ORIGINAL ARTICLE

Family Burdens in patients with Schizophrenia

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ABSTRACT

Introduction: People with schizophrenia need the role of the family as a caregiver. ***Objectives:*** The aim of this study was to describe the burden of the family as a caregiver for schizophrenia patients in outpatient polyclinic setting, Menur Mental Health Hospital Surabaya. ***Methods:*** Total participants were 160 family caregivers who carry out routine check-ups for family with schizophrenia. The data was obtained using the Indonesian version of the Zarit Burden Interview (ZBI) questionnaire and Cronbach alpha (α) was 0.931. Descriptive statistics were used to describe and categorize the family caregiver burden. ***Results:*** The results showed that the majority of participants had burden score in the category no burden – low burdens: 64 participants (40.0%), the mild – moderate burden category was 84 participants (52.5%), moderate – severe burden was 11 participants (6.9%), very severe burden category was only 1 participant (0.6%). In addition, the demographic data showed that most of the participants were adult (55%), and the majority of caregivers are female (54.4%), the majority of education was senior high school (51.9%), for and most of the participants were unemployed (45.6%). ***Conclusion:*** This study was needed to provide evidence for evolving intervention among family caregiver.

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Introduction

People with schizophrenia need the role of the family as a caregiver, it can increase their health outcome (Anggraini & Novitasari, 2021; Kertapati, 2019; Patricia, Rahayuningrum, & Nofia, 2019). Caregivers who take care of patients with severe mental disorders, such as schizophrenia face burdens (Ayudia, Siswadi, & Purba, 2020; Tamizi et al., 2020). Different levels of burden can be found in each family, depending on the patient, caregiver, and environment (Gooding, Littlewood, Owen, Johnson, & Tarrier, 2019; Zwicker, Denovan-Wright, & Uher, 2018). Factors affecting the caregiver's burden are fulfilled the patient's need as well as assisting for routine treatment, the type and severity of mental illness, disability of patients, relapse (Hasnawati & Susanti, 2021; Shamsaei, Cheraghi, & Bashirian, 2015), and financial to support the treatment (Kamil & Velligan, 2019; Meilani & Nk, 2019). Furthermore, families also face difficult experiences such as changes in their daily activities. So, they need knowledge when caring for schizophrenic patients (Ayudia et al., 2020; Guan et al., 2020; Sreeja, 2013). It can maintenance their quality of life (Tristiana, Triantoro, Nihayati, Yusuf, & Abdullah, 2019).

According to WHO, the prevalence of people with mental disorders was around 0.2% to 2% or 24 million people in worldwide, and the ratio of men and women is similar (Fitriani &

Handayani, 2020). The prevalence of mental disorders in Indonesia based on basic health research (Riskesdas) in 2018 was increased, became 7 per mil household, which means per 1000 houses, there were 450 thousand people with severe schizophrenia. The prevalence of mental disorders among aged 15 years in Malang City, East Java was 15-20% (Health, 2018). Meanwhile, in Surabaya, based on data at the Menur Mental Health Hospital that was 9,994 outpatients with mental disorders, 70% were male and 30% were female. Preliminary studies show that family caregiver for patients with schizophrenia with a duration of more than 10 years was experiencing boredom due to relapse (25 patients). However, these 22 patients experienced normal stress (88%) and 3 patients had mild stress (12%). The family may at the stage of acceptance of the patient's condition.

Family's burden who take care of schizophrenia patients was physical, psychological, and negative stigma from the social environment (Mento, Rizzo, & Settineri, 2019; Yunita, Isnawati, & Addiarto, 2021). The burden can be a source of stress and it can be divided into the objective burden and subjective burden (Fekete, Tough, Siegrist, & Brinkhof, 2017; Fitriani & Handayani, 2020). Furthermore, this burden has an impact on family life such as financial worry (Aubeeluck & Luximon-Ramma, 2020), disturbances in carrying out daily household activities and limitations in carrying out social activities (Niman, 2019; Reupert et al., 2021). Based on this background it was needed to describe the family burden as caregiver for schizophrenia patients in outpatient hospital setting, Menur Surabaya as primary data to develop further intervention.

Methods

The participants of this study were family caregivers for Schizophrenia patients from the Outpatient Polyclinic of Menur Mental Health Hospital, Surabaya. We collected the data using simple random sampling technique. Total sample in this study was 160 people. The data was obtained using the Zarith Burden Interview (ZBI) questionnaire (Zarit, Reever, & Bach-Peterson, 1980) to measure the caregiver burden. There are five answer choices: always; often; sometimes; rarely; and never. The reliability of the Indonesian version of the ZBI was Cronbach Alpha: 0.931. We used descriptive statistical techniques in the SPSS application to measure the mean, median, frequency, standard deviation, and percentage.

Results

Table 1 showed the minimum, maximum and mean of the family burden. The minimum and maximum values were 1. Meanwhile the mean and median value were 1.68 and 2.00 with standard deviation 0.628

Table 1. Descriptive statistic of variable

Variable	Min	Max	Mean	Med	SD
Family burden	1	4	1.68	2.00	0.628

Table 2 showed the frequency distribution of family caregiver burden scores based on the Zarit Burden Interview (ZBI). The majority of participants had burden score in the category no burden – low burdens: 64 participants (40.0%), the mild – moderate burden category was 84 participants (52.5%), moderate – severe burden was 11 participants (6.9%), very severe burden category was 1 participant (0.6%).

Table 2. Frequency distribution of family caregiver burden

Burden Score	Category	n	Percentage (%)
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
Total		**160**	**100.0**

Additional Results

Table 3. Characteristic of participants by age group

Age	n	Percentage (%)
Children	22	13.8
Adolescents	50	31.3
Adults	88	55.0
Total	**100**	**100.0**

Table 3 showed the characteristic of participants by age group. There were 22 children (13.8%), 50 adolescents (31.3%), and 88 adults (55.0%).

Table 4. Characteristic of participants by gender

Gender	n	Percentage (%)
Male	73	45.6
Female	87	54.4
Total	**100**	**100.0**

Table 4. Showed the gender of the participants was 87 women (54.4%) and 73 men (45.6%).

Table 5. Characteristic of participants by education

Education	n	Percentage (%)
Out of school	5	3.1
Elementary school	21	13.1
Junior high school	28	17.5
Senior high school	83	51.9
Bachelor's degree	23	14.4
Total	**160**	**100.0**

Table 5 showed characteristic participants by education degree. There were 5 participants out of school (3.1%), 21 participants (13.1%) had elementary school degree, 28 participants (17.5%) had junior high school degree, 83 participants (51.9%) had senior high school degree and 23 participants (14.4%) had bachelor's degree**.**

Table 6. Characteristic of participants by occupation

Occupation	n	Percentage (%)
Unemployed	73	45.6
Civil servants	7	4.4
Private employee	53	33.1
Self-employee	20	12.5
Household assistant	7	4.4
Total	**160**	**100.0**

Table 6 showed the characteristic of participants by occupation. There were 73 participants unemployed (45.6%), civil servants were 7 participants (4.4%), private employee were 53 participants (33.1%), self-employed were 20 participants (12.5%), household assistants were 7 participants (4.4%).

Table 7. Characteristic of participants by income

Income	n	Percentage (%)
< Rp 1.851.083	95	59.4
>Rp 1.851.083	65	40.6
Total	**160**	**100.0**

Table 7 showed the income of participants. The income < IDR 1,851,083 was 95 people (59.4%) and > IDR 1,851,083 was 65 people (40.6%).

Table 8. Characteristic of participants by relationship with patients

Income	n	Percentage (%)
Parents	74	46.3
Spouse	19	11.9
Children	17	10.6
Siblings	50	31.3
Total	**160**	**100.0**

Table 8 showed the relationship of participants with the patients with schizophrenia. Relationships as parents were 74 people (46.3%), relationships as spouse were 19 people (11.9%), relationships as children were 17 people (10.6%), relationships as siblings were 50 people (31.3%).

Table 9. Characteristic of participants by duration for caring the patients

Duration for caring the patients	n	Percentage (%)
< 3 years	34	21.3
3-5 years	47	29.4
6-10 years	43	26.9
>10 years	36	22.5
Total	**160**	**100.0**

Table 9 showed the duration of for caring the patients. There were participants who are caring the patients less than 3 years were 34 participants (21.3%), caring for 3-5 years were 47 participants (29.4%), caring for 6-10 years were 43 participants (26.9%), caring more than 10 years were 36 participants (22.5%).

Table 10. Characteristic of patients by age

Patient's age	n	Percentage (%)
Children	43	26.9
Adolescents	79	49.4
Adults	38	23.8
Total	**160**	**100.0**

Table 10 showed the characteristic of patients by age. There were 79 patients (49.4%) were adolescents, children were 43 patients (26.9%), and adults were 38 patients (23.8%)

Table 11. Characteristic of patients by gender

Patient's gender	n	Percentage (%)
Male	76	47.5
Female	84	51.5
Total	**160**	**100.0**

Table 11 showed the characteristic of patients by gender. There were 76 patients (47.5%) and 84 patients (51.5%) were female.

Table 12. Characteristic of patients by routine treatment

Routine treatment	n	Percentage (%)
Routine	160	100.0
Not Routine	0	0.0
Total	**160**	**100.0**

Table 12 showed whether the patients always conduct treatment routine and 100% of schizophrenia had routine treatment.

Discussion

The aim of this study was to describe the burden of the family as a caregiver for schizophrenia patients in outpatient, Menur Mental Health Hospital Surabaya. The results showed that the majority of participants had burden score in the category, no burden – low burdens: 64 participants (40.0%), the mild – moderate burden category was 84 participants (52.5%), moderate – severe burden was 11 participants (6.9%), very severe burden category was 1 participant (0.6%).

There were several factors that affect care giver burden, such as from patients, caregivers, especially due to lack of knowledge (Yazici et al., 2016) and stigma from communities (Bonsu, Salifu Yendork, & Teye-Kwadjo, 2020). Caregivers should have the knowledge and competence to provide care for family with chronic mental illness (Jagannathan, Thirthalli, Hamza, Nagendra, & Gangadhar, 2014). Family caregivers who are caring schizophrenia patients had high level of burden compared to caregivers who are caring for family members with chronic illnesses (Hsiao, Lu, & Tsai, 2020). Recent onset schizophrenia was also related to caregiver burden (Crespo-Facorro et al., 2021). However, from the results of interviews, it was found that many families experienced mild to moderate burdens because the family had adapted to the condition of their family member, and they also had duration for caring the patients more than two years. Based on this condition, they were able to cope with family members and they had strategies if the patients relapsed. It was similar with previous study (Lal et al., 2019; Rahmani et al., 2019). Furthermore, the family was not feeling shame with the condition of their family members.

The burden has impact on the physical condition of the family caregiver because of the tension when patients experience a relapse and the patients unable to fulfill their daily needs (Wan & Wong, 2019). This situation takes the caregiver's time and energy, recreational activities, socialization, and sleep so it can affect the physical condition. The communities also have bad stigma among people with schizophrenia as well as their families (Guan et al., 2020; Singh, Mattoo, & Grover, 2016; Yin, Li, & Zhou, 2020). Schizophrenia was a disease that cannot be cured, aggressive behavior, and was dangerous for others (Da Silva, Baldaçara, Cavalcante, Fasanella, & Palha, 2020). It also makes the family caregiver burden. So, family will choose to hide family members with schizophrenia at home. Further study is needed to develop intervention to decrease family caregiver burden. Family therapy such as supportive therapy and psychoeducation to reduce stress and the burden of care. Psychoeducation is a family mental health treatment therapy by providing information and education through therapeutic communication (Sulung & Foresa, 2018; Walke, Chandrasekaran, & Mayya, 2018).

Conclusion

The majority of the family caregiver burden was mild to moderate (52.5%), the age group of family caregiver was adults (55%), the majority of gender of the family was female (54.4%), the most predominantly education was senior high school (51.9%), the most respondents were unemployed (45.6%), the majority of respondents' income was < Rp. 1,851,083 (59.4%), Most of participants were parents (46.3%), the duration of caring the patients was 3-5 years (29.4%). Further, most of patients were adolescents (49 .4%), and the gender was female (51.5%). This study was used as evidence based of further research to evolve the intervention and it needs strategy to cope with the burden of family caregiver.

Ethics approval and consent to participate

We already obtained the informed consent from participants, and we ensured confidentiality. This study was granted by ethical clearance number 070/313/305/2001 by Menur Mental Health Hospital Surabaya, Indonesia.

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