

Family Burden Effect on the Ability in Taking Care of Schizophrenia Patient

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ABSTRACT

The existence of schizophrenia affects family systems and the ability to care. The study aimed to determine the relationship between family burden and the familial ability to treat schizophrenic patients. The design used was descriptive analysis with a cross-sectional approach. The population consisted of the family of schizophrenic patients in Menur Mental Hospital, Surabaya, Indonesia. In total, 21 respondents were obtained through consecutive sampling. The independent variable was the family burden and the dependent variable was the ability of the family to care for schizophrenic patients. The data was collected using a questionnaire and the results were analyzed using the Spearman Rho correlation test. The results showed that burden has a moderate relationship with the family ability ($p = 0.008$) ($r = 0.656$). The subjective burden was greater than the objective one. A lower burden felt by the family will improve their caring abilities. The families should be able to manage their existing and objective goals so then they can treat schizophrenia patients well.

Keywords: *subjective burden, objective burden, schizophrenia, Indonesia*

Introduction

Schizophrenia is one type of mental disorder that is causing a serious problem. The maladaptive behavior of schizophrenia patients has become a family burden that produces stressor. The burden faced by the family causes high family stress.¹⁻³ The perceived burden of the family can be either objective or subjective.⁴ Objective burdens can be limited social relations and work activities, financial difficulties and disturbing the physical health of the family members while the subjective burden can be a feeling of loss, sadness, anxiety, embarrassment and stress. The high burden felt by the family affects the willingness of the families to care for the patient and this often leads to recurrence in patients. Schizophrenia patient recurrence contributes to high schizophrenia rates both nationally and globally.

The prevalence of severe mental disorders including schizophrenia in Indonesia according to Riskesdas is 1.7

per 1000.⁵The incidence of schizophrenia in East Java was 0.22% while in Surabaya, it was 0.2%. Data from the Menur Mental Hospital Surabaya from January until March 2016 showed that there were 5,819 patients; 90% were schizophrenic and 80% of them had relapsed. The incidence of schizophrenia is difficult to decrease due to high recurrence rates. The causes of recurrence were due to not taking their medication and contacting the doctor regularly, stopping the drug immediately, a lack of support from their family and the existence of severe problems that create a stress relapse in the client.⁶⁻¹⁰

People with schizophrenia will be abnormal in their functionality in their daily activities. The family should do the tasks such as recognizing family problems, making the decision to take appropriate actions, taking care of their family members, modifying a healthy family environment and utilizing health service facilities. This high burden is a factor that affects the intention of the family to carry out the task of caring for schizophrenic patients. The stronger the intention, then there is also an impact on how strong the family belief is when it comes to showing the ability to care for schizophrenic clients.^{7,11}This study wants to explain the relationship between family burden with family ability to care for patients with Schizophrenia.

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Method

Study Design, Setting and Sampling: The research used a descriptive correlational research design with the cross-sectional approach. The population consisted of the family of schizophrenic patients who were treated at Menur Mental Hospital in Surabaya. The sample totaled 21 respondents obtained through the consecutive sampling technique.

Study Variables: The independent variable was a family burden and the dependent variable was family ability in taking care for Schizophrenia patient. The family burden was measured by a modification of the Caregiver Burden Index questionnaire.¹² The family ability variable questionnaire was developed based on the concept of the family task which as modified for families with schizophrenia.¹³

Data Analysis: The data obtained was then analyzed using the Spearman Rank test with a significance $\alpha \leq 0,05$.

Results

Based on Table 1, it can be explained that the majority of respondents (62%) were siblings; 29% were 20-30 years old, 48% were working as employees and earned 500.000-1.000.000 rupiahs every month.

Respondents' (family) characteristics

Table 1: Characteristics of the respondents

Characteristics	Category	f	%
Relationship	Husband	0	0%
	Wife	1	5%
	Father	4	19%
	Mother	3	14%
	Siblings	13	62%
Age	20-30	6	29%
	31-40	5	24%
	41-50	4	19%
	51-60	4	19%
	>60	2	10%
Education	Elementary	7	33%
	Junior High School	3	14%
	Senior High School	6	29%
	College/University	5	24%

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Job	Trader	1	5%
	Employer	10	48%
	Farmer	5	24%
	Others	5	24%
Salary	500.000-1.000.000	8	38%
	1.000.000-2.000.000	6	29%
	>2.000.000	7	33%
Insurance	BPJS	13	62%
	ASKES	6	29%
	No	2	10%
Drug Adherence	Not consume	3	14%
	Not a routine	17	81%
	Routine	1	5%
Control history	No	4	19%
	Not regularly	14	67%
	Regularly	3	14%

Respondents' (patient) characteristics

Table 2: Characteristics of the patients

Characteristics	Category	f	%
Gender	Man	14	67%
	Woman	7	33%
Education	No	1	5%
	Elementary	6	29%
	Junior High School	7	33%
	Senior High School	4	19%
	College/University	3	14%
Age	<=20	2	10%
	21-30	8	38%
	31-40	6	29%
	41-50	2	10%
	>50	3	14%
Marital Status	No	13	62%
	Merit	5	24%
	Widow	2	10%
	Widower	1	5%
Suffering Time	1-10 years	14	67%
	11-20 years	5	24%
	21-30 years	0	0%
	>30 years	2	10%
Relapse	once	13	62%
	twice	5	24%
	>twice	3	14%
Treatment	Routine	8	38%
	Not	13	62%

Table 2 shows that the majority of schizophrenic patients (67%) were male, 21 -30 years old, 33% had been to junior high school, 38% were unmarried and 67% had experienced a mental disorder for 1 - 10 years.

Family Burden in Caring for Schizophrenia Patients

Table 3: Family burden

Variable	Category	n	%
Family Burden	Mild	10	48
	Moderate	9	43
	High	2	10
Total		21	100

Based on Table 3, all of the respondents are experiencing a burden mostly at moderate (43%) and mild (48%) levels. The burden has been described in Table 4.

Table 4: Description of the family burden

Family Ability	Category					
	Mild		Moderate		High	
	Σ	%	Σ	%	Σ	%
Subjective	1	5	10	48	10	48
Psychological	1	5	9	43	11	52
Mind	1	5	9	43	11	52
Objective	15	71	4	19	2	10
Physical	10	48	0	0	11	52
Social	8	38	11	52	2	10
Finance	4	19	12	57	5	24

Table 4 explains that the subjective burden is the highest. Most of the burden is within the psychological and mind burden categories.

Family Ability in Taking Care of Schizophrenia Patients.

Table 5: Family Ability

Variable	Category	f	%
Family Ability	Less	9	43
	Moderate	10	48
	Good	2	10
Total		21	100

Table 5 shows that most of the respondents have either a moderate (48%) or lesser (43%) ability to take care of their patients. The distribution of the family ability has been described in Table 5.

Table 6: Distribution of family ability

Family Ability	Category					
	Good		Moderate		Less	
	Σ	%	Σ	%	Σ	%
Identify the family health problem	1	4,8	17	81	3	14,3
Make decisions	3	14,3	4	19	14	66,7
Caring for the family member	11	52,4	8	38	2	9,5
Modify the conducive environment	5	24	2	10	14	66,7
Utilize the health services	6	28,6	2	9	13	62

Based on Table 6, it can be explained that most of the families are caring very well for the schizophrenic family member (52.4%). However, there are 66.7% families who are not making the decision to solve the problem and modify the environment (66.7%).

Relationship between Family Burden with the Family Ability to Care for Schizophrenic Patients

Table 7: Cross-tabs of family burden with family ability

Family Burden	Family Ability						Total	
	Less		Moderate		Good		Σ	%
	Σ	%	Σ	%	Σ	%		
Low	8	38	1	4,8	1	4,8	10	47,6
Mild	0	0	9	42,8	0	0	9	42,8
High	1	4,8	0	0	1	4,8	2	9,6
Total	9	42,8	10	47,6	2	9,6	21	100

Spearman's Rho p = 0,008

The statistical test shows that there is a relationship between family burden with the family ability with a medium relationship level ($p = 0,008$, $r = 0,561$). A high burden that is felt by the family will decrease the ability of the families to care for patients with schizophrenia.

Discussion

Family Burden in Caring for Schizophrenia Patients:

The families experience burden when treating patients with schizophrenia.^{14,15}The family burden is the impact of the illness on the family members affecting their emotional stress.^{1,16}The burden is felt when a

schizophrenic family member needs more attention from the family. This affects their role and family function.

The subjective burden is described as the psychological reaction of the family members.¹⁷ The subjective burden felt by the family during the treatment of schizophrenia is expressed as a feeling of sadness, confusion, anxiety, suffering and embarrassment due to the unnatural behavior shown by the patient, such as being angry without a cause, and refusing to eat, drink and take a bath for a long time. Families tend to have protective feelings as well as feeling shame from their neighborhood and surroundings. The families are more likely to hide the patients. Psychological burden is also felt as a mind burden. This burden is caused by a family that is concerned about the future of their patient. Schizophrenia patient families are always thinking about the many problems caused by unusual patient behavior.¹⁸ The family should have sufficient resources to survive life with the patients. The mind burden felt by the family affects them psychologically, as the family is the primary caregiver of schizophrenia patients.

The family also experiences an objective burden. This can be explained as a burden associated with the care given by the family.⁴ Based on Table 4, the high objective burden of the family is in the form of physical burden, financial burden and social burden. The physical burden creates a negative impact on the physical health of the family.¹⁷ They feel physically exhausted because have to stay up with the patient every night causing less rest, while in the daylight, they must keep working and move. The financial burden was also felt by almost 57% of families, includes the number of costs incurred to meet the needs of the patients such as medical expenses, day-to-day expenses, hospital transportation and hospitalization costs.^{4,17,18} The majority of families (48%) are employees who work, so they often have to leave a job that results in reduced revenue. The social burden felt by the family related to constraints of the number of activities and time means that the family cannot spend their time elsewhere because they must always take care of the schizophrenic patient.¹⁸ The community are also keeps a distance from the family and patient. They were refuse the existence of the patients and their families in the neighborhood.

Family Ability in Taking Care of the Schizophrenia Patient: The family ability to provide care consists of five family health tasks.¹³ The family must be able to

perform the patient's Activity Daily Living, instrumental Activity Daily Living (iADL) and psychosocial needs.¹⁹ The family should be trying to keep the patients engaged with their regular medication and consultations with the health services, they can treat the patients in recurrence and when meeting all patient daily needs. The results showed that 81% of families were able to recognize the health problems. This means that the families understand the causes, symptoms, treatment and consequences of schizophrenia which strongly supports the families in caring for and meeting the needs of their patients every day.

The results showed that 66.7% of the family have less of an ability to make the decision to take appropriate action and to modify the healthy family environment. Appropriate decisions begin with the family foresight in terms of observing the signs and symptoms that occur in patients, including immediately seeking the right information and to decide what actions are to be taken by the family.¹³ The results show that most families bring the patient to a shaman before professional health services. They do not allow the patients to leave the home, separating the patients from society or placing them in a special room not far from home. The family is the most important in solving problems through the family decisions based on the shared rights and responsibilities that ultimately determine the service that is to be used.²⁰ The family decision to bring the patients to a shaman is influenced by the family understanding of the causes of schizophrenia, and if they are related to the spiritual aspect of life, such as involving spirits and witches.²¹

The family ability to modify the healthy environment is still felt as being less. Maintaining a comfortable home can be done by building good communication and providing support in various situations.¹³ The results show that both the patients and their families experience social stigma. The families do not always address the stigma well; the family can project shame and anger toward the patients with schizophrenia. The conducive environment referring more to emotional expression is an indicator of the quality of the emotional environment for schizophrenic patients.²² The families show a high emotional expression.²³ The family difficulties in modifying the environment can be affected by the time spent treating patients with schizophrenia.²⁴ The long duration of care makes some families feel saturated and tend toward high emotional expression. The family must create an acceptance for a patient's condition, including

respecting and cultivating an attitude of responsibility toward the patient so then they does not lose their role in the family.

Relationship between Family Burden with the Family Ability to Care for Schizophrenic Patients:

The research findings showed that the subjective burden is higher than the objective burden. Families who have a burden may not be able to treat the patients well.¹ Subjective burden has an impact on the lack of family ability to make decisions to determine the appropriate actions, to make modifications to a healthy family environment and to support the patient's recovery process. Families with a high subjective burden will find it difficult to modify the family environment. Psychologically, the family cannot control their emotions because of the unusual patient behavior; they become increasingly depressed and give continuous criticism to the patient with schizophrenia.^{6,25,26} Family with a high emotional expression will not solve the problem and this causes a recurrence in the patient.²⁷ Families need help to lower the subjective burden, both psychologically and in their mind.

Conclusion

Families who treat patients with schizophrenia feel a higher subjective than objective burden. The subjective burden will decrease the ability of the family to care for the patient with schizophrenia, especially when it comes to making decisions and modifying their environment. Nurses need to develop a family psychoeducation approach to help the families break down their perceived burden. This is so then they are able to perform their family care tasks.

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