the family coping variable showed no relationship with caregiver burden. These include the denial variable dimension (r = −0.20; p > 0,05), humor (r = −0.16; p > 0.05), self-blaming (r = −0.64; p > 0.05), and substance use (r = −0.13; p > 0.05). Three dimensions of the family coping variable exhibited a strong negative relationship with the burden of family caregivers, including the dimensions of emotional support (r = −0.71; p = < 0.001), behavioral disengagement (r = −0.68; p < 0.001), and religion (r = −0.67; p < 0.001). Furthermore, the seven dimensions of the family coping variable exhibited an extremely strong negative relationship with the burden of family caregivers. The acceptance variable dimension was most prominently related to the burden of family caregivers among the seven dimensions of the coping variable (r = −0.82; p = < 0.001).

The results of bivariate non-parametric statistical tests between the burden of family caregivers and coping are also reported. The research results suggest a significant relationship between burden and coping in families that have members with mental disorders, with results of p = < 0.001 and r = −0.82 [Table 3].

Table 1: Characteristics of families with schizophrenia, *n*=73

Variable		*n* (%)
Age	<17 years	8 (10.96)
	17–35 years	19 (26.03)
	36–50 years	34 (46.57)
	50–65 years	12 (16.44)
Gender	Man	18 (24.66)
	Woman	55 (75.34)
Level of education	Not in school/not finished elementary school	30 (41,09)
	Elementary school	19 (26.03)
	Junior High School	16 (21.92)
	Senior High School	6 (8.22)
	Diploma/Bachelor's degree	2 (2.74)
Work	Not working/Homework	12 (16.44)
	Farmer/plantation	32 (43.83)
	Private	19 (26.03)
	Self-employed	8 (10.96)
	Civil servant	2 (2.74)
Relationship with Family	Parent	26 (35.61)
	Child	9 (12.33)
	Siblings/relatives	24 (32.88)
	Partner	14 (19.18)

Discussion

This study aimed to identify the relationship between the burden on caregivers and family coping for patients with schizophrenia.

Among these attributes, "caregiving is taking strength" and "conflicting demands" are considered the heaviest family burdens. This is because individuals with schizophrenia experience issues with social and emotional functioning and have difficulty finding decent job opportunities. Therefore, throughout their lives, they depend on support from family members, which induces confusion between the desire to help individuals with schizophrenia and their obligations, as they also have their responsibilities.[20] Motivated by feelings of humanity and sibling bonds, significant steps are taken by the family. Family members act as informal caregivers, attempting to spend much time together and helping to increase assertive behavior. The presence of family is crucial for patients with schizophrenia.[21] Moreover, families do not expect much from individuals with schizophrenia because they are aware of their psychological and social challenges that may persist lifelong. An individual with schizophrenia who meets his or her needs and does not cause difficulties for the family exceeds the family's expectations because he or she is considered capable of living independently.[22]

Other results also report that the religious attribute in the coping variable has the highest score among the attributes that form the structure of the family coping variable, where the score obtained showed a mean value and standard deviation of 3.1027 ± 0.57710. Not ignoring the roles of other attributes that form the coping variables, the role of religious attributes provides a concrete direction and goals to illustrate the importance of a religious spiritual approach as an inner defense mechanism in addressing complex challenges in the lives of families of patients with schizophrenia.[23] Additionally, this religious approach is adopted by caregivers of individuals with schizophrenia as a positive coping mechanism to remain calm and peaceful and ensure the psychological well-being of the family.[24] This can contribute to the creation of harmony in the family, which can improve the quality of life of individuals with schizophrenia as well as of caregivers.[25]

It is noteworthy that the venting attribute has the second-highest score after the religious dimension in the coping variable, illustrating the significance of expressing one's feelings to others to obtain a response. Patients with schizophrenia experience complex issues; therefore, management has different levels, starting from the intrapersonal, interpersonal, community, organizational, to structural levels.[26] Thus, revealing family problems

Table 2: Frequency of perceived subjective burden and family coping with schizophrenia, *n*=73

Variable	Dimensions	Mean±Standard Deviation
Burden	Reduced life satisfaction	2.6438±0.63179
	Physical exhaustion	2.5616±0.66638
	Wish to run away	2.7397±0.72701
	Depersonalization	2.7808±0.67178
	Decreased standard of living	2.7123±0.65573
	Health affected by caregiving	2.7945±0.66581
	Caregiving is taking strength	2.8493±0.63838
	Conflicting demands	2.8356±0.68746
	Worried about the future	2.7260±0.62938
	Relationships with others are suffering	2.6575±0.58260
Coping	Instrumental support	2.7192±0.78610
	Emotional support	2.6164±0.90339
	Active coping	2.7329±0.79966
	Planning	2.7329±0.72688
	Acceptance	2.7534±0.70771
	Self-distraction	2.7740±0.79948
	Denial	2.6712±0.48030
	Humor	2.3904±0.33589
	Self-blaming	2.0342±0.45130
	Behavioral disengagement	2.7466±0.79549
	Venting	2.8493±0.82784
	Positive reframing	2.7466±0.73656
	Substance use	1.3425±0.32142
	Religion	3.1027±0.57710

Table 3: Description of the relationship between dimensions of family coping and family burden variables with schizophrenia, *n*=73

Variable	Burden	
	r	*p*
Instrumental support	−0.75	0.001
Emotional support	−0.71	0.001
Active coping	−0.79	0.001
Planning	−0.80	0.001
Acceptance	−0.80	0.001
Self−distraction	−0.76	0.001
Denial	−0.20	0.097
Humor	−0.16	0.167
Self-blaming	−0.64	0.591
Behavioral disengagement	−0.68	0.001
Venting	−0.79	0.001
Positive reframing	−0.79	0.001
Substance use	0.13	0.269
Religion	−0.67	0.001
Family coping	−0.82	0.001

owing to the presence of patients with schizophrenia is not meant to disgrace the family, but to identify ways to secure assistance from others in resolving challenges experienced by individuals with schizophrenia, especially for psychosocial recovery through cognitive and behavioral reconstruction. This occurs when issues are discussed with mental health nurses, who can provide better health education according to the care needs of individuals with schizophrenia.

The characteristic attributes of positive psychology, in general, always contribute to reducing mental stress. As this research reports, humor, a part of positive psychological attributes, contributes to reducing the subjective burden felt by families of individuals with schizophrenia.[27] However, the results of this study are different because there is little correlation between humor and subjective feelings of burden. In line with the results of other studies, owing to the impact of schizophrenia, families feel extremely burdened, and this feeling exceeds the risk of the disease itself, inducing prolonged depression despite efforts to remain cheerful.[28] Others choose not to remain in the same family as a patient with schizophrenia to avoid prolonged shame; this is a significant reason why many patients with schizophrenia experience neglect.[29]

Overall, the research results suggest a correlation between subjective family burden and coping in families with patients with schizophrenia, revealing that family members feel burdened by the presence of patients with schizophrenia—this aligns with the results of previous studies.[30] Family members must explore internal and external resources (environment) to devise coping mechanisms. Effective coping strategies enable families to achieve adaptive coping.[13] The results of this research suggest a tendency to explore and apply adaptive coping when experiencing stress due to a burden.

Mental nursing interventions for families experiencing psychosocial problems caused by feelings of burden owing to the presence of patients with schizophrenia aim to impart skills in identifying resources to devise adaptive coping mechanisms.[13] Additionally, empowerment interventions for families have proven to be effective in dealing with schizophrenia.[31]

The limitation of this study conducted in Lamongan City is the sample size of 73 people, which may be relatively small to generalize to the population in Indonesia; therefore, further research needs to be conducted for a larger population. In addition, the design of this study is cross-sectional; thus, longitudinal research is recommended to confirm the relationship between related variables. Despite these limitations, this study is important because it identifies family burdens that can be triggers for choosing adaptive coping in solving problems in families with people with mental disorders.

Conclusion

This research reveals the burden caregivers experience in their families owing to the presence of patients with schizophrenia, especially in the caregiving taking strength variable, and that coping efforts are mainly based on a religious approach. Overall, there exists a significant negative correlation between subjective burden and family coping. The results are applicable

for families who must care for patients with schizophrenia, as they can choose alternative coping strategies depending on their personal and environmental resources. This study faced difficulties reaching many respondents who were disinclined to participate owing to the perceived stigma.

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Conflicts of interest

Nothing to declare.

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