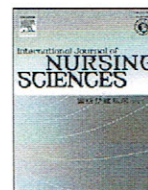




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Original Article

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 Colaizzi 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.© 2018 Chinese Nursing Association. Production and hosting by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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

Table 1
Characteristics of participants.

N	Gender	Age (Year)	Relationship	Duration of Care (Year)	Occupation	Education
P1	Female	52	Mother	6	No Work	Elementary
P2	Male	58	Father	5	Self-employment	Senior High
P3	Female	49	Mother	5	No Work	Elementary
P4	Male	48	Spouse	15	Private-employment	Junior high
P5	Female	36	Siblings	4	No Work	Senior High
P6	Female	45	Mother	5	No Work	No
P7	Female	56	Mother	6	Private-employment	Elementary
P8	Male	54	Siblings	5	Private-employment	Junior high
P9	Female	51	Mother	8	No Work	No
P10	Female	40	Sister in Law	4	Private-employment	University
P11	Male	58	Father	10	Self-employment	Elementary
P12	Female	47	Mother	6	Private-employment	Senior High
P13	Female	26	Child	5	Civil-government	University
P14	Female	54	Mother	5	Private-employment	Elementary
P15	Male	58	Spouse	23	Self-employment	University

patient, 1 child, 2 siblings and 1 sister-in-law. Family members who are suffering from schizophrenia (6 female and 9 male) are aged in the range of 20–60 years old. Most schizophrenia patients do not work, only two people work at home as a tailor and a painter. Most of them (12 people) regularly control their illnesses with health services and are taking regular medication. All patients experienced a recurrence more than three times in one year and are already diagnosed with schizophrenia at least 5 years ago.

3.2. Risk factors of family resilience

Two themes were abstracted from the family members' experiences related to risk factors of family resilience in taking care of patients with Schizophrenia. The themes are care burden and stigma (Table 2). The details of each theme are described.

3.2.1. Care burden

Care burdens felt by the participants is classified into six kinds, they are confusion about the illness, emotional, physical, financial, time and social burden. The family members complained confusion about the disease process of Schizophrenia. They have asked many times "can schizophrenia be cured?". Family members are also confused about patients' behaviors: sometimes they looked normal but sometimes they seem abnormal. Emotional burden is felt by all

participants, they complained of sadness due to unmanageable patient behavior, feel fear of patient's harmful behavior, embarrassment due to poor patient behavior in society, worrying about the patient's future and angry with uncontrollable patient behavior thus making the family lose control of their emotions. The physical burden experienced is being physically exhausted, because they have to take care of the patient every time, and have no time for resting. This situation decreased the family health status due to the condition of being continuously physically exhausted accompanied by psychological problems. Families suffered from physical illnesses such as high blood tension and digestive problems.

The financial burdens experienced by participants are medical expenses and daily needs cost of patients with schizophrenia. Medical expenses are used for regular control at health service centers, drug purchase, and transportation to health service centers. While the daily needs cost are used for meals, pocket-money, snacks and patients' personal needs. The participants' time burdens include complaining of having to always take care of the schizophrenic patient, causing participants do not have enough time to do personal interests, such as to relax and pamper themselves. The social burden experienced by participants is an obstacle to not being able to work or having to sacrifice their working time due to taking care of the patient.

The care burden felt by the participants during taking care of

Table 2
Identified resilience risk-factor themes and exemplary significant statement from family of schizophrenia patient.

Theme	SubTheme	Significant Statement
Care burden	Confusion about the illness	'Maybe he (patient) can heal but he needs a long time ... but even when he recovered, he relapsed again, our family does not understand this disease (Schizophrenia)' (P13) (P8)
	Emotional Burden	'Every moment, I can't escape thinking of him ... his future, his fate' (P3) (P11)
		'When the voices come (hallucinations) at night, his behavior begins to get strange and I can't sleep, I'm afraid he will hit me or damage the house ...' (P8)
	Physical Burden	'when he relapses ... he can go out without wearing clothes, go anywhere ... as his mother I am very ashamed ...' (P6)
		'I feel annoyed almost every day, and when I can't stand it, I hit her (patient)' (P12) (P7)
	Financial Burden	'I never get good sleep every night, morning is coming soon ... I had to wake up again to care for her (patient) again' (P1)
	Time Burden	'my head becomes dizzy, my neck too tense ... it always happens when she relapses ... I feel like I will explode ...' (P15) (P4)
'We should sell our motorbikes, sometimes sell our bird collection ... yes for treatment for him (patient), his meals and daily needs ...' (P11)		
Stigma	Social Burden	'He (the patient) must be watched from afar, especially if he is on the porch of the house, there are passers-by who call out and spit on him ... if he is not guarded, there is always a problem ... must always be guarded' (P8)
	Labelling	'I have not been working for 2 weeks ... because he was hospitalized again ... (must keep in hospital)' (P14)
	Stereotype	'The neighbor sometimes calls him (patient) ... "madman" (P3) (P8)
		'He's such a disgrace to the family' (P2) (P10)
	Separation Discrimination	'His behavior is sometimes strange ... all day sitting on the edge of the trench in front of the house while daydreaming' (P8)
		'when he relapses ... he will be dangerous, sometimes uncontrollable' (P6) (P14)
		'Neighbors who do not dare come here (to the house), afraid of him' (P6) (P8)
		'We are rarely invited to public events, if invited, they (neighbor) always order us to come alone, and that my father (patient) should stay at home' (P13)

patients with schizophrenia is perceived as a situation which can result in negative outcomes for the family to survive, rise up and overcome problems. The following is a psychological burden quote by the family:

'Caring for such patients (schizophrenia) makes us unable to enjoy life, and strange behavior often embarrassment of the family sometimes he can go out without wearing clothes, go anywhere ... as his mother I am very ashamed' (P6)

3.2.2. Stigma

The stigma experienced by participants is divided into four kinds, namely labeling, stereotyping, separation and discrimination. Labeling is felt by participants because of special terms addressed by the public to schizophrenia patients. They are called "madman" and say schizophrenia cannot be cured. Stereotypes are experienced by expressions of thinking and behavior of schizophrenic patients who are considered threatening and endangering to their environment. Participants perceived separation by a social distance from the environment, for example, neighbors keep their distance between them and the family and the patient with Schizophrenia in daily activities. The family experienced discrimination, as they are not involved in surrounding environment activities due to unpredictable patient behavior.

The different types of stigma felt by participants come from the family itself and from the community being a risk factor for the family in fostering the ability of family resilience, as seen in the following phrase:

'We (the family) ourselves feel the presence of him (patient) as a stain on the family, so badly ... and there is no one, the neighbors will hang out and keep their distance from us (family) ... from him (patient), sometimes they closed the door when he (patient) was passing their home ...' (P3) (P6) (P8)

4. Discussion

Researchers made efforts to ensure the trustworthiness of data obtained through three ways, namely built a trusting relationship (rapport) with participants before the study begins, conducted member checks and peer checking [20–22]. Rapport was built by researchers through a one-off home visit before a formal interview, the researchers familiarize themselves with discussing the development of the condition of schizophrenic patients while fostering the researcher's sensitivity to the participant's lifestyle in treating schizophrenic patients. Member check carried out by returning the transcripts once to the participant to perform data validation. Peer checking is done through a reanalysis of data by A. Y and N as senior qualitative research by giving double coded of the transcripts to inform the coding framework and ensure a robust analysis.

Themes associated with risk factors of family resilience which taking care of schizophrenia patients was identified in this research will be discussed below.

4.1. Care burden

The results showed various types of burdens, they are confusion about the illness, emotional, physical, financial, time and social burden. The findings of this study are consistent with some previous investigations of families caring for chronic and schizophrenic patients which are subjected to both subjective and objective burdens, and can be physical, psychological or emotional,

social and financial [23–25]. Family members feel a burden during caring because Schizophrenia is a chronic disease and takes a long time for treatment.

One of the burdens found is confusion about the illness as they do not understand schizophrenia. The perceived confusion is uncertain, a volatile behavior of patients with schizophrenia, susceptible to change and no symptoms of recovery while the family still hopes that the patient can recover as before. The findings of this study are supported by the opinion by Lim and Ahn [26] where a poor family understanding of schizophrenia may affect family perception about the perceived burden of care. Families have thought schizophrenia is like a physical disease that will recover quickly, so the patient returns to normal after taking medicine given by the doctors. But in fact, the patient's condition does not improve as expected, the patient still behaves strangely, is difficult to control and even worsens despite taking the medicine. This situation makes families confused because it is not in line with their expectations. Inadequate information about Schizophrenia causes false perceptions as stated by Chou [27], the burden felt by caregivers is a subjective perception based on the gap between expectations and existing abilities and reality. It is therefore imperative for mental health personnel (nurses or doctors) in hospitals to explore the level of family understanding of schizophrenia and provide appropriate and complete information on causes, disease prognosis, treatment and healing processes of schizophrenia. Through the provision of information about Schizophrenia, the family will have a realistic expectation of the future prognosis of schizophrenia and may reduce the burden of care [26,28,29].

The confusion about the illness during caring for of the patient may be unresolved, affect the family emotionally and develop into a emotional burden. The emotional burden as a result of this study is in line with some previous research, where families experience feelings of sadness, shame, worry, suffering and fear during accompanying and caring for patients with Schizophrenia. Families feel worried about the future, are stressed, and feel unable to cope with problems [25,30]. The behavior displayed by schizophrenic patients directed to family members, communities and surrounding environment often foster feelings of distress. Family members experience prolonged sadness and fearfulness when finding difficulty to direct the patient's behavior, especially when the patient is behaving aggressively. The emotional burden experienced by families is also reinforced by family concerns about the future of the patient [31]. Research data shows that most participants (66.67%) are mothers as the primary caregiver, and deeply think about who will care and meet the daily needs of patients if the mother is gone. Research conducted by Hanzawa [32] also stated that mothers will have more concern than other family members when providing care to sick family members.

Feelings of sadness, fear, and worry felt by the family increase emotional burdens when the family must deal with the community. Families who care for patients with Schizophrenia still think Schizophrenia is a disgrace, and the presence of schizophrenia patients as family members cause feelings of shame. The family attempts to hide unruly behavior of patients and keep patients at home to reduce feelings of shame. The family effort has a limited ability when the family is not able to cover the shame, while the behavior of the patient with schizophrenia also cannot be controlled, and will bring up another subjective burden directed to patients with Schizophrenia, which is anger. Some families describe expressive and passive expressions of anger toward the patient, other family members and the environment as an outburst of unstoppable emotion during caring for the schizophrenic patient. The entire psychological burden found in this study illustrates the negative feelings of the family during the care of patients with

schizophrenia. Negative feelings can have a negative impact on the family functioning as caregivers [25].

The care burden experienced by the family becomes more severe when the family is faced with demands of physical conditions as a primary caregiver, material needs and demands from surrounding environments and work, which in this study is a manifestation of objective burden. According to World Health Organization [30], objective burden includes disturbance of relationships among family members, limitations of social relations and work activities, financial difficulties and negative impacts on the physical health of family members. Physical burden found in the study is in line with physical burden conveyed by World Health Organization [30], where the family feels exhausted because of having to keep the patient in recurrence, having physical complaints such as high blood pressure and digestive problems. The family also feel difficulty in sleeping at any moment thinking of the schizophrenic patient's condition. Decreasing the family health status illustrated subjective families' psychological burden [33,34].

This study also identifies financial burden, which includes the cost of treatment and patient's needs [29,30]. Cost of treatment was used for medical expenses, hospital visit costs, hospitalization and accommodation costs to health services. Schizophrenic patients have higher frequencies of eating (more than three times a day) which causes an increase in daily financial needs. It is understandable because patients who take antipsychotic drugs have an increase in appetite. Increasing financial needs causes families to experience financial problems related to needs of shelter, food, transportation, medicine, finance, and crisis intervention [29,35]. Declining and limited financial conditions of families have the potential to reduce family economy, affect subjective perceptions of family and become a burden of care that negatively impacts on the quality of family life [25].

This study also identifies families' burden of time because they need to monitor the patient at all times. These findings are in line with some studies, and the amount of time required by caregivers in one day is related to objective caregiver's level [36–38]. The data says the family should limit the time to work, must go home on time and often having difficult ways to perform personal activities such as watching television comfortably, sleeping and doing a hobby. Caregivers spending time with sick family members have an impact on fulfilling personal needs and causes a burden for caregivers [37].

This study finds that because families feel a social burden, they have limited time for working in the work environment and society because they have to treat patients with Schizophrenia. This finding is in line with several studies, because of the family task to care for sick family members, they must be willing to resign from their jobs and not be included in social environment activity, and eventually have limited social activities in society and are perceived as a social burden [24,39,40]. This situation has serious consequences for families who care for patients with Schizophrenia. A father in this study had permission not to work in one day because of taking patients with Schizophrenia to health care services, and he would get a cut of his salary for one day. These conditions lead to decreased work productivity, lowered family income, and decreased social activity in the work environment and led to social burdening and degrading of quality of family life [41].

All different types of burdens, called confusion about the illness, emotional, physical, time, financial and social burden generated in this study, are risk factors for families' resilience during the caring process of patients with Schizophrenia. Risk factors are indicators that influence the dynamics of family resilience where the risk factor is perceived to encourage negative outcomes in the family [13,14]. The mind and psychological burdens experienced by the family will raise negative feelings affecting the role and family

function in caring for the patients. Physical, financial, time and social burdens were felt by the family which may degrade the quality of family life. The decrease in family functionality and quality of family life have the potential to be a risk factor for family resilience. The mental health worker, a psychiatric nurse, should be able to assess the family situation in detail, especially the various burdens of care felt by the family during the caring process of patients with Schizophrenia. Nurses should intervene to reduce the burden of care, which impacts on improving the quality of family life and family functions to strengthen family resilience during caring for patients with Schizophrenia.

4.2. Stigma

This study identifies stigma as risk factors experienced by families during the care of patients with schizophrenia. A stigma is a negative feature possessed by a person, being an individual or group attribute, and can be a barrier to gaining attention, opportunity and social interaction [42,43]. The perceived family stigma results in the presence of schizophrenia patients in the family, who, by the environment, are considered to have special characteristics in terms of abnormal thinking and negative behavior. The results show family perception about stigma, based on families' attitudes and responses from society related to schizophrenia patients, are in line with stigma dimension according to Link & Phelan, namely labeling, stereotype, separation, and discrimination [43].

Labeling is felt by the family when the surrounding community, such as neighbors or extended family, calls a family member suffering from schizophrenia by a term of "madness", also indicating that the patients are hard to cure. Labeling is a differentiator, stamp or naming based on the special features of community members [43]. The term becomes accepted by the family and is perceived as a disgrace to the family, which causes the family to feel ashamed about the existence of schizophrenic patients as a family member. Embarrassment is an indicator of stigma because the family feels blamed by the environment, the family is considered responsible for the illness, and the family has a close relationship with the patient [44,45]. Embarrassment due to the stigma has an emotional consequence that affects the quality of family life and decreases family function [45].

A stereotype in this study is perceived by the family as a description of schizophrenic patients' behavior delivered by the community, such as unkempt appearance, illogical mindset and aggressive behavior. Stereotypes are defined as attributes belonging to certain social groups with special features, in which Schizophrenia patients have been treated in mental health services, have unnatural behavior and tend to disrupt the environment [46–48]. Families often feel uncomfortable with environmental assumptions about sick family members, but families also acknowledge the truths that are conveyed. Families feel that the situation is experienced as creating a bad reputation for the family, which causes social consequences both to the patient and social environment around the family, such as blaming the patient, avoiding interaction with the patient and not engaging the patient in interacting with the environment [49]. The social consequences experienced by families can degrade the quality of family life and have an impact on the declining of family functionality [45].

Separation was experienced by families involved in this study as a form of the community response to the existence of patients with Schizophrenia that affects the family. The family feels shunned in the sense that neither friends nor extended family wants to engage with the families in a variety of matters because they do not want to be affected by the unnatural and dangerous behavior of Schizophrenic patients. Separation is a distance of an unstigmatized group from a stigmatized group, is and known as a success the labeling

process with negative attributes to individuals or groups [43]. Separation is experienced by patients with Schizophrenia, and an extended family is a tangible form of stigma, often dodging or moving away from the family and the patient with Schizophrenia. The patients are considered to harm other people and their environment and cause unwanted problems [46,50]. Separation is experienced by families, resulting in interpersonal consequences by avoiding social relationships with the environment, tending to hide the patient's existence, and making them the family's big secret. Such interpersonal consequential situations cause the family to feel emotionally exhausted, thus degrading the quality of family life and affecting the family's ability to function optimally in caring for patients [45].

Discrimination is felt by the family through perceiving different behaviors by the community. Families often do not get their rights related to social activities in the community, because they think the patient's behavior related to family involvement will affect the running of social activities. Discrimination is a negative and degrading behavior because of the connection of a person to an undesirable group [48,51]. Discrimination received by families who care for patients with mental disorders leads to feelings of discomfort, neglect, and are not considered to exist in society [52]. Discrimination can occur because the family has a close relationship with both interactions and genetics with the patient, so not involving the family is an option that cannot be avoided by the community. Discrimination is one of the social consequences that must be borne by the family and will affect the quality of family life and decrease family function in caring for patients with schizophrenia.

Stigma is experienced by the family in labeling, stereotyping, separation and discrimination, in this study based on family perceptions, which is part of the risk factors for family resilience. A risk factor is an aspect whose presence is perceived to induce negative outcomes for the family [13,14]. Labeling perceived by the family can lead to emotional consequences, stereotypes, and difference cause social consequences, while separation leads to interpersonal consequences. The three consequences, emotional, social and interpersonal according to [45], will affect the quality of family life. This situation can encourage negative outcomes in the family, especially in supporting the family functionality and becomes a factor of families' vulnerability in growing resilience.

Health workers, especially nurses, must be able to assess family situations and conditions related to family perceptions of perceived stigmas due to the presence of schizophrenic patients. Then, nursing interventions can be planned to increase the resilience of families facing stigma. It is important for nurses to develop continuous efforts to provide interventions for community environment to reduce stigma. These interventions are expected to improve the quality of family life and have an impact on improving family functions to strengthen family resilience skills in caring for patients with Schizophrenia.

4.3. Research implication

This study yields important information about family members' experiences with care burdens and stigma that can lead to negative results in achieving family resilience during the care of patients with Schizophrenia. These findings are expected to be a basis for the development of early detection assessment forms, especially for psychosocial problems related to family resilience in caring for Schizophrenia patients. Other information obtained in this study is the existence of family risk factors that must be managed to achieve family resilience, meaning that this study can be used to develop a family resilience model, especially in families with Schizophrenic patients. The study also yielded information that in growing

resilient families with schizophrenic patients, families experienced care burdens and stigma as risk factors which can strengthen and be integrated with the theory of Resilience Model of Family Stress, Adjustment and Adaptation by McCubbin and McCubbin [18] as variables constructing risk factors. The nurse, as a health service worker, in conducting a family assessment is expected to identify the care burden and stigma experienced by the family and develop interventions to assist families in minimizing risk factors in order to help families in achieving resilience skills faster.

4.4. Research limitation

This research has several limitations. The design used was a qualitative approach, and the results are qualitative in nature in which need to be re-examined with another research design that can test the validity and reliability until the data can be used as an instrument standard. Another limitation is related to the persistence of other unexamined factors in family resilience, that is a family protective factor which is may overcome negative outcomes generated by risk factors.

5. Conclusions

This research explained care burdens and stigma as risk factors that must be managed by family members to survive, rise up and become better in caring for patients with Schizophrenia. Nurses as health service workers have a central role in assessing the level of care burden and stigma experienced by family members in order to help family in achieving resilience.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijnss.2018.06.002>.

References

- [1] Kemenkes RI. Riset kesehatan dasar. 2013.
- [2] Puspitasari E. Role of family's support for schizophrenia patient's treatment. Surakarta: Universitas Muhammadiyah Surakarta; 2009.
- [3] Kartika A, Amalia B, Isma FM. Relapse rate in first-episode of schizophrenic patients with low treatment compliance within three years. *J Kesehat Indones* 2014;2:49–54.
- [4] Amelia D. Relaps in schizophrenia patients. *J Ilm Psikol Terap* 2013;1:52–64.
- [5] Kusumawardani W. Relationship between burden and families coping with families ability caring schizophrenia patients. *Fakulta Keperawatan, Universitas Airlangga*; 2016.
- [6] Fadli SM, Mitra. Knowledge and emotional expression of family and relaps frequency of schizophrenic patients. *J Kesehat Masy Nas* 2013;7:466–70.
- [7] Akbar M. Schizophrenia: psikosis (mental illness). Jakarta: Balai pustaka. 2008.
- [8] Amaresha AC, Venkatasubramanian G. Expressed emotion in schizophrenia: an overview. *Indian J Psychol Med* 2012;34:12–20. <https://doi.org/10.4103/0253-7176.96149>.
- [9] Darwin P, Hadisukanto G, Elvira SD. Burden of care and emotional expression of nurses work with schizophrenia patient in mental hospital. *J Indones Med Assoc* 2013;63:46–51.
- [10] Suryani Komariah M, Karlin W. Family's perception about schizophrenia. *J Unpad* 2014;2:124–32.
- [11] Sun J, Buys N, Tatow D. Ongoing health inequality in Aboriginal and Torres Strait Islander population in Australia : stressful event, resilience, and mental health and emotional well-being difficulties. *Int J Psychol Behav Sci* 2012;2: 38–45. <https://doi.org/10.5923/j.ijpbs.20120201.06>.
- [12] Patterson JM. Integrating family resilience and family stress theory. *J Marriage Fam* 2002;64:349–60. <https://doi.org/10.1111/j.1741-3737.2002.00349.x>.

- [13] Mackay R. Family resilience and good child outcomes: an overview of the research literature. *Soc Pol J NZ* 2003;1–14.
- [14] Amagai M, Takahashi M, Amagai F. Qualitative study of resilience of family caregivers for patients with schizophrenia in Japan. *Ment Health Fam Med* 2016;12:307–12.
- [15] Deist M, Greeff AP. Resilience in families caring for a family member diagnosed with dementia. *Educ Gerontol* 2015;41:93–105. <https://doi.org/10.1080/03601277.2014.942145>.
- [16] Faqurudheen H, Mathew S, Kumar TM. Exploring family resilience in a community mental health setup in South India. *Procedia Econ Financ* 2014;18:391–9. [https://doi.org/10.1016/S2212-5671\(14\)00955-1](https://doi.org/10.1016/S2212-5671(14)00955-1).
- [17] Lietz C, Julien-Chhinn F, Geiger J, Piel M. Cultivating resilience in families who foster: understanding how families cope and adapt overtime. *Fam Process* 2016;x:1–13.
- [18] Friedman MM. *Keperawatan Keluarga: teori dan praktek*. Jakarta: EGC; 2003.
- [19] Speziale HJS, Carpenter DR. *Qualitative research in nursing: advancing the humanistic imperative*, third ed. Philadelphia: Lippincott Williams & Wilkins; 2003.
- [20] Guba E, Lincoln Y. *Fourth generation evaluation*. Newbury Park: Sage Publication; 1989.
- [21] Hall J, Stevens P. Rigor in feminist research. *Adv Nurs Sci* 1991;13:16–29.
- [22] Afyati Y. Validitas dan reliabilitas dalam penelitian kualitatif. *J Keperawatan Indonesia* 2008;12:137–41.
- [23] Chou KR. Caregiver burden: a concept analysis. *J Pediatr Nurs* 2000;15:398–9.
- [24] Grandon P, Jenaro C, Lemos S. Primary caregivers of schizophrenia outpatients: burden and predictor variables. *Psychiatr Res* 2008;158:335–43.
- [25] Urizar A, Maldonado J. Burden of care in families of patients with schizophrenia. *Qual Life Res* 2006;15:719–24. <https://doi.org/10.1007/s11136-005-4629-2>.
- [26] Lim Y, Ahn Y. Burden of family caregivers with schizophrenic patient in Korea. *Appl Nurs Res* 2003;16:110–7.
- [27] Chou Y-C, Fu L-Y, Lin L-C. Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *Int Psychogeriatr* 2011;23:562–72. <https://doi.org/10.1017/S1041610210001225>.
- [28] Karanci N. Caregiver of Turkish schizophrenia patient: casual attribute, burden and attitude to help from the health professional. *Soc Psychiatr Psychiatr Epidemiol* 1995;30:261–8.
- [29] Kizilirmak B, Küçük L. Care burden level and mental health condition of the families of individuals with mental disorders. *Arch Psychiatr Nurs* 2016;30:47–54. <https://doi.org/10.1016/j.apnu.2015.10.004>.
- [30] World Health Organization. *Investing in Mental Health*. Geneva: World Health Organization; 2008.
- [31] Jungbauer J, Angermeyer M. Living with a schizophrenic patient: a comparative study of burden as it affects parents and spouses. *Psychiatry* 2002;65:110–23.
- [32] Hanzawa S, Tanaka G, Inadomi H, Urata M, Ohta Y. Burden and coping strategies in mothers of patients with schizophrenia in Japan. *Psychiatr Clin Neurosci* 2008;62:256–63.
- [33] Fujino N, Okamura H. Factors affecting the sense of burden felt by family members caring for patients with mental illness. *Arch Psychiatr Nurs* 2009;23:128–37.
- [34] Mengdan L, Lamber C, Lambert V. Caregiver burden and coping pattern of Chinese parents of a children with mental illness. *Int J Ment Health Nurs* 2007;16:86–95.
- [35] Mohr WK. *Psychiatric mental health nursing*, sixth ed. Philadelphia: Lippincott Williams Wilkins; 2006.
- [36] Chii JC, Hsing-Yi C, Pin C, Hsiu HW. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Arch Gerontol Geriatr* 2009;48:419–24.
- [37] Juvang L, E LC, Lambert VA. Predictors of family caregiver's burden and quality of life when providing care for a family member with schizophrenia in the people's Republic of China. *Nurs Health Sci* 2007;9:192–8.
- [38] Rafiyah I, Sutharangee W. Review: burden on family caregivers caring for patients with schizophrenia and it's related factors. *Nurse Media J Nurs* 2011;1:29–41.
- [39] Fitriyarsi R. The grieving process experienced family and charges in treating children with autism. *J Ners* 2010;5:181–90.
- [40] Goncalves-Pereira M, Xavier M, Van Wijngaarden B, Papoila AI, Schene AH, Caldas-de-Almeida JM. Impact of psychosis on Portuguese caregivers: a cross-cultural exploration of burden, distress, positive aspects and clinical-functional correlates. *Soc Psychiatr Psychiatr Epidemiol* 2013;48:325–35.
- [41] Maldonado J, Urizar A, Kavanagh D. Burden of care and general health in families of patients with schizophrenia. *Soc Psychiatr Psychiatr Epidemiol* 2005;40:899–904.
- [42] Goffman E. *Stigma: notes on the management of spoiled identity*. Harmondsworth, Middlesex: Penguin Books; 1963.
- [43] Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol* 2001;27:363–85.
- [44] Larson J, Corrigan P. The stigma of families with mental illness. *Acad Psychiatr* 2008;32:87–91.
- [45] Park S, Park KS. Family stigma: a concept analysis. *Asian Nurs Res* 2014;8:165–71. <https://doi.org/10.1016/j.anr.2014.02.006>.
- [46] Ariananda RE. *Public stigma toward to schizophrenia patients*. Semarang: Universitas Negeri Semarang; 2015.
- [47] Baron R, Byrne D. *Psikologi sosial*, tenth ed. Jakarta: Penerbit Erlangga; 2004.
- [48] Taylor SE, Peplau LA, Sears DO. *Psikologi sosial*, twelfth ed. Jakarta: Kencana Prenada Media Group; 2009.
- [49] Koschorke M, Padmavati R, Kumar S, Cohen A, Weiss HA, Chatterjee S, et al. Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Soc Sci Med* 2017;178:66–77. <https://doi.org/10.1016/j.socscimed.2017.01.061>.
- [50] Parcesepe AM, Cabassa LJ. Public stigma of mental illness in the United States: a systematic literature review. *Adm Policy Ment Health* 2013;40:384–99. <https://doi.org/10.1007/s10488-012-0430-z>.
- [51] Syaharia ARH. *Mental illness stigma from metal islamic health perspective*. Yogyakarta: Universitas Islam Negeri Sunan Kalijaga; 2008.
- [52] Kadri N, Manoudi F, Berrada S, Moussaoui D. Stigma impact on Moroccan families of patients with schizophrenia. *Can J Psychiatr* 2004;49.