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Original Article

Family members' perspective of family Resilience's risk factors in taking care of schizophrenia patients

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ABSTRACT

Objectives: The study was conducted to illustrate the risk factors of family resilience when taking care of patients with schizophrenia.
Methods: The research used qualitative design with an interpretive phenomenology approach, with in-depth interviews. The subjects were 15 family members who cared for patients with schizophrenia at the Menur Mental Hospital, Surabaya, Indonesia. The samples were obtained by purposive sampling technique. The data was collected by interview and using field notes, then analyzed by Collaizi technique.
Results: This research produced two themes, they were care burden and stigma. Care burdens felt by families were confusion about the illness, emotional, physical, time, financial and social burdens, which leads to decrease in family quality of life. Families also experienced stigma called labeling, stereotyping, separation and discrimination. Stigmas meant that families faced psychological, social and intrapersonal consequences. This decreased the family quality of life and functionality of the family, and there were opportunities for negative results to family resilience. Health workers, especially psychiatric nurses, should review care burdens and stigma to develop nursing interventions so families are able to achieve resilience.
Conclusions: This research explained how care burden and stigma are risk factors that must be managed by families to survive, rise up, and become better in caring for patients with schizophrenia. Nurses have a central role in assessing the level of care burdens and stigma in order to help families achieve resilience. Further research may focus on family-based nursing interventions to lower care burden, and community-based interventions to reduce stigma.

1. Introduction

Schizophrenia is one type of mental health disorder that is still a complicated problem. The prevalence of severe mental illnesses, including schizophrenia, based on Riskesdas 2013 [1] is present in 1.7 per 1000 people, which means more than 400,000 people suffer from severe mental disorders in Indonesia. The incidence of schizophrenia is difficult to decrease due to high recurrence rates. The recurrence rate of schizophrenia patients in Indonesia is 50%–80% [2], 57% within 3 years [3] and 70%–82% in the first five years [4].

Based on a study by Kusumawardani [5] at the Menur Mental Hospital, Surabaya, Indonesia, 90% of patients are diagnosed with schizophrenia. Majority of them (80%) already experienced recurrences. The cause of relapse, according to Fadli & Mitra [6], is the inability of the family to control emotions, and the existence of stressful family life problems [7], so continuous criticism from the family is the cause of patient recurrence [8]. The phenomenon shows families have not been able to care for family members who have schizophrenia. The inability is influenced by the various stressors. The stressors involve many kinds of care burden [9], negative perceptions or stigma [10] and a lack of support from their surrounding environment. The stressors experienced by families may be mediated by resilience [11], the ability of families to survive and rise up to determine what they will do, and the capability to care for family members suffering from schizophrenia. Family resilience is a dynamic process between risk factors and protective factors [12]. Risk factors can encourage negative outcomes in

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families, while protective factors help reduce the negative outcomes [13]. Protective factors interact with risk factors and generate power for family to overcome the adversity.

Growing the ability of family resilience is not an easy effort. Families should be able to identify risk factors and manage these to achieve a dynamic family situation and have the ability to survive while caring for patients with schizophrenia. Families need help from health professionals, such as psychiatric nurses, to identify and manage family risk factors. There have been several studies of family resilience in caring for patients with mental disorders including schizophrenia, but the study focuses more on family resilience indicators [14–17]. The study has not yet exploited risk factors for family resilience. The research is expected to complement the pre-existing theory by adding components in risk factors to The Theory of Resiliency Model of Family Stress, Adjustment and Adaptation by McCubbin and McCubbin [18]. This theory explains that the resilience process consists of two stages, namely the adjustment stage and the adaptation stage. Each stage describes the family's ability to deal with stressors from outside the family (risk factors) using family strength, family resources and problem-solving abilities in the family (protective factors). Families in the adjustment phase will encounter accumulated demands (risk factors) in the form of stressors, tensions or transitions. Meanwhile, the family's protective factors present themselves in the form of family functions, family resources, family coping and problem-solving. The family conducts the assessment process by focusing on the stressors (the existence of the demands of risk factors) and resulting in an understanding that the accumulation of demands is so severe, thus the family falls into a crisis phase. The family becomes inadequate and disturbs the pattern of family functions, and goes on to run into imbalances and dissonance. Families at a given moment will be able to respond to the demands of the crisis and make changes in the assessment process, in which the family now goes into the adaptation phase, where the focus of family assessment is based on the real situation. Families are able to balance the risk factor with the protective factor. So, the family reaches a balance, rises from a family crisis situation, and is able to deal with problems well. The family regains the family function, can walk in harmony and balance, and even has more power to grow into a strong family, which is when the family has reached resilience.

This study aims to describe the risk factors of family resilience during the care of patients with schizophrenia using qualitative research methods with a phenomenology approach. Identifiable risk factors are expected to serve as a review component for the mental health nurse, thus more quickly stimulating families to achieve family resilience.

2. Material and methods

2.1. Research design

The research was performed as qualitative research based on a interpretive phenomenological approach. A qualitative research design was used to answer the research objective in getting experiential meaning from research subject related to risk factors of family resilience during the caring of patients with Schizophrenia.

2.2. Participant and recruitment

The population was family members who cared for patients with schizophrenia at Mental Hospital Menur, Surabaya, Indonesia. The study involved 15 family members as participants obtained by purposive sampling techniques. The inclusion criteria were family members as primary caregivers of patients, more than 20 years old, living in one house with the patients and have been caring the patients for at least 1 year. The patient should be diagnosed as having schizophrenia for at least three years, proved by medical records, and have already experienced at least one recurrence. Participants were family members who accompany patient at the outpatient unit of the Mental Hospital Menur. The participants were recruited on the basis of ethical principles. Participants involved in the research have previously received a written explanation regarding the purpose of research, procedures, rights and obligations, benefits and disadvantages during the study. Only participants who have given informed consent were involved in the study. This study has obtained ethical approval from the Ethical Committee of Menur Mental Hospital with the number 423.4/72/305/2017.

2.3. Data collection and analysis

Before starting the data collection, the researchers carried out interview guidance trial tests on three participants to validate the questions that were listed with the assistance of a supervisor involved in mental health nursing. Data were collected by in-depth interviews using semi-structured interview guides and completed with field notes Formal interviews were conducted at participant home and take 44–60 min for each participant. Participants were asked the question *'could you please explain the difficult problems which are hard to be overcome during caring for patients with Schizophrenia?'* and *'according to the difficult problems, what situations contribute to the complication and inhibition of the family's capability to survive and overcome the problem?'*. Questions were open-ended and interviews were recorded by a voice recorder. The interview process was carried out until no new data founded. Three researchers conducted the interviews, namely, R.F., R.D.T, and H.E.N. All of them already have experienced, as found in an in-depth interview, performing the duty of mental health nursing lecture and have undertaken qualitative research before. Interview results were written as verbatim transcripts and constructed after each completed interview with one participant. Regular discussion between three researchers was done in order to integrate the research finding.

Risk factors for family resilience were analyzed and interpreted using analytic analysis according to Collaizi [19] consisting of nine steps. The analysis includes: 1) describing phenomena to be studied, 2) collecting descriptions of phenomena through participants' opinions, 3) reading the entire description of phenomena submitted by participant, 4) re-reading interview transcripts and citing meaningful statements, 5) making outlines of meaningful statements, 6) organizing collections of meanings formulated into groups of themes, 7) writing complete descriptions, 8) meeting participants to validate the compiled descriptions and 9) incorporating validation results data into full description. Data collection was conducted simultaneously with data analysis process until data saturation occurred. Demographic data was described and presented in the table of participants characteristic.

3. Results

3.1. Demographic data

Descriptive statistics of the characteristics of participants are shown in Table 1. This study followed 15 family members as primary caregivers of schizophrenia patients (10 females and 5 males), aged within the range of 26 years–58 years old. The educational level of participants varies from unschooled to university. Most of the participants (10 people) are working, as civil servants, private or self-employed, while five people are not working. The majority of participants are parents (7 mothers and 2 fathers), 2 spouses of the