



Relationship between Family Burden, Stigma, Stress, Social Support, Family Acceptance, and Family's Ability in Caregivers of Patients with Schizophrenia

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ABSTRACT: The family's ability as a caregiver for schizophrenic patients is very necessary because it can affect the success of the treatment process provided. This article aims to determine the relationship between family burden, stigma, stress, social support, family acceptance and family's ability in caregivers of patients with schizophrenia. This study used a quantitative method with a cross-sectional study design. The study was conducted at the outpatient polyclinic at Teuku Umar General Hospital with a total sample of 98 family members of schizophrenic patients. The results of this study indicate that family burden, stress, stigma, and acceptance are related to the family's ability to provide care to schizophrenic patients ($p = 0.0001 < 0.05$). Only the social support variable has no relation with the family's ability to provide care to schizophrenic patients ($p = 0.145 > 0.05$). The lack of a relationship between the social support variable and family's ability is consistent with the stigma variable's results, which indicates a negative stigma from the community towards the family, so social support becomes unnecessary. This study concludes that families can better care for schizophrenic patients when their burden, stress level, and stigma are reduced or lower. The greater a family accepts schizophrenia patients, the greater their ability to care for them.

KEYWORDS: Caregivers, Family, Patient, Relationship, Schizophrenia.

INTRODUCTION

Schizophrenia is a serious mental illness that affects how a person thinks, feels, and behaves. People with schizophrenia may seem like they have lost touch with reality, which can be distressing for them and for their family and friends [1]. Schizophrenia is characterized by psychosis (loss of contact with reality), hallucinations (false perceptions), delusions (false beliefs), disorganized speech and behavior, flattened affect (restricted range of emotions), cognitive deficits (impaired reasoning and problem solving), and occupational and social dysfunction [2]. WHO noted schizophrenia affects approximately 24 million people or 1 in 300 people (0.32%) worldwide. This rate is 1 in 222 people (0.45%) among adults. It is not as common as many other mental disorders. Onset is most often during late adolescence and the twenties, and onset tends to happen earlier among men than among women [3]. This figure is quite high and can affect family dynamics because schizophrenia causes the whole family to be affected, at least to feel the suffering. In dealing with schizophrenia, treatment programs alone are not enough because the patient's recovery lies not only in pharmacological drugs and other therapies but also in the role of the family and the community environment [4]. Families have an important role because they are an important factor in determining the success of treatment for patients with schizophrenia. Family members who consistently support patients and help them maintain an optimal treatment program will have an important impact on the success of the treatment program provided. Unfortunately, the family aspect has not been seen as something important in the treatment process; in fact, some families still consider patients only as a burden and stop treatment without a doctor's approval [5].

In the context of treating patients with schizophrenia, family motivation and knowledge are very important. However, what frequently becomes a problem is families' lack of knowledge and motivation to provide care. Even some families do not control the patient and ignore whether the patient is taking medication or not [6]. The lack of family knowledge and motivation in caring for schizophrenic patients can be seen from some research literature, which states that family knowledge about caring for people with mental disorders is still minimal and low, and this is further exacerbated by the fact that most families experience stress and are unable



to control their emotions when dealing with schizophrenic patients [7]. Of course, this condition does not develop naturally, but it is influenced by various stressors, including negative stigma and a lack of support from the surrounding environment [8]–[10].

Theoretically, the family's ability to care for members with schizophrenia is influenced by many factors. Lawrence Green stated that, in general, these factors are related to three things. First, there are predisposing factors in the form of health knowledge and attitudes, community beliefs and traditions about health, and community values. Second, enabling factors, namely the availability of public health service facilities such as public health centers, integrated healthcare centers, hospitals, midwives, and doctors practicing independently; and third, reinforcing factors in the form of supports or drivers, such as support from health workers [11]. Related to this, the results of the author's search in several kinds of literature show that family burden [12], stigma and stress [10], social support [13], and acceptance from the family itself are all related to the ability of families to care for patients. These conditions are indeed very justified because, in practice, caring for schizophrenic patients has an impact on increasing family burdens such as the objective, subjective, iatrogenic, stress, and stigma burdens that emerge from the surrounding environment [9], [14], [15]. From some of the literature, it can be seen that the treatment of schizophrenia patients is complex because it involves various conditions and situations, not only in the aspect of medical treatment but also in the context of the family and social environment. From the patient's side, they really need good care to support their recovery, while from the family's point of view, good knowledge and understanding are needed in carrying out treatment so that the presence of schizophrenia patients does not become a source of new problems for the family.

Therefore, this study aims to examine several factors related to the family's ability to care for schizophrenic patients. The urgency of this study is based on the argument that the ability of the family to care for schizophrenic patients is very necessary because if the family is unable to afford it, the treatment of the patient will not be successful, even though real care must be started by family members and not by health workers. This means that if there is no cooperation between the family and health workers, it will worsen the patient's condition. Another reason for the study's urgency is Indonesia's high prevalence of severe mental disorders. Schizophrenia still reaches 400,000 people or as much as 1.7 per 1000 in the Indonesian population. Then in Aceh, this phenomenon reached 8.7 per 1,000 households, which means that 8.7% of 1,000 households in Aceh have members with schizophrenia. The value of 8.7% is above the national average of 6.7%. More specifically, in the Aceh Jaya region, the number of cases of schizophrenia continues to increase every year. There will be 134 schizophrenics in 2020. The data that the author obtained from Aceh Jaya Health Office until May 2022 shows that the number of people with schizophrenia has reached 377 people. One of the hospitals that later became the main referral hospital in Aceh Jaya was the Regional General Hospital Teuku Umar, which was a non-BLUD/BLUD general hospital. The data that the authors obtained from the hospital from January 2021 to January 2022 showed that there were 98 patients with schizophrenia. In the context of Aceh, studies have not been found that examine the relationship between the family's ability to care for schizophrenic patients with family burden, stigma, stress, social support, and acceptance, so this is interesting to study.

METHOD

This study used a quantitative approach and a cross-sectional design to examine the relationships between family burden, stigma, stress, social support, and family acceptance with the family's ability as caregivers of patients with schizophrenia. Families of schizophrenic patients who accompanied patients took medication and cared for patients at home and at the outpatient polyclinic at Teuku Umar General Hospital in Aceh Jaya comprised the study sample, which numbered 98 in total. The research data collection period was from August 26th, 2022, to October 7th, 2022. The data collection tool used in this study was a questionnaire, which consisted of three parts, namely sections A, B, and C. Part A of the questionnaire contained demographic information on respondents and schizophrenic patients; part B of the questionnaire contained family abilities as measured using the Caregiver Competence Scale (CCS), developed by Skaff [16] with Cronbach's alpha 0.9. Then Part C of the questionnaire contains the independent variables of the study. In Part C of the questionnaire, family ability variables were measured using the Zarit Burden Interview (ZBI) questionnaire developed by Zarit, Reever, and Bach-Peterson in 1980 [17]. The stigma variable was measured using the Affiliate Stigma Scale questionnaire developed by Mak and Cheung in 2008 [18]. The stress variable was measured using the Kingston Caregiver Stress Scale (KCSS) questionnaire developed by Kilik & Hopkins in 2006 [19]. Social support variables were measured using the Multidimensional Scale of Perceived Social Support (MSPSS) questionnaire developed by Zimet et al. in 1988 [20]. The family acceptance variable of changing conditions is measured using the Acceptance and Action Questionnaire (Revised), which was developed by Hayes et al. in 2004.



The researcher back-translated all of the questionnaires used as research instruments because they were written in English and needed to be translated into Indonesian. Back translation is performed by Faculty of Nursing Lecturers who are experts in their fields. The research instrument has also passed validity and reliability tests on 30 patient families at the Aceh Government Hospital from August 3–4, 2022. The results of the instrument validity test showed that the variables family burden, stigma, stress, social support, acceptance, and family ability were declared valid ($r_{\text{count}} > 0.361$) and reliable with a Cronbach alpha value for family burden = 0.962, stigma = 0.955, stress = 0.952, social support = 0.948, acceptance = 0.915, and family ability = 0.910. This research has also received permission from the ethical committee of the Faculty of Nursing at Syiah Kuala University with the research code 112015170522 on May 31, 2022. The data analysis technique used in this study is descriptive statistics, aimed at explaining or describing the characteristics of each research variable. Then analyze, the correlation coefficient to measure the direction and strength of the relationship between the independent variables—family burden, stigma, stress, social support, and acceptance—and the dependent variable, namely family ability, using the Pearson Correlation Product Moment parametric test (r^2 test).

RESULT

This research was conducted from August 26, 2022, to October 7, 2022, at the outpatient polyclinic of Teuku Umar General Hospital in Aceh Jaya. This study's respondent characteristics included age, gender, education, occupation, relationship with patients, family size, distance from home to hospital, and hospital transportation costs. Then the characteristics of the patients include age, gender, education, occupation, medical diagnosis, duration of suffering from schizophrenia, and type of medication.

Table 1. Characteristics of respondents and schizophrenic patients (n = 98)

Respondent Characteristic	F	%	Pasien Characteristics	F	%
Age			Age		
19-40 years	13	13,3	19-40 years	78	79,6
41-64 years	85	86,7	41-64 years	20	20,24
Gender			Gender		
Man	14	14,3	Man	75	76,5
Women	84	85,7	Women	23	23,5
Education			Education		
Basic	46	46,9	Basic	50	51,0
Middle	49	50,0	Middle	45	45,9
Higher	3	3,1	Higher	3	3,1
Work			Work		
Trader	32	32,7	Trader	22	22,4
Farmer	60	61,2	Farmer	3	3,1
Government officials	3	3,1	Government officials	-	-
Housewife	2	2,0	Housewife	17	17,3
Laborer	1	1,0	unemployment	56	57,1
Relationship with patient			Medical diagnosis		
Parent	71	72,4	Paranoid	82	83,7
Wife	17	17,3	Not Detailed	16	16,3
Husband	2	2,0			
Siblings	6	6,1			
Child	2	2,0			
Number of family			Long suffered from schizophrenia		
≤ 5 people	83	84,7	≤ 5 Years		
> 5 people	15	15,3	> 5 Years	28	28,6
				70	71,4



The distance between the house and the hospital			Drug type		
≤ 5 Km	76	77,6	Antipsychotics and Antidepressants	11	11,2
> 5 Km	22	22,4	Antipsychotics and Antianxiety	61	62,2
Transportation Cost to Hospital			Antipsychotics, Antidepressants and Antianxiety	26	25,5
≤ Rp. 50.000,-	81	82,7			
> Rp. 50.000,-	17	17,3			

Table 1 shows that of the 98 families of schizophrenia patients, there are 85 people (86.7%) in middle adulthood (41–64 years), 84 people (85.7%) are women, 49 people (50.0%) with education in the middle, 60 people (61.2%) work as farmers, and 71 people (72.4%) are the patient's parents. Eighty-three people (84.7%) had five family members, 76 people (77.6%) had a 5 km distance from their house to the hospital, and 81 people (82.7%) needed an IDR 50,000,- trip to the hospital. Then, out of 98 schizophrenia patients, 78 (79.6%) were young adults (19–40 years old), 75 (76.5%) were men, 50 (51.0%) had primary education (graduated elementary or junior high school), 56 (57.1%) did not work, 82 people (83.7%) had a medical diagnosis of paranoid schizophrenia, 70 people (71.4%) had schizophrenia > 5 years, and 61 people (62.2%) received antipsychotic and antianxiety treatment.

Table 2. The relationship between family burden, stigma, stress, social support, and acceptance with the family's ability to care for schizophrenic patients

Variable	<i>r</i>	<i>p-value</i>
Family burden	-0,432	0,0001
Stigma	-0,629	0,0001
Stress	-0,432	0,0001
Social support	0,148	0,145
Family acceptance	0,795	0,0001

Table 2 shows that the family burden variable is related to the family's ability to care for schizophrenic patients ($p = 0.0001$) with a negative relationship ($r = -0.432$). This means that the lower the family burden, the higher the family's ability to care for schizophrenic patients. The stigma variable is also related to the family's ability to care for schizophrenic patients ($p = 0.0001$), with a negative relationship ($r = -0.629$). This means that the lower the stigma, the higher the family's ability to care for schizophrenic patients. The stress variable is related to the family's ability to care for schizophrenic patients ($p = 0.0001$) with a negative relationship ($r = -0.432$). This means that the lower the stress, the higher the family's ability to care for schizophrenic patients. However, table 2 also shows that social support has no relationship with the family's ability to care for schizophrenic patients ($p = 0.145$). The test results on the acceptance variable showed that there was a relationship between family acceptance and the family's ability to care for schizophrenic patients ($p = 0.0001$) in the form of a positive relationship ($r = 0.792$), which means that the higher family acceptance, the higher the family's ability in caregivers of patients with schizophrenia.

DISCUSSION

In Indonesia, most of the caregivers of schizophrenic patients are their own family members, so it can become a burden and create stress for the family. Not only that, families who care for family members with schizophrenia also experience financial, emotional, physical, and social burdens that cause a decrease in their ability to provide care and lead to failure in caring for individuals with schizophrenia at home [21], [22]. It was also confirmed from the results of this study that family burden has a fairly strong relationship with the family's ability to provide care, and the relationship is in the form of a negative one. This means that if the family burden is low, the family's ability to care for schizophrenic patients will increase and can support the success of treatment. This study showed a strong relationship between stigma and the ability of families to provide care. These findings are consistent with previous research indicating that family caregivers of schizophrenic patients face stigma and discrimination in everyday life [23]. This negative stigma basically reduces the quality of family life and family functionality, and there is a possibility of a negative



outcome on family resilience. Koschorke et al. suggest in their research that the stigma associated with schizophrenia significantly affects the ability to care for families. The negative stigma received by the family can adversely affect the process of caring for patients with schizophrenia, so this negative stigma needs to be minimized. Widyowati, Murti, and Sudiyanto stated that social stigma increases the probability of recurrence of schizophrenia compared to patients who do not receive social stigma [24]. This was also confirmed by Hanik, Herrawati, and Andri that the stigma experienced by families has a negative impact on the healing process of schizophrenia patients because it can cause families to feel sad, embarrassed, shocked, annoyed, anxious, and blame each other, which will ultimately affect the quality of the process for schizophrenic patients [25]. In addition to these impacts, Ong, Ibrahim, and Wahab said that families as caregivers also tend to experience social problems because they care for patients with schizophrenia at home [26]. Even though one of the efforts to prevent relapse in schizophrenic patients is to involve the family and reduce the stigma in society, Widyowati et al. confirmed that the frequency of schizophrenia relapse decreased after family involvement in providing care for each patient's activities [24].

The study's results also show a fairly strong relationship between stress and family capacity. The lighter the stress, the higher the family's ability to care for schizophrenic patients, and vice versa. The results of this study are in line with the results of several other studies, which state that almost all families of schizophrenic patients experience psychological pressure in the form of feelings of pressure or stress [27]. The stress experienced by the family is determined by how they perceive the problematic situation they are facing. Therefore, the family needs the help of health workers, including nurses, especially to change the family's perspective on the causes of stress, which were initially considered threats, heavy burdens, and difficulties faced alone but became a motivating challenge for the family as a whole, faced together by all family members so that they were determined to care for schizophrenic patients. If it is managed properly, the stress experienced by the family can be adequately managed, making the family more resilient [9].

Based on the results of the study, it is known that there is no moderate relationship between social support and family abilities. These results differ from the research by El-Monshed and Amr which states that social support plays an important role in the recovery of schizophrenic patients who are cared for by their families at home. The negative stigma from society explains the absence of a relationship between social support and family ability in this study. Negative stigma from the community indicates that the community is less able to accept the presence of schizophrenic patients in their environment, so it will impact community support for families caring for schizophrenic patients at home [28]. This is as stated by Karaçar and Bademli in their research, namely that when the perceived level of social support decreases in families of schizophrenic patients, this indicates increased stigmatization and vice versa [29]. From the results of this study, it can be stated that families of schizophrenic patients who seek treatment at the outpatient polyclinic at Teuku Umar Hospital, Aceh Jaya Regency, do not make social support an encouragement to carry out care for schizophrenic patients at home. Finally, research shows that there is a strong relationship between acceptance and family capacity. This means that the higher the acceptance, the greater the family's ability to care for schizophrenic patients. This is in line with the results of Darni, Yusuf, and Tristiana's research which found that family intervention in the form of acceptance supported a decrease in the number of schizophrenic patients because family acceptance has a positive effect on the length of time family members experience schizophrenia [30].

CONCLUSION

The results of this study indicate that family burden, stress, stigma, and acceptance have a relationship with the family's ability to provide care to schizophrenic patients ($p=0.0001<0.05$). Only one variable has no relationship, namely social support ($p=0.145>0.05$). The absence of a relationship between the social support variable and family capacity is in line with the results of the stigma variable, which indicates that there is a negative stigma from the community towards the family so social support becomes something that is not needed. Based on the results of the study, it can be concluded that the lower the family burden, the higher the family's ability, the lower the stigma, the higher the family's ability, the lower the stress, and the higher the family's ability and the higher the family's acceptance of schizophrenia patients, the higher the family's ability to do as a caregiver.

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