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The Subjective Burden of Caregivers of Patients with Schizophrenia in Pekanbaru

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ABSTRACT

Schizophrenia is a severe mental disorder experienced for a long time and accompanied by several times relapse. It gives negative impacts, recognised as the objective and subjective burdens, on families who care for schizophrenic patients (caregiver). The objective burdens were related to high medical costs, while the subjective burdens were related to emotional and social pressure in treating a schizophrenic patient. This study aimed to identify the subjective burden of caregivers of patients with schizophrenia in Pekanbaru City. It will be the basis for determining the appropriate treatment for schizophrenic patients in the community. The method used was a survey involving 31 caregivers as research samples determined using cluster sampling techniques, obtained from 6 sub-districts of 12 subdistricts, namely Rumbai, Rumbai Pesisir, Senapelan, Payung Sekaki, Sukajadi, and Marpoyan Damai. Researchers used the Indonesian version of the Zarit Caregiver Burden Scale as a research instrument, validated by Utami (2011). The statistical analysis used was a descriptive statistical analysis. This research showed that most caregivers suffered from subjective burden in the moderate category (38.70%). The main burden includes the feeling of unable to care while feeling overburdened occupied the second position and the lowest was the feeling of rejection. Female caregivers mostly felt a higher burden than males. Furthermore, caregivers aged over 60 years old showed the feeling of overburdened and unable to care higher than other ages, but lower in rejection than others.

Keywords: *Subjective Burden, Caregiver, Schizophrenia*

INTRODUCTION

Schizophrenia is a severe mental disorder that consists of several symptoms, such as distortion of thinking, perception, affect, sense of self, motivation, behavior, and interpersonal functions (Halgin & Withbourne, 2011). The most influential symptom of schizophrenia is the disorder of thoughts, emotions, and behavior. The disorder appears not logical thinking, wrong perceptions and attention, flat or not appropriate affects, and various strange motor activity disturbances. Schizophrenic patients also withdraw from others and reality. They often enter into a fantasy world, full of delusions and hallucinations (Davison, et al., 2014).

According to the National Institute for Mental Health (NIMH), the prevalence of schizophrenia reaches 1% of the world's population, covering around 2.2 million people in the United States (Veague, 2007; Durand & Barlow, 2007). Besides, Veague (2007) said that schizophrenia in various countries is not much different at 1% of the population. He also said that there was no difference in the prevalence of schizophrenia in terms of race, ethnicity, culture, or religion (Veague, 2007). By referring to the World Health Organization (WHO, 2016), people with schizophrenia in Southeast Asia reached 6.5 million people. Based on the Indonesia Health Ministry data, the prevalence of schizophrenia has significantly increased, from 0.17% in 2013 up to 0.67% in 2018.

This significant increase needs to be considered by the Indonesian government because it has become chronic and requires high care costs. The period of the disorder lasts a long time and has little possibility to achieve complete recovery. During the disease, people with schizophrenia generally experience some acute symptoms that are not too severe but still interfere with their functioning

(Davison, Neale, & Kring, 2014). Despite substantial advances in treatment, schizophrenic recovery is rare (Durand & Barlow, 2007). Besides that, Veague (2007) said that patients of schizophrenia who have received early treatment from a psychiatrist still need to meet the psychiatrist regularly for years. The disease is delayed ten years from the beginning of the onset of symptoms until receiving the appropriate diagnosis and treatment (Veague, 2007).

The length of the disordered period and the least possibility of experiencing a complete cure caused the caregiver to bear the burden of care both in medical expenses and time spent in care. Wu (2005) said that the cost of treatment and care of schizophrenia in the United States reaches more than \$ 62 billion each year, it does not include indirect costs, such as family care and lost income (Halgin, & Withbourne, 2011). There is no information about how much the families incur the medical and care costs in Indonesia, but as a developing country, it is a heavy burden due to Indonesia's average income is lower than the people in the United States. This economic burden is referred to as an objective burden by Hoenig and Hamilton (1996).

The term burden in care is closely related to the impact and consequences of caring. Hoenig and Hamilton (1996) divided the burden in care into an objective and subjective burden. The objective burden is the burden of care that impact health, financial loss, and daily chores. Simultaneously, the subjective burden is a burden perceived subjectively by caregivers due to caring for family members who have mental disorders (Awad, & Voruganti, 2008), usually associated with caregivers' psychological burdens. Dillehay and Sandys (1990: 268) defined subjective burden as "the psychological state resulting from combinations of physical work, emotional pressure, social constraints, and financial demand accruing because of patient-care requirements."

Caregivers of patients with schizophrenia feel an objective burden and experience a heavy emotional burden (Durand & Barlow, 2007). Darwin et al. (2013) said that most caregivers (67.7%) perceived a high burden in treating patients with schizophrenia. Research in the United States showed that the burden felt by caregivers, 34% is related to behavioral problems and resource demands and disruption, 21% is due to the deterioration of daily living, and 38% is related to patient helpfulness (Perlick et al., 2006). Some research in developing countries research conducted by Urizar and Maldonado (2006) in Chile showed that all caregivers experienced burden in a very high category. Likewise, in India, Chadda, Singh, and Ganguly (2007) also showed that most caregivers of patients with schizophrenia felt a high burden, especially on two of the burden factors: taking responsibility and physical and mental health.

In line with the research described above, research conducted by Ratnawati, Husada, and Loebis (2014) in Indonesia showed that most caregivers feel burdened in treating patients with schizophrenia. Specifically, the research results of Winahyu, Hemchayat, and Charoensuk (2014) showed that 48.9% of the sample in Indonesia felt a high burden. Another research conducted in Indonesia in the city of Semarang showed that most schizophrenic patient caregivers felt burdened that had an impact on the emergence of discomfort (Fitrikasari et al., 2012). In contrast, a study in Bogor, Indonesia, found out that 41.4% of caregivers did not have the burden of caring for family members with schizophrenia. Most caregivers claimed that they had surrendered to God for the disease given to the patient with schizophrenia (Metkono, Pasaribu, & Susilo, 2014).

In conclusion, the burden felt by caregivers in Indonesia varies, depending on the study area. Most likely, in the area with minimal mental health service facilities, the caregiver burden will be higher because difficult access causes a high perceived subjective burden (Corrigan & Penn, 1999; Penn & Martin, 1998). Kung (2003) adds that coping responses affect the caregiver's burden. If the source of coping is available and easily accessible, the burden will be lower, and vice versa. The highest subjective burden experienced by caregivers is to worry about the patient's future, distress, frustration, and family conflict (Kung, 2003). Furthermore, Quah (2013) explains that caregivers feel overloaded due to taking care of patients with schizophrenia. In other studies, Barrowclough, Tarrier, and Johnston (1996) found that 2/3 of family members experience significant stress and subjective burden due to the caring of patients with schizophrenia. A study conducted by Magana and Gracia (2007) showed that

12-18% of caregivers are at risk of experiencing depression, and 40% of caregivers are depressed. Furthermore, Mitsonis et al. (2012) stated that caregivers experience great psychological distress; specifically, they experience somatisation, interpersonal sensitivity, depression, anxiety, hostility, and obsessive-compulsive symptoms.

The subjective burden is also influenced by culture. White caregivers feel more burdened than black caregivers. White caregivers also exhibit more excellent resistance to patients with schizophrenia they care (Rosenfarb, Bellak, & Aziz, 2006). Awad and Voruganti (2008) concluded that ethnicity and culture play an essential role in shaping caregivers' perception of perceived burden. Given the burden of schizophrenic caregivers is influenced by culture, it is necessary to research to see whether the burden of schizophrenic caregivers in Pekanbaru is different from other areas. In this case, the researcher aims to know how much the burden experienced by the caregiver of schizophrenia patients in Pekanbaru and how demographic status effect it. This study's results are useful for consideration in determining the steps to be taken by various stakeholders related to this problem.

METHOD

Participants

The population in this study was all caregivers of patients with schizophrenia in Pekanbaru. Based on the Ministry of Health of the Republic of Indonesia data in 2013, the estimated number of patients with schizophrenia in Pekanbaru is 899 people, but there is no data on the exact number of caregiver populations. The number of samples in this study was 31 females and males caregivers of patients with schizophrenia. The research samples were taken using cluster sampling. The researcher randomly selected 6 of the 12 districts in Pekanbaru, namely Rumbai, Rumbai Pesisir, Senapelan, Payung Sekaki, Sukajadi, and Marpoyan Damai. All caregivers in the six sub-districts were determined as research samples. The data of caregivers in each district were obtained from Primary Health Care. Previously, researchers had obtained a permit from the Pekanbaru Public Health office to access data from each Primary Health Care.

Instruments

This study is a survey in which researchers obtained data using the Indonesian version of the Zarit Burden Caregiver Scale, validated by Utami (2011). Zarit Burden Caregiver Scale consists of 22 questions with 5 points Likert scale. The score given for each answer is 1-5, i.e., score 1 for Never, score 2 for Rarely, score 3 for Occasionally, score 4 for Frequently, and score 5 for Always. The total score ranges from 22-110. The results of the scale reliability testing using the internal consistency approach showed Alpha values 0.921. It can be concluded that this measuring instrument is suitable to be used as a research instrument.

Procedures

In collecting the data, the researchers visited each caregiver's homes, but only a small part of the addresses was found because some had moved, and some had the wrong addresses. Only 31 caregivers who had been visited gave consent to becoming respondents in this research. They have signed the consent letter that had been prepared by the researcher.

FINDINGS

Demographic Data Description

The results of the study found out that the majority of caregivers were female (71%), who biological mothers (51.6%), aged 51-60 years (35.5%), worked as housewives (51.6%), graduated from elementary school (48.4%) and lived in Rumbai Pesisir subdistrict (48.4%). Detailed demographic data of the research subjects can be seen in Table 1.

Table 1: Demographic Data of Participants

Detailed Demographic Caregiver Data	Frequency (%)
<i>Sub-district</i>	
Rumbai Pesisir	15 (48.4)
Rumbai	3 (9.7)
Senapelan	4 (12.9)
Payung sekaki	2 (6.5)
Sukajadi	4 (12.9)
Marpoyan Damai	3 (9.7)
<i>Age</i>	
< 21 years	1 (3.2)
31-40 years	2 (6.5)
41-50 years	9 (29)
51-60 years	11 (35.5)
61-70 years	8 (25.8)
<i>Gender</i>	
Male	9 (29)
Female	22 (71)
<i>Profession of Caregivers</i>	
Entrepreneur	9 (29)
Civil Servant	1 (3.2)
Farmer	1 (3.2)
Housewife	16 (51.6)
Labor	1 (3.2)
Retired	2 (6.5)
Scavengers	1 (3.2)
<i>Education of Caregivers</i>	
Not completed in Elementary School	3 (9.7)
Graduated Elementary School	15 (48.4)
Graduated from Junior High School	4 (12.9)
Graduated from Senior High School	8 (25.8)
Graduate Bachelor Degree	1 (3.2)
<i>Relationship with Patient</i>	
Biological mother	16 (51.6)
Biological father	3 (9.7)
Children	2 (6.5)
Young sister/brother	2 (6.5)
Old brother	2 (6.5)
Old sister	2 (6.5)
Husband	1 (3.2)
Wife	2 (6.5)
Grandmother	1 (3.2)

General Description of Caregivers' Burden

Descriptive analysis results show that the total burden score's empirical mean is 59.26, with a standard deviation of 16.234. When compared with the hypothetical mean of 66, it can be concluded that the empirical mean is lower than the hypothetical mean. That is, the subjective burden perceived by the caregiver is slightly below the average in the population.

On the empirical mean and standard deviation, which refers to five categorisations, the collected data can be seen in Table 2.

Table 2: Caregiver Subjective Burden Categorisation

Categorisation	Score Interval	Frequency	Percentage
Very High	84-101	3	9.67
High	68-83	7	22.58
Moderate	52-67	12	38.7
Low	35-51	7	22.58
Very Low	29-34	2	6.45
Total		31	100

Based on table 2, it is known that the subjective burden felt by the caregiver is mostly in the moderate category (38.70%), while the least is in the lowest category (6.45%). It means that the subjective burden perceived by caregivers is not too high or too low, and only a few feel very low.

Caregiver Burden Descriptions Based on Burden Aspects

Three aspects analyzed the burden: feeling burdened, rejection, and feeling unable to care. It was analyzed using One Way ANOVA statistical analysis, which revealed a value of $F = 5.076$ with a significance value of 0.008 ($p < 0.05$). It means that there are significant differences between the mean values of feeling burdened, feeling of rejection, and feeling unable to care.

Based on the analysis of each burden aspect's mean, caregivers' tremendous burden is the feeling of being unable to care, the mean = 2.89 and the standard deviation (SD) = 0.803. Feeling unable to care is related to the perception of inability to care due to a lack of personal and financial resources. The feeling of being burdened occupies the second position with a mean value = 2.83 with SD = 0.836. Feeling burdened is related to the negative evaluation from caregivers about their caring. In comparison, the lowest aspect is the feeling of rejection, with mean = 2.26 with SD = 0.929. This feeling of rejection is related to hostility and irritation towards patients.

Description of Caregiver Burden Based on Caregiver Gender

The burden felt by male caregivers is significantly different from female caregivers. The difference can be seen from the statistical analysis results using independent sample t-test obtained t value = -2.754 with a significant value = 0.01 ($p < 0.05$). Based on the mean score of the burden, it is known that women show a higher burden than men, where the mean score of the burden of women is 63.91 while the men are 47.89.

In more detail, based on the gender of the caregivers, the analysis of the burden's aspects by using an independent sample t-test showed that there were significant differences in feeling overburdened and rejection between male and female caregivers with a value of $t = -2,869$ and significant value = 0.008 ($p < 0.05$) for aspects of feeling overburdened and the value of $t = -3.274$ and significant value = 0.003 ($p < 0.05$) for the rejection aspect. The feeling overburdened by female caregivers (mean = 24.59) is higher than male caregivers (mean = 17.78). Likewise, with the rejection aspect, male caregivers (mean = 15.05) showed a higher rejection than female caregivers (mean = 9.89).

In contrast to the second aspect described above, the aspect of unable to care did not differ significantly between male and female caregivers; the results of statistical analysis by using independent sample t-tests obtained a value of $t = -1,637$ with a significant value = 0.112. The meaning is that the feelings of inability to care felt by male caregivers are the same as female caregiver.

In terms of the caregivers' age analysis, there is no significant relationship between caregivers' age and the burden. The results of statistical analysis using the Spearman rank-order correlation obtained $r = 0.200$ with sig = 0.282 ($p > 0.05$). All aspects of burden are also not significantly related to caregivers' age. Detailed description can be seen in Table 3 below.

Table 3: Correlation of caregiver’s age and the aspects of burden

Burden Aspects	Value of r	Significance
Feeling overburdened	0.242	0.189
Feeling rejection	0.037	0.845
Feeling unable to care	0.299	0.102

Further analysis based on burden categorisation showed that the caregivers who age over 60 years old have the feeling overburdened and unable to care that higher than other ages, but lower in rejection than others. It can be concluded that even though caregivers aged 60 years showed a higher feeling overburdened and unable to care, caregivers tend to be lower in rejection to schizophrenic patients.

Description of Caregiver Burden Based on Patients Gender

The statistical analysis results using the independent sample t-test showed no difference in burden between caregivers who care for male and female patients. Likewise, with the three aspects of burden studied, there were no significant differences in feeling overburdened, rejection, and feelings of unable to care between caregivers caring for male and female patients. Detailed results of the statistical analysis can be seen in the following Table 4.

Table 4: The difference in the burden and aspects of the burden-based on the gender of patients

Burden Aspects	Mean Score	t-test
<i>Burden</i>		
Male	61.54	t = 1.479
Female	51.43	Sig. = 0.150
<i>Feeling overburdened</i>		
Male	22.96	t = 0.526
Female	21.43	Sig. = 0,603
<i>Feeling rejection</i>		
Male	14.33	t = 1.481
Female	10.86	Sig. = 0.149
<i>Feeling unable to care</i>		
Male	24.25	t = 1.933
Female	19.14	Sig. = 0.0603

Description of Caregiver Burden Based on Age of Patients

Statistical analysis that refers to the Spearman rank-order showed no significant relationship between burden scores and caregiver age, $r = -0.220$ and $sig. = 0.233$. The aspects of burden, namely feeling overburdened, rejection, and feeling unable to care, also did not significantly correlate with the caregiver's age. Detailed results of the statistical analysis can be seen in Table 5 below.

Table 5: Correlation of patient’s age and the aspects of burden

Burden Aspects	Value of r	Significance
Feeling Overburdened	-0.161	0.387
Feeling Rejection	-0.246	0.183
Feeling unable to care	-0.179	0.335

Further analysis on the categorisation of burden aspects and age of patients being treated reveals that caregivers who care for patients aged 41-60 years tend to report more rejection and feel unable to care in the low category compared to caregivers who care for patients aged 20-40 years. It can be assumed that caregivers who care for patients aged 20-40 years showed a higher burden than caregivers who treat patients aged 40-60. The burden arises from a high sense of rejection (hostility towards patients) and a feeling unable to care.

DISCUSSION

Based on demographic data, most caregivers in Pekanbaru were women, biological mothers, aged 51-60 years, working as housewives, graduated from elementary school, and living in Rumbai Pesisir subdistrict. This study's results are in line with research conducted by Rafiyah and Sutharangsee (2011) and Ratnawati, Husada, and Loebis (2014) in Indonesia, which showed that most of the caregivers are women. Mohamad et al. (2013), in their research in Malaysia, also showed similar results that depicted that most caregivers in Malaysia were also female and parents aged over 50 years. Indonesia and Malaysia have a similar culture in that the mother is considered the most responsible person in providing childcare. Moreover, if the child is suffering from an illness, the mother's role becomes crucial in taking care. Besides, in Indonesia and Malaysia, research in Mexico also showed that most caregivers are female and play a role as mothers and are 55 years old (Magana, & Garcia, 2007).

Base on statistical analysis, the burden of schizophrenic caregivers in Pekanbaru is a moderate category. This study's results differ from the results of research conducted in other regions in Indonesia, where several studies have shown that caregivers experienced a high burden (Ratnawati, Husada, and Loebis, 2014; Winahyu, Hemchayat & Charoensuk, 2014; Fitrikasari et al., 2012). It may be caused by several factors, including the perception of caregivers for patients with schizophrenia they care for, knowledge, education, income, access to mental health facilities (Corrigan & Penn, 1999; Penn & Martin, 1998; Kung, 2003; Urizar & Maldonado, 2006; Magana, and Gracia., 2007; Sefasi, 2008). Pekanbaru is the capital of Riau Province, which has adequate road access and transportation and the availability of medical staff and Mental Hospital. It likely causes the burden felt by the caregiver to be classified as moderate (not high).

Based on the analysis of the burden aspects, mostly caregivers felt unable to care because of a lack of personal and financial resources. This lack of personal resources is likely related to a large number of caregivers with primary school education, which impacts the lack of knowledge needed in providing care. The result is in line with research in Indonesia, which showed that caregivers' education is negatively related to the burden; the higher the education, the lower the perceived burden (Ratnawati, Husada, Loebis, 2014). Furthermore, interviews with several caregivers showed that they believe alternative medicines (such as asking for prayer water) are needed to help cure patients with schizophrenia. It impacts the increasing amount of funds spent on treatment to add to the financial burden, where the financial burden is related to the caregiver's subjective burden (Awadalla et al., 2005). Therefore, the research results that need to be underlined are that most caregivers have a low level of education. A concrete step is needed to increase caregiver knowledge about the care of schizophrenic patients so that it is expected to reduce the subjective burden felt by caregivers.

Based on the study sample's demographic data, namely gender, female caregivers showed a higher burden than male caregivers. In more specific, female caregivers feel overburdened higher than males. It is in line with Ratnawati, Husada, and Loebis's (2014) research, which showed that female caregivers in Indonesia felt more depressed and burdened than male caregivers. Research in other countries such as Canada and the United States also showed how women feel burdened than men (Schneider, Steele, Cadell & Hemsworth, 2010). The results of another study also showed that all the samples studied in particular who acted as mothers who were older, not well educated, and unemployed felt a very high degree of burden (Urizar & Maldonado, 2006; Maldonado, Urizar & Kavanagh, 2005; Caqueo & Gutierrez, 2006). The burden can cause psychological distress to the caregivers. Mitsonis et al. (2012) showed that female caregivers' psychological distress was found to be higher than male.

In the analysis on the caregiver's age and the patient's age, it was found that there was no relationship between the caregiver's or patient's age with the burden that was perceived by caregivers. However, further analysis based on burden categorisation, caregivers aged 60 years showed a feeling overburdened and feel unable to care, this condition showed higher number, but the lower number in rejection which is compared to those who were less than 60 years. It is in line with Urizar and Maldonado's research (2006), which showed that older caregivers feel a higher burden. Feeling unable to care and overburdened did not lead to the emergence of rejection to patients. Alternatively, in other

words, caregivers who are over 60 years of age show a higher acceptance of the patients. This acceptance was said by Suryani (2015) as a coping strategy used by caregivers in Indonesia. This acceptance is also usually accompanied by hope. In Indonesian culture, a mother is considered as someone who naturally can give unconditional acceptance to her child. Especially when mothers are to be older, they tend to show their wisdom.

The gender of the patient being treated is not related to the burden felt by the caregiver. It is different from the research results by Mors, Selensen, and Therkilden (1992), which showed that caregiver distress is also influenced by the patient's gender, where high distress was seen in caregivers who care for male patients. Based on the age of the patients, it is no relationship between the age of the patients being treated with the burden perceived by the caregiver. However, based on descriptive data, it can be assumed that caregivers who care for patients with schizophrenia aged 20-40 years showed a higher burden than caregivers who care for patients with schizophrenia aged 40-60 years. It arises from a high sense of rejection (hostility towards patients) and a feeling unable to care. This study's results are in line with research by Maldonado, Urizar, and Kavanagh (2005), which showed that caregivers who care for younger patients felt a higher burden.

CONCLUSION

In conclusion, although caregivers' burden in Pekanbaru is moderate, female caregivers felt burden more than male. The condition caused by the majority of caregivers in Pekanbaru is female, aged over 60 years, and low educated. They do not have enough knowledge about schizophrenia and the treatment. Therefore, empowering the community to help caregiver is an essential intervention in Pekanbaru. The researcher suggests primary health care to build a community mental health worker (CMHW). They are recruited from people in the community. CMHW can help caregivers to give knowledge about treating schizophrenia and social support. It is assumed that the burden can decrease significantly.

This research has weaknesses, especially in methodology and statistical analysis. The minimal number of samples makes the research results considered weak and difficult to generalise. The descriptive statistical analysis used is also insignificant for theoretical applications. Therefore, future research is expected to involve a larger number of samples and a wider generalization area. Also, more variables should be used, for example, by correlating burden with spirituality/religiosity.

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