

ORIGINAL RESEARCH

KNOWLEDGE, PERCEPTION, AND BURDEN OF FAMILY IN TREATING PATIENTS WITH SCHIZOPHRENIA WHO EXPERIENCE RELAPSE

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Abstract

Background: Schizophrenia is a mental disorder with a high incidence and relapse due to a lack of family support. Families do not understand how to treat patients with schizophrenia. There are several factors related to the family's abilities in treating patients with schizophrenia, there are the level of family's knowledge, perception, and burden.

Objective: This study aimed to describe the knowledge, perception and burden of family in treating patients with schizophrenia who experience a relapse.

Methods: The research used descriptive quantitative method. Samples were selected by consecutive sampling technique and obtained 100 respondents. Data were collected by a questionnaire consisting of family knowledge and perception developed by the researcher, and Zarit Burden Interview scale was used to measure the family burden. Data were analyzed using percentages, score T, and the Zarit Burden Interview analysis.

Results: Findings showed that 31 respondents (31%) had good knowledge, 42 respondents (42%) had sufficient knowledge, and 27 respondents (27%) had insufficient knowledge. In terms of perception, 66 respondents (66%) had a positive perception and 33% had a negative perception. In addition, 42 respondents (42%) had moderate to heavy burden levels, 23 respondents (23%) had a very heavy level of heavy burden, and 3 respondents (3%) with very heavy levels of burden.

Conclusions: Based on the results, it is necessary to increase the frequency of health education for the families. In addition, it is also important to hold a sharing program between families to reduce family burden.

KEYWORDS

family's burden; knowledge; perception; schizophrenia

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INTRODUCTION

Schizophrenia has been known as a severe and chronic mental disorder that affects all aspects of the life of the sufferer ([Suryani et al., 2013](#)), because there was a group of psychotic symptoms that affected various areas of individual functioning, including thinking, communicating, receiving and interpreting reality, feeling and showing emotions, and behaving socially acceptable ([Stuart, 2009](#)). Data from the World Health Organization (WHO) showed that people with mental disorders diagnosed with schizophrenia were around 24 million worldwide ([Who, 2014](#)). While the prevalence of schizophrenia in Indonesia showed an increase from 1.7 to 7 per mile ([Riskseddas, 2018](#)). Furthermore, data in Indonesia had been a shifted, schizophrenia usually

occurred in the age of around 18-45 years changed to a younger age of 11-12 years ([Arif, 2006](#)).

Schizophrenia is a disease that needs serious attention from the government because of its impact on the state's burden, as a result of the patient's unproductivity and ongoing medical costs ([Suryani, 2015](#)). Based on a recent study, the prevalence of relapse in people with schizophrenia was in the range of 50-92% globally ([Weret & Mukherjee, 2014](#)). [Keliat \(2011\)](#) explained several factors affected patient relapse, they were patients, doctors, nurses, and families. Families had a very important role in caring for family members with mental illness and providing support during the recovery period ([Sadock & Sadock, 2010](#)).

[Berglund et al. \(2003\)](#) stated that the family's ability in caring for patients with schizophrenia might reduce the percentage of relapse within a year. The ability of the family in caring for patients with schizophrenia is strongly influenced by several factors. These factors were family's knowledge, perception, and burden ([Chien & Lee, 2002](#); [Knock et al., 2011](#)). It was important for families to have knowledge related to the concept of schizophrenia, appropriate treatment methods, and treatment that should be done ([Suryani, 2015](#)). Perception was the identification and interpretation of stimulus based on information received ([Stuart, 2009](#)). Perception in the family was useful to determine the care to the patient ([Dalky, 2012](#)). The level of family burden also greatly influences the family's role in caring for patients with schizophrenia. According to [Adeosun \(2013\)](#), it was known that a high family burden cause the family cannot performed their role properly.

Based on an interview conducted on January 2014 at the X Mental Hospital to the nurses in the outpatient unit, it was revealed that the high rate relapse of patients with schizophrenia could be caused by a lack of family's ability in caring for their family members. The family assumes that patients who have been allowed to go home after hospitalization means that they have been fully recovered and no longer need to take medicine. This assumption might derive from the lack of family's knowledge and perception. Whereas according to [Motlova et al. \(2006\)](#) the key in preventing relapse in patients with schizophrenia was adherence to long-term treatment and it is influenced by knowledge and perception about the treatment.

In addition, researchers interviewed 3 families of patients with schizophrenia who took their family members for treatment due to relapse. Based on the interview it was found that the family had been felt tired and angry because the patient had relapsed several times. Further the family added, that the family did not understand how to treat patients with schizophrenia properly to prevent relapse. The family explained that sometimes families feel burdened with the responsibility of caring for patients, because family activities were disrupted. Besides being burdened in activities, the family was also burdened in economic because they have to spend large amounts of money for treatment. Therefore, families felt depressed and lack of motivation in caring for the patients. Further based on observations in the outpatient unit, it was identified that most families only waited outside the examination room when the patient was being examined, so the families could not take the opportunity to discuss with the doctor about the patient's progress. This might influences the family's knowledge and perception regarding caring to the patients. Therefore, it is important to find out the knowledge, perception and also family's burden in caring for patients with schizophrenia who experience relapse as the consideration for future appropriate interventions.

METHODS

Study Design and Sample

The research design was quantitative-descriptive design. The variables of this study were the level of family knowledge, family

perceptions, and the level of family burden. The samples in this study were taken by consecutive sampling technique. The respondents were the families of patients with schizophrenia who took patients to the outpatient unit at Hospital X, with the inclusion criteria of the respondents were 1) families who live with the patients; 2) respondent is patient's family; and 3) one of the respondent's family is patient with schizophrenia who experience relapse. Data collection was carried out within one month, and was obtained 100 respondents. This study was conducted in July 2014.

Instrument

The data were collected using questionnaires. The questionnaire was made into three parts, including instruments that measure family knowledge, perceptions and burdens. The family knowledge and perception questionnaire was compiled by researchers based on various relevant sources of theory. The knowledge questionnaire measured about the concept of schizophrenia and how to treat patients with schizophrenia, while the instrument for measuring the level of family burden using a Zarit Burden Interview which was used to measure the family burden in caring for the elderly ([Bédard et al., 2001](#)). This instrument was translated through back translation and modified by researchers so that it was in accordance with the research. The results of the validity test for knowledge instruments were 0.313 - 0.904 and perceptions were 0.672 - 0.765 while the reliability for knowledge, perception and zarit burden interview were 0.781, 0.765, and 0.830 ([Yap, 2010](#)) consecutively.

Data Analysis

Data were analyzed using descriptive quantitative method with distribution frequencies. Data analysis to measure perception factors using T scores, because the number of items from each aspect is different. The perceptions using T score categorized as: 1) T scores > 31.2, it means respondents had positive perception and 2) T scores ≤ 31.2, it means respondents had negative perception. While family burden was analyzed used the standard instrument of Zarit Burden Interview which categorized as: 1) scores 0 – 19 as no/minimal burden; 2) scores 20 – 38 as moderate to severe burden; 3) scores 39 – 57 as severe to very severe burden; scores 58 – 84 as extremely severe burden and knowledge were calculated using the percentage categorized into good (percentage of correct answers 76 – 100%); moderate (percentage of correct answers 56 – 75%); and low (percentage of correct answers less than 55%).

Ethical Consideration

All respondents involved in the study were given information about research and has agreed to participate in research voluntarily. In addition, the research process has obtained research approval and permission from the West Java Provincial Mental Hospital by letter No. 423.4 / 8920 / Pendik / 2013.

RESULTS

Table 1 shows more than a half of respondents are males; most of them are in early and late adult development. Nearly two fifths of the respondents are parents with the primary level of education,

and three fifths of the respondents are working. The duration of illness is 1 to 5 years for just under a half of patients' and all of the patients had experienced relapse between 1 to 5 times.

Table 1 Respondents' Characteristics (n=100)

Characteristics	Frequency	Percentage (%)
Gender		
Male	58	58
Female	42	42
Age (years old)		
18-25	5	5
26-40	36	36
41-60	52	52
> 60	7	7
Family Relationship with Patients		
Parents	24	24
Husband/Wife	29	29
Brother/sister	8	8
Child		
Education Level		
Primary Education (SD/SLTP)	44	44
Secondary Education (SLTA/SMA)	43	43
Higher Education	13	13
Working Status		
Working	64	64
Not working	36	36
Duration of Illness (Years)		
1-5	47	47
6-10	35	35
>10	18	18
Frequency of Hospitalization		
Never	25	25
1-5 times	64	64
6-10 times	7	7
>10 times	4	4

Table 2 Frequency Distribution of Families Knowledge to Caring for Patients with Schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
Good	31	31
Moderate	42	42
Low	27	27
Total	100	100

Table 2 shows that a significant proportion of family has moderate to good knowledge to caring for patients while those who lack knowledge in treating patients are only less than one third. While **Table 3** shows that more than two-thirds of families have a positive perception of schizophrenia and only less than one-third of respondents have negative perceptions.

Table 3 Frequency Distribution of Families Perception about Schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
Positive	66	66.00
Negative	34	34.00
Total	100	100.00

Table 4 Frequency Distribution of Family Burden in Caring for Patients with schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
No/minimal burden	32	32
Moderate to severe burden	42	42
Severe to very severe burden	23	23
Extremely severe burden	3	3
Total	100	100.00

Based on **Table 4**, almost one third of families have a minimum burden and more than two thirds have moderate burden to extremely severe burden.

DISCUSSION

There were several factors that influence the family's ability in caring for family member who suffer from schizophrenia. The first factor is the knowledge of the family about the illness. In this study it was found that there were 31 respondents (31%) who had good knowledge, 42 respondents (42%) who had moderate knowledge, and 27 (27%) respondents had low knowledge. Having good knowledge is very important for family in determining how to care for patients. As revealed by [Li et al. \(2007\)](#) that providing knowledge to families about schizophrenia was important, especially for families with low levels of education. There were several reasons why many respondents has moderate and low level of knowledge. According to [Li et al. \(2007\)](#) one of the factors that influenced a person's level of knowledge was the level of education. Nearly half of the respondents had primary education levels (44%), and as many as 43% respondents had secondary education levels, while only a small proportion of respondents who has high level of education (13%). Based on these data it can be seen that the education level of most respondents was still low. [Yusuf et al. \(2009\)](#) explained that the level of education determines how families care for the patients and to prevent patients from relapse. Low education level of respondents in this study may lead to the lack of initiative of the respondents in seeking information relating to the diagnosis and treatment of the patients, this statement was supported by the research results of [Adeosun \(2013\)](#).

In general, the level of families education determine the families response in receiving information related to the recovery of patients, and will influence their ability in caring for the patients ([Suryani et al., 2016](#)). Knowledge about diagnoses, treatment, and

patient care are very important for the family ([Li et al., 2007](#)). This knowledge is not only important for the preventing patient relapse, but also important for the families who care for them. Good knowledge reduced the families level of stress when treating for the patients and will further improve the quality of care ([Chien & Lee, 2002](#)).

On the other hand, most of the age of the respondents was in the late adult range of 41 to 60 years (52%). [Chien et al. \(2004\)](#) explained that at this age a person has experienced physical and psychological deterioration, so that respondents became more passive in seeking information about patient's illness. Furthermore, this age is also called transitional age, at this age a person is more concerned with his own health status so there is not enough time to find information about schizophrenia. According to [Kate et al. \(2013\)](#), family caregiver with productive age had better experiences in treating patients with schizophrenia compare to nonproductive ones.

The Mental Hospital where this study was conducted, has been had a counseling program for families and patients about mental illness, but counseling about schizophrenia itself was very rare. Health education was always given to the families of patients by nurses when doing assessment. However there were some families who did not accompany patients when the health education was given. When the doctor provides consultation to patients and families, information about the diagnosis and treatment for the patients were provided. However, it was difficult to understand by the patients and families. So, it is necessary to provide a planned psycho education for the families of patients to overcome various psychosocial problems due to their lack of knowledge about schizophrenia ([Suryani et al., 2016](#)).

Based on analyzing the incorrect answer by most respondents, it was found that the concept of relapse; and what the family must do if the patient has a relapse was the most wrong answered by the respondent. The steps that must be carried out by the families when the patient have relapse are: first, bring the patient to a calm place and make him relaxed, second, assessing what is experienced by the patient, third, giving pharmacological therapy according to his schedule, and fourth bring the patient to treatment immediately ([Stuart, 2009](#)). However, the answer of most respondents was directly gave the drug to patients, even if it was not a medication schedule. That means the respondent's knowledge regarding the actions that must be taken when the patient deterioration was very lacking, this could be caused by a less of counseling about relapse. This condition can strengthen the reason for the frequent of patients experiencing relapse in the past year. Based on the data there were 86 respondents (86%) who often experienced relapse. In addition, from the study, it can be seen that the education background of the respondents was low and most of them were elderly and had experienced physical deterioration, thus the method of health education that had been carried out by the hospital was less effective for respondents with these characteristics.

Beside knowledge, family's perception also has important aspect in caring for family's member with schizophrenia. Based on the results of the study, 66 respondents (66%) had a positive

perception and 34 respondents (34%) had a negative perception. Positive perceptions of the respondents can be influenced by several factors such as acceptance to the patient's condition. This was indicated by the sincere love of the family while caring for the patient. This sincerity arises because most of the respondents are parents of the patients. This is related to affective function in the family, which is the basis of family strength. Affective functions in the family include nurturing, fostering, a balance of mutual respect, transition and identification, separation and coherence ([Friedman et al., 2010](#)). From the demographic data, it was found that the relationship between respondents and patients as parents was 39 respondents (39%). Sincere attention and affection from the family and the people closest to the patient will greatly help the healing process of the patients ([Sulistiyorini et al., 2013](#)). In addition to the acceptance of the patient's condition, perception is also influenced by the culture that develops in the community about schizophrenia. Culture in the community will shape the family mindset of caring for patients with schizophrenia. As there are some cultures that assume that the patient's illness is a cause by magical things or something, so it will not be recovered if taken to the doctor or to the hospital, except to the dukun (traditional healer) ([Suryani et al., 2013](#)). Such perceptions will cause the families provides inappropriate care to the patient. So that the patient difficult to recover and often experiences relapse ([Papastavrou et al., 2009](#)). According to [Dalky \(2012\)](#), there were several ways to improve families' perceptions in caring for patients with schizophrenia including sharing between family members, having faith in religion, praying, accepting the patient's condition, and having support from other families.

Although most respondents showed positive perceptions, there were still 21 respondents (21%) who had negative perceptions. Negative perceptions can occur due to a lack of information about schizophrenia. It could be cause by having wrong information about schizophrenia and its treatment. The level of education can affect people's perception. The education level of the respondents in this study was mostly low. [Srinivasan and Thara \(2001\)](#) found that people with a low level of education more often stated that the causes of schizophrenia were supernatural, while people with a high level of education could better understand about the causes of schizophrenia because they were able to access and receive information correctly.

Most families of people with schizophrenia have experienced burden in caring for the family's member with schizophrenia ([Suryani, 2015](#)). From the results of this study it was found that the level of burden with the highest percentage was moderate to severe burden. Some respondents even have severe burden. This level of severe burden can be related to the duration of illness, frequency of relapse, family relationships with the patient, and the occupational status of the respondent.

According to [Gutiérrez-Maldonado and Caqueo-Úrizar \(2007\)](#), family burden was divided into 2 types, namely subjective and objective burden. Subjective burdens were feelings of stress, anxiety, confusion and loss. Whereas objective burden included economic burdens, family boundaries for socializing and activities, and a setback in inter-family relations ([Knock et al.,](#)

2011). Based on the research of Adeosun (2013), it was found that factors that might affect the level of family burden were the work status of a person, the age of the family caregiver, and the duration of patients' illness. Schulze and Angermeyer (2003) added that the developing of stigma in society also greatly affects the level of burden.

Based on the result of this study about the occupational status of the respondents, most of respondents (64%) had jobs and only a small portion of respondents (36%) who did not work. This means that the families had income to pay for the patient's treatment. In addition, most respondents were not burdened with costs, because there is health insurance namely Kartu Indonesia Sehat (Indonesia Health Card) for treatment in mental health hospital. However, families felt burden for having difficulty in managing time between working and caring for the patients. Adeosun (2013) stated that higher levels of burden were seen in family caregiver who works, because they had to divide the time between caring for patients and work. Because the family's obligation to care for the patient, many families felt that they were losing their normal lives, feeling that their own time was diminishing or not even there (Knock et al., 2011).

The duration of the illness can also increase the burden on respondents. Demographic data showed 47 patients (47%) had schizophrenia for 1-5 years, 35 patients (35%) for 6-10 years and 18 patients (18%) for > 10 years. Adeosun (2013) revealed that families became more afraid of their future lives due to chronic diseases of the patients because they took up most of their time to care for patients over a long period of time. Families must spend a lot of energy and set-aside time to treat patients for years. The age of most respondents in this study was in the old age range; this age is an age where there have been some physical and psychological deterioration. Respondents might have health problems, so they have limitations and feel heavy burdens in caring for the patients. Study by Chien et al. (2004) which aimed to measure the level of families' burden in caring for patients with schizophrenia showed that the level of burden was higher in families that have health problems, weak functions, and low social support from other family members is needed to participate in caring for patients, so the family burden is reduced and patient care becomes more optimal.

The families have been faced the burden on their own, because of the lack of support provided by the health care center or related hospital. Kertchok et al. (2011) explained that there was a need for programs from health workers, especially nurses, regarding intervention to families who care for patients with schizophrenia so that families would have a normal life. In addition, patients who often relapse also add to the burden of the family in caring for the patient (Farkhah et al., 2017). The results of the study showed that 86 patients often experienced relapse. Frequent relapse would make the families felt anxious, worried and depressed about the future of themselves and the patient (Chien et al., 2004).

Stigma from the community can also added burden to the family (Suryani, 2015). There were various stigmas arose from the public about schizophrenia (Suryani et al., 2016). Angermeyer

and Matschinger (2003) explained that there are 4 types of stigma namely interpersonal interaction, structural discrimination, a developing image of mental disorders, and social access. Stigma could interfere family's relationships with local communities so that families feel isolated (Suryani, 2015). The families considered that the patient was the cause of various problems. These condition made families felt anxious and worried about their own lives (Suryani, 2015). This was also supported by Christopher (2012) which stated that the majority of respondents in their study felt fear and anxiety about their health and their lives in the future, . The conditions described above reinforce the results of this research in which the level of respondents' burden were at moderate to severe levels, and even very heavy burden. This was in accordance with the research conducted by Papastavrou et al. (2009) that found that 43% of respondents in his study had a high level of burden with a score of 24/42 using the Family Burden Scale (FBS).

Based on the results of the study, it can be seen that the factors of low knowledge and high family burden in treating patients were the most experienced factors in families of patients with schizophrenia. This showed that both of these factors could be the cause of relapse in patients with schizophrenia, so these need to be considered by nurses. Nurses need to assess family knowledge about patient care and provide education if family knowledge is low. As well as the burden of the family, assessment of the family burden needs to be done. Furthermore, the factors that influence the family burden are also important to be studied and examined through further research.

CONCLUSION

All patients with schizophrenia in this study experienced a relapse, and based on the research it was seen that family knowledge was inadequate in treating patients with schizophrenia, as well as family burden, most of which were at moderate and high levels, while the family's perception of schizophrenia is good.

Mental Hospital in the setting of study was expected to develop a mental health program to increase the optimal families' role in the family's daily life of patients with schizophrenia in the term of increasing knowledge and family's perception, by increasing regular counseling regarding patient diagnosis, treatment, the cause of relapse, and how to care for the patients at home, thus the family would have a good knowledge and a positive perception about schizophrenia. Moreover, the factors that influence the family burden are also important to be studied in further research.

Declaration of Conflict of Interest

The authors declare that there is no conflict of interest.

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Authors Contributions

All authors have contributed in the preparation of the manuscript. SS: Managing the research process, developing the idea for research proposal,

checking and finalizing manuscript before submitting it. EWN: Writing for research proposal, collecting and analyzing data. AN: collecting and analyzing data, and drafting manuscript.

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