

Conference Paper

Caring for Schizophrenia at Relapse: Study Phenomenology

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Abstract.

Relapse in schizophrenic patients is a challenge that must be faced by patients and their families being treated. Family, especially those who are caregivers, have an important responsibility in handling and preventing relapse in schizophrenia patients in all situations.. This study was to explore family life experiences in treating schizophrenia who had a relapse at Cianjur City. This study uses a qualitative method with a phenomenological approach. Participants in this study were 6 families with the criteria of being a Schizophrenic family, caring for and living with schizophrenia for more than 2 years, and having a minimum high school education. Family experiences were explored through unstructured in-depth interviews and data analysis using the Colaizzi method. The results of the study obtained 3 themes, namely experiencing a heavy burden, needing support, being patient, and seeking God's help in caring for. It was concluded that the families felt the burden for taking care of members who experienced a relapse. Nurses holding mental programs need to carry out visitation programs for families who have members experiencing recurrence and carry out health promotions related to Schizophrenia care.

Keywords: caregiver, relapse, schizophrenia

1. Introduction

Schizophrenia is one of the most common severe mental disorders in society. Schizophrenia is a clinical syndrome characterized by changes in cognitive, emotional, perceptual, and other aspects of behavior [1]. Negative symptoms of schizophrenia include difficulty initiating conversation, blunted or flat affect, reduced motivation, reduced attention, passivity, apathy, social withdrawal, and discomfort [2]

Data from the World Health Organization (WHO) in 2016 states that globally there are 21 million people with schizophrenia. Based on the results of the Basic Health Research (Riskesdas) in 2018, the prevalence of severe mental disorders in Indonesia is 7 per 1000 of the total population, this prevalence has increased compared to 2013 which

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was 1.7 per 1000 of the total population. In 2018, the number of severe mental disorders in West Java totaled 55,133 people. Cianjur Regency as one of the regencies in West Java reaches 21% or 540 thousand people who experience mental problems, Ninety-eight thousand experience schizophrenia or acute depression. These data indicate that the number of people with mental disorders is quite high and is expected to continue to increase.

Relapse will have a negative effect on schizophrenic patients [3] Relapse will also affect the patient's quality of life and social functioning [4]. Schizophrenic patients will feel discriminated against in their environment because of the stigma from society, lose the opportunity to work, feel useless and worry about their future. Schizophrenic patients will achieve healing and be able to feel functioning if a schizophrenic patient can recognize the need for consultation, social guidance, and skills training to get opportunities like other healthy people. This condition requires the cooperation of health workers, the community, patients, and their families.

Relapse in schizophrenic patients can be dangerous and detrimental to families, communities, and patients themselves. Patients who show signs of relapse usually have deviant behavior such as throwing tantrums, destroying things, injuring, and killing others and themselves. If this happens, the family can be harmed materially because the patient has to be hospitalized again in a mental hospital, so the family will spend a lot of money on the patient's treatment.

Five subjects cause schizophrenic patients to relapse, including the patient himself, the doctor or health worker, the person in charge of the patient, the family, and their environment [5]. Families, especially those who are caregivers, have important responsibilities in the process of hospitalization, preparation for discharge, and continuum of care. The role of the family as a caregiver is very important in dealing with and preventing relapse symptoms because they are responsible for providing direct care to schizophrenic patients in all situations (continuum of care).

Buckley revealed that the relapse of schizophrenic patients can be significantly reduced from 65% to 25% if they receive maximum care from their families while at home [6]. On the other hand, if they do not get proper treatment, they will tend to relapse easily. Schizophrenic patients who have poor family support are 6 times more likely to experience a relapse compared to schizophrenic patients with families who have good support [7].

Schizophrenic patients require continuous care. The family is the main supporter in the healing process of schizophrenic patients, especially to prevent relapse. Therefore, family participation is needed in providing support to schizophrenic patients.

Based on this background, the researcher is interested in conducting qualitative research on the family's experience in treating schizophrenia who has relapsed in Cianjur Regency. Exploration of family experiences in treating relapse of schizophrenia patients has not been widely discussed in the socio-cultural context of Indonesian society. Qualitative research with an appropriate phenomenological approach is used to explore family experiences in treating schizophrenia when experiencing a relapse [8]The phenomenological approach can dig into real and in-depth related to the stigma of mental disorders so that it can be used for the development of mental health nursing and the improvement of nursing care in the future.

2. Methods

This research used a qualitative method with a descriptive phenomenology approach. This study explores in-depth information about family life experiences in caring for schizophrenic patients who experience relapses. The data collection technique in this study used a structured interview with the core question in this in-depth interview was to tell the family's experience when caring for a schizophrenic family member who experienced a relapse and was developed according to the research question. The sampling method from this study uses purposive sampling with participant inclusion criteria, including participants are family members who become caregivers for schizophrenic patients who have experienced a relapse, participants who can communicate well, participants who live in 1 house with schizophrenic patients and become caregivers for schizophrenic patients for more than 2 years, and participants and schizophrenic patients live in the working area of Karangtengah-Cianjur Health Center. This research was approved by the Ethics Committee of Jenderal Achmad Yani University (No. 018/KEPK/FITKES-UNJANI/VI/2022). This study uses data analysis with the Colaizzi method, with steps including acquiring a sense of each transcript, extracting significant statements, formulating meaning, organizing formulated meanings into clusters of themes, exhaustively describing the invented phenomenon, describing the fundamental structure of the phenomenon, and returning to the participants [8]

3. Results

Participants in this study were 6 families of schizophrenic patients in the working area of Karangtengah-Cianjur Health Center. Family experience caring for schizophrenic patients is more than 2 years. Five participants were female and one participant was male, all participants were Muslim. Participants' ages ranged from 26 to 46 years. All participants took high school education and all participants were married. Family experiences in caring for schizophrenic patients are described in 3 themes, namely having heavy burdens, needing support, and being patient and seeking God's help in caring for them.

3.1. Having Heavy Burdens

Based on the results of the study, the theme of having a heavy burden was found, there were no sub-themes in this theme. In this study, almost all participants expressed this. This theme illustrates the feeling of difficulty and heaviness felt by the family in caring for a schizophrenic family member. Participant 1 revealed that while caring for her schizophrenic child she sometimes felt angry, following her statement:

"...if there was chaos (a schizophrenic patient) I was very upset, how about that? When unstable (schizophrenic patient), it's confusing, scary, irritable, talks without direction, arbitrarily, refuses to hear other people's opinions... well the main thing is the condition is different, those things become a burden for me to deal with..." (P1.4)

The same thing was also expressed by P.4. who expresses feelings of fear when family members of schizophrenic patients experience a relapse, the following statement:

"...when hallucinations appear (schizophrenic patients) such as hearing voices, talking to themselves, irritable, not willing to listen to advice.....sometimes I am afraid when (schizophrenic patients) are angry, afraid of his children too, it makes me feel a burden too, miss." (P4.6)

Participant P2 also had a response that was almost the same as the participant P4 when caring for a family member who has schizophrenia, Participant P2 revealed that the family must be ready if one day the patient becomes angry and the treatment is given also has a long duration, following his statement:

“...In my opinion, people who are sick like this take a long time to get treatment. If it relapses, we have to be prepared too because they like to get angry and are difficult to control. And it is a burden that my family and I feel here” (P2.7)

The same thing was also expressed by P6 who revealed that when symptoms of schizophrenia appeared in her child, her child’s emotional condition was unstable, and considered her mother as an enemy, following her statement:

“...if my child’s condition is sick like this, it’s hard to change without medicine, sometimes his emotions are unstable, sometimes his parents are considered as enemies, but when they are stable they like to massage me (his parents)...” (P6 .7)

3.2. Needing Support

In the theme of needing community support, there are no sub-themes in this theme. There were 4 participants who said they needed community support, namely participant 1, participant 2, participant 3, and participant 4. This was revealed because the family’s expectation in the community was the existence of community support when family members with schizophrenia experienced a relapse. When the community provides support to the family, the family will feel comfortable in providing care for patients, thus helping the healing process of schizophrenic patients. The following is the expression of participant 4 who reveals that the family hopes that the community can feel what the patient and family are experiencing, as follows:

“My hope as a mother who has a sick family member (schizophrenia), especially if it relapses, I hope that the community should be able to feel what I feel, ...” (P4.18)

In addition, participant 2 revealed that the family wanted the community not to discriminate against their child as a schizophrenic patient, following his statement:

“I hope that they (the community) can behave normally with my child, for example, if the child has a relapse, why don’t you just let it be, you don’t have to talk about weird things like that.. society please don’t treat it like that...” (P2.8)

The same thing was expressed by participant 1 that the families of schizophrenic patients wanted the community not to discriminate against schizophrenia with other diseases, the following statement:

“The community should behave the same way, don’t differentiate between mental illness and other illnesses, they should motivate them to seek treatment, the patient will recover, the community should provide support like that...” (P1.17).

Participant 3 revealed that the family wanted the community not to think badly of the patient and family, following his statement:

"Well, I hope that the community does not think badly of our family, including those who are sick (schizophrenic patients), don't say bad things... just talk about good things..." (P3.15)

3.3. Being Patient dan Seeking God's Help in Caring For Schizophrenic Patients

Based on the results of the study, it was found the theme of being patient and seeking God's help in caring for schizophrenic patients. Three participants expressed feelings of being patient and surrendering to Allah SWT while caring for patients with schizophrenia, namely participants 1, 3, and 4. Based on the analysis and reading of participant transcripts repeatedly, the researchers realized from the information that this theme was quite important for participants to be raised and used as a new insight even though few participants revealed it. This theme is identical to the religion of the Indonesian nation and this is supported by the religious characteristics of the majority of Muslim participants. So this concept needs to be discussed.

While caring for family members with schizophrenia, participants felt their patience was tested so they felt strong in facing this life. This statement was expressed by 3 participants in this study, namely participants 1, 3, and participant 4, following the statement of participant 1:

"Well, we just have to be patient and just surrender to Allah... whatever his condition he is still a member of our family, if we are not patient it will make it even more difficult to take care of him later..." (P1.25).

Participant 3 also expressed the same thing, patience and surrender to Allah, because Allah has given us a normal life compared to the life of schizophrenic patients. Here's his statement:

"So let's just leave it to Allah, we're also grateful that we are still given a normal life.. because taking care of it won't be as hard as someone who has experienced it... just be patient for now..." (P3.20).

In addition, participant 4 revealed that being a patient can make it easier for families to care for schizophrenic patients. The following is his statement:

"Well, we pray that we will be given strength and patience in caring for, yes, that's what we did until finally we were able to take care of..." (P3.16)

4. Discussion

In this discussion section, the researcher describes the interpretation of the research results by comparing the research findings with the results of previous studies, either through journals, concepts, or related theories. Family experiences in caring for schizophrenic patients are described in 3 themes, namely having heavy burdens, needing support, and being patient and seeking God's help in caring for them.

4.1. Having Heavy Burdens

This theme arose because almost all participants expressed the burden felt by the family as a caregiver while caring for a schizophrenic family member when experiencing a relapse. In this case, the family who cares for the schizophrenic patient is called the caregiver. Caregivers are individuals who provide care to others to meet their needs [9].

Schizophrenic clients will experience a drastic decline in various life functions. Therefore, schizophrenic clients need a caregiver, because the client will not be able to take care of themselves independently. Caregivers will help clients slowly return to their functions until they client can readjust to society. The role of the caregiver according to Alexander consists of 39% of parents, 25% of siblings, 7.8% of children, 7% of spouses (husband/wife), and 20% of others [10]. However, the dominant caregiver is a woman, namely the client's mother [11].

There is an influence on the mental status of the family when one family member has schizophrenia. Townsend states that families who have family members with schizophrenia will experience great upheaval in themselves [12]. Buckley revealed that relapse of schizophrenic patients can be significantly reduced from 65% to 25% if they receive maximum care from their families while at home [6]. On the other hand, if they do not get proper treatment, they will tend to relapse easily. Poor family support affects schizophrenic patients so that they have a 6-fold chance of experiencing a relapse compared to families who have good support [13].

Caregivers are faced with various experiences in caring for schizophrenic clients, especially the burden experience which is also a global problem at this time [11]. The level of burden experienced by caregivers in caring for schizophrenic clients is at the middle and high levels [14]. Research by Marimbe stated that as a result of the high caregiver burden, 68% of caregivers experienced general mental disorders to the worst idea of suicide [15]. The burdens experienced by caregivers include physical, psychological, and social burdens [16]. The physical burden felt by the caregiver in caring for the schizophrenic client is related to the caregiver's health status, while the psychological burden experienced by the caregiver in caring for the schizophrenic client is related to the conflict experienced by the caregiver [16].

Research stated that the physical and psychological burden experienced by caregivers who care for schizophrenic clients is at a moderate level. The data showed that 33% of caregivers experienced a decrease in health status (42% difficulty sleeping, 32% insomnia, 39% body pain, 48% headache, 31.7% nausea/vomiting or gastritis), and 54% felt less work outside the home, 44% financial burden, 56% frustration, 66% stress, and 37.9% anxiety [17] [18].

The high caregiver burden will be related to the caregiver's emotionality. The higher the caregiver's burden, the higher the caregiver's emotional level [19]. The research stated that caregivers experience high emotional levels in caring for schizophrenic clients [20]. As a result, caregivers often show excessive emotional expressions to clients such as criticizing clients, showing hostility, speaking in a high tone, and expressing anger excessively [19].

The implication of this theme is that the family feels a heavy burden as a result the family is unable to care for family members when experiencing a relapse so that it has an impact on the healing process.

4.2. Needing Support

In this theme, almost all participants need community support when family members have a relapse. The results of this study are in line with the preliminary study conducted by researchers which states that there are still many people who do not care about schizophrenia patients who are having relapses, even the stigma of society is getting higher when family members have relapses.

Birchwood explain that the social environment has a significant impact on healing people with schizophrenia. Not only with the family, but the great involvement of other people also shows an increase in the quality of life for people with schizophrenia [21].

The family is the main supporter and has a very important role in the recovery process of schizophrenia patients, especially in preventing patient relapse. Therefore, nurses need to work with the families of schizophrenic patients in dealing with patients during the recovery period. One of the efforts so that families can care for and make patients independent at home is to involve the role of the family in caring for patients.

Research conducted by Sari and Fina states that there is a significant relationship between family support and prevention of relapse in schizophrenic patients (p-value 0.000) which includes the relationship between family emotional support and prevention of relapse in schizophrenic patients (p-value 0.005), the relationship between family informational support and prevention of relapse in schizophrenic patients (p-value 0.002), the relationship between family instrumental support and prevention of relapse in schizophrenic patients (p-value 0.000), and the relationship between family assessment support and prevention of relapse in schizophrenic patients (p-value 0.014) [22].

Other research that supports this result was conducted by Rasmun, Sukamto, and Piyanti (2013) regarding the factors that cause relapse in schizophrenic patients, including ineffective therapeutic regimens (62.7%), poor family attitudes towards schizophrenic patients (54.9%), and poor family behavior towards schizophrenic patients (60.8%) [23]. Farkhah also said that the most dominant factor in patient relapse is the caregiver's quality of life. So in this case nurses play an active role in improving the caregiver's quality of life and the importance of caregiver support groups to improve the caregiver's quality of life [13].

The most important social support is family support. The success of treatment in patients with regular drug consumption must be supported by good family support. Family is an important part of the healing process of mental patients. Family support is needed by people with mental disorders in motivating them during care and treatment. The family must always guide and direct it so that clients with mental disorders can take medication correctly and regularly, besides that the family is also in charge of providing for the client's medical expenses. Not only that, the family must give the patient a comfortable feeling, feel loved even when experiencing a problem, guide the patient to carry out activities according to his abilities, and motivate the client to recover [24]

The implication of this theme is that with good support for the caring family, it can give strength to the family by feeling cared for, feeling excited, and even feeling accepted by the current conditions so that they feel calmer in undergoing a problem.

4.3. Being Patient dan Seeking God's Help in Caring For

Patience is self-defense to carry out various obediences, stay away from prohibitions, and face trials willingly and resignedly [25]. In caring for schizophrenia, the family plays a fairly difficult role. Many problems must be faced during treatment for schizophrenic family members, such as receiving treatment and negative attitudes from the environment and feeling the impact of caring for schizophrenia. Based on the results of this study, it was revealed that when having a family member with schizophrenia, the family must be more patient in caring for it, especially when experiencing a relapse. In facing this problem, the family asks Allah for help by being patient in facing the problem.

Humans have been given the power to create and maintain their lives. Allah SWT has provided humans with various extraordinary potentials as provisions to achieve their life goals that are blessed by Allah SWT. A person dealing with any problems in this world will generally surrender to God. Relationships with God can be a source of strength for someone in living life when facing problems [26]

Satrianegara states that the involvement of religion and spirituality affects the ability to survive and overcome anxiety in dealing with problems. In addition, spirituality is needed in the healing process [27]. This statement is supported by research which states that there is a beneficial effect in integrating spirituality into mental health care. The results of research conducted by Hefti show that 70–80% of the application of religious activities or spiritual activities can overcome daily difficulties and frustrations. Religion can help patients to improve emotional adjustment and maintain hope, purpose, and meaning in life [28].

Humans are divine beings, so they need to fulfill spiritual needs. The fulfillment of spiritual needs is not only a formality, but the ability to understand and practice their religious beliefs so that they can gain strength and peace in their lives . Praying to Allah SWT is a way of inner relief that will restore peace of mind to those who do it. Getting closer to God will also provide clues about the values of the meaning of life, so it is hoped that anxiety can be reduced .

Being grateful a person can have advantages both emotionally and interpersonally [29]. A person can improve their new coping abilities, both consciously and unconsciously, by seeing and positively interpreting suffering. McCullough say that a grateful person has positive coping. Positive coping is useful in dealing with life's difficulties, seeking support from others, interpreting experiences from a different perspective, and setting plans to solve problems [30]. Watkins also stated that a grateful person can indicate how he feels happy (well-being) through satisfaction with his life [31]. This statement is in line with the results of this study, although mental health nurses feel a heavy burden in carrying out their duties and roles, through gratitude mental health nurses are still able to carry out the mental health program until now.

This statement is supported by research which states that there is a beneficial effect in integrating spirituality into mental health care. The results of the study show that 70-80% of the use of religious activities or spiritual activities can overcome daily difficulties and frustrations. Religion can help patients to improve emotional adjustment and maintain hope, purpose, and meaning in life. Therefore, nurses can integrate elements of religion into the therapy protocol for schizophrenia [28].

The implication of this theme is that with the family being patient in caring for the family, it can help the family realize that something happened according to the provisions of Allah swt, in this case the family is able to do good coping when experiencing a problem.

5. Conclusion

Family experiences in caring for schizophrenic patients are described in 3 themes, namely experiencing a heavy burden, needing support, being patient, and seeking God's help in caring for them. It was concluded that the family felt the burden that had to be carried out caring for family members who experienced a relapse. Nurses holding mental programs need to carry out visitation programs for families who have Schizophrenia family members who experience relapse, carry out health promotions related to Schizophrenia care.

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7. Conflict of Interest

The authors have no conflict of interest to declare.

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