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# Relationship between social support and family caregiver burden in schizophrenia patients

*by* Dya Sustrami

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RESEARCH ARTICLE

# Relationship between social support and family caregiver burden in schizophrenia patients

Dya Sustrami[1], Ah Yusuf[2], Rizki Fitryasari[3], Ferry Efendi[4], Riski Firlana Aysha[5]

## Abstract

**Objective:** To assess the impact of social support on family caregivers of schizophrenia patients.

**Method:** The cross-sectional, observational study was conducted at Menur Mental Health Hospital, Surabaya, Indonesia, from June to July 2021, and comprised family caregivers aged 20-60 years who lived with schizophrenia patients. Data was collected using the Indonesia version of Zarit Burden Interview and the social support questionnaire**.** Data was analysed using SPSS 25.

**Results:** Of the 160 subjects, 87(54.4%) were males and 73(45.6%) were females, and 88(55%) were adults, while 36(22.5%) had duration of care >10 years. All the 160(100%) patients had been receiving regular treatment. There were 64(40%) respondents who reported having good social support. The correlation between social support and the family caregiver burden related to schizophrenia patients was significant ($p < 0.05$).

**Conclusion:** There was a significant relationship between social support and burden on family caregivers of schizophrenia patients.

**Keywords:** Caregiver, Schizophrenia, Burden, Psychiatric, Ambulatory care. (JPMA 73: S-42 [Suppl. 2]; 2023)

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## Introduction

Schizophrenia affects around 20 million people worldwide.[1] In Indonesia, 13% of the diseases are mental health disorders and this figure will increase to 25% by 2030. Basic Health Research in Indonesia (RISKESDAS) showed that there were 6% people with schizophrenia in East Java.[2] Furthermore, in Surabaya, data from Menur Mental Health Hospital (MMHH) in 2020 showed that there were 9,994 outpatients with schizophrenia.[3] These numbers indicate a large number of family caregivers also for schizophrenia patients.

Patients with schizophrenia have functional disabilities,[4] and need support, especially from their families.[4,5] However, family caregivers often experience a psychological and physical burden in caring for such patients. They experience a feeling of boredom, fatigue and a decrease in quality of life.[6,7]

Family caregivers have many stressors when caring for patients with schizophrenia.[8] They have to spend most of their time taking care of the patients to obtain health outcomes. Caregivers also experience social stigma,[9,10] which causes shame and social withdrawal among them. In addition, the high cost of care and changes in the roles and responsibilities of the family caregivers cause uncertainty in life.[9]

Social support is needed to maintain the psychological wellbeing and to share the burden of family caregivers.[6,11] Previous studies regarding social support have show heterogeneity.[12] The current study was planned to assess the relationship between social support and the burden of family caregivers of schizophrenia patients.

## Subjects and Methods

The cross-sectional, observational study was conducted at MMHH, Surabaya, Indonesia, from June to July 2021. After approval from the institutional ethics review board, the sample was raised using random sampling technique. Those included were family caregivers from among those who visited the MMHH outpatient clinic, were aged 20-60 years, and lived with the patients. Informed consent was obtained from all the subjects, and those who did not want to participate were excluded.

After the researcher was screened by polymerase chain reaction (PCR) test for coronavirus disease-2019 (COVID-19), data was collected using a self-reporting questionnaire with all the relevant permissions in hand.[13,14] The questionnaires were distributed among the subjects, and those who wanted to withdraw after going through the questionnaires were allowed to do so.

The Family caregiver burden was assessed using the Indonesian version of Zarit Burden Interview (ZBI).[15] The questionnaire has 22 items under 4 domains: emotional component (15 items), physical health (2 items), social burden (3 items), and financial burden (2 items). The tool is scored on a Likert scale, with 0=never and 4=always. Score

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0-21 indicates no burden, 21-40 mild-moderate burden, 41-60 moderate to severe burden, and 61-88 a very severe burden. Cronbach's alpha of the questionnaire was 0.931.[14]

The questionnaire used to assess social support had four domains; appraisal support, informational support, instrumental support and emotional support. The 10-item instrument is scored using a Likert scale, with 0=never and 4=always. Total score 36.8 indicates good social support, 25.4-36.8 moderate social support, and ≤25.4 low social support. The questionnaire had internal consistency, with Cronbach's alpha value 0.951.[13]

Data was analysed using SPSS 25. Descriptive statistics were used to express frequencies and percentages of each variable. Spearman rho was applied to determine the relationship between two variables. P<0.05 indicated statistical significance.

## Results

Of the 160 subjects, 87(54.4%) were males and 73(45.6%) were females, and 88(55%) were adults, while 36(22.5%) had duration of care >10 years. All the 160(100%) patients had been receiving regular treatment (Table 1).

**Table-1:** Demographic Characteristic of the study participants.

| **Characteristic** | **Total participants n (%)** |
|---|---|
| **Age** | |
| Children | 22 (13.8) |
| Adolescents | 50 (31.3) |
| Adult | 88 (55.0) |
| **Gender** | |
| Female | 73 (45.6) |
| Male | 87 (54.4) |
| **Occupation** | |
| Unemployed | 73 (45.6) |
| Civil servants | 7 (4.4) |
| Private employee | 53 (33.1) |
| Self-employee | 20 (12.5) |
| Household assistant | 7 (4.4) |
| **Income** | |
| < Rp 1.851.083 | 95 (59.4) |
| >Rp 1.851.083 | 65 (40.6) |
| **Relationship with patient** | |
| Father or mother | 74 (46.3) |
| Husband or wife | 19 (11.9) |
| Children | 17 (10.6) |
| Sibling | 50 (31.3) |
| **Duration caring for the patients** | |
| < 3 years | 34 (21.3) |
| 3-5 years | 47 (29.4) |
| 6-10 Years | 43 (26.9) |
| >10 years | 36 (22.5) |
| **Treatment routine** | |
| Yes | 160 (100.0) |
| No | 0 (0.0) |

**Table-2:** Distribution of study variables.

| **Variables** | **n (%)** |
|---|---|
| **Burden Score** | |
| 0-20 (No burden – low burden) | 64 (40.0) |
| 21-40 (Mild – moderate burden) | 84 (52.5) |
| 41-60 (Moderate – severe) | 11 (6.9) |
| 61-88 (Very severe) | 1 (0.6) |
| **Social support** | |
| Good | 115 (71.9) |
| Moderate | 24 (15.0) |
| Low | 21 (13.1) |

**Table-3:** Correlation between family caregiver burden and social support.

| **Burden** | **Social support** | | | | |
|---|---|---|---|---|---|
| | **Low** | **Moderate** | **Good** | **Total** | ***p*-value** |
| | **n %** | **n %** | **n %** | **n %** | |
| No burden – low burden | 2 (1.3) | 12 (7.5) | 50 (31.3) | 64 (40.0) | < 0.05 |
| Mild – moderate burden | 14 (8.8) | 10 (6.3) | 60 (37.5) | 84 (52.5) | |
| Moderate – severe | 4 (2.5) | 2 (1.3) | 5 (3.1) | 11 (6.9) | |
| Very severe | 1 (0.6) | 0 (0.0) | 0 (0.0) | 1 (0.6) | |

Overall, 64(40%) respondents reported having no burden, 84(52.5%) had mild-moderate burden, 11(6.9%) had moderate to severe burden and 1(0.6%) respondent had severe burden (Table 2).

The correlation between social support and the family caregiver burden related to schizophrenia patients was significant ($p< 0.05$) (Table 3).

## Discussion

The family caregivers of schizophrenia patients were found to have good social support, and, as such, reported low burden. The finding supported previous studies in this regard.[16,17]

The patients need full assistance from their families which can cause burden to the caregivers,[18] like suffering emotionally, physically, socially and financially.[19] There are two types of burdens experienced by families; objective and subjective burdens. Objective burdens are related to social problems, activity problems, financial difficulties and negative impacts on the physical health. Subjective burden is associated with a psychological response, such as sadness, anxiety, fatigue and less self-efficacy.[11] These feelings are also felt by family caregivers when caring for their family with schizophrenia.[20]

Social support refers to the presence of comfort, attention, appreciation or availability of help from others.[11, 21] Social support usually can be classified into appraisal support, informational support, instrumental support and emotional support.[22] There are several factors that influence social support, such as receiver, provider and structural social networks.[23] This needs motivation of other family members and healthcare providers as a social network to support the family caregivers.

Social support from the community and other family members is required to overcome the problems experienced by the family caregiver.[11,24] In addition, social support diminishes negative feelings when caring for schizophrenia patients.[25] These negative feelings are the results of problems that arise in the caring process for the family caregivers of schizophrenia patients. Increasing social support has an effect on caregiver's health and patient's health outcome.[16]

The current study has limitations, like it did not measure the actual task of family caregiving, and did not calculate the sample size either. Further studies are needed to go beyond these limitations.

## Conclusion

There was a relationship between social support and the burden on family caregivers of schizophrenia patients. Support from other family members, nurses as well as the community at large may help reduce the burden of the individual family caregiver.

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**Conflict of Interest:** None.

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