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ORIGINAL RESEARCH

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CAREGIVERS' NEEDS IN CARING FOR RELATIVES WITH SCHIZOPHRENIA IN MEDAN INDONESIA: A PHENOMENOLOGICAL STUDY

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Abstract

Background: A caregiver is a primary nurse and has a major role in providing care for people with schizophrenia. Caring for those with schizophrenia for a long period of time is challenging for families, especially for caregivers. Various needs ought to be studied by nurses to assist caregivers in providing optimal care for family members who experience schizophrenia.

Objective: This qualitative study aims to explore the needs of caregivers in treating schizophrenia at home.

Methods: This study employed a phenomenological study design. A total of 10 respondents were selected using a purposive sampling with criteria: 1) having family members diagnosed with schizophrenia, 2) directly involved in taking care of patients at home, 3) caring for patients with schizophrenia for more than one year, 4) willing to be a participant by signing an informed consent, and 4) being able to identify what is needed in treating schizophrenia. Colaizzi's method was used to analyze the data.

Results: There were four themes of the caregivers need in caring for schizophrenia patients at home, including 1) seeking information about schizophrenia, 2) sought healing through regular treatment, 3) looking for appropriate rehabilitation for relatives with schizophrenias, and 4) utilizing mental health facilities.

Conclusions: It is expected that nurses have the knowledge and skills in identifying and helping the families, especially the caregivers, to meet unmet needs so they can optimize home care.

Keywords: need; caregiver; schizophrenia

INTRODUCTION

Schizophrenia is a persistent and serious neurobiological disorder of the brain, a clinical syndrome that can result in damage to life both individually, family and community (Stuart, 2014). Schizophrenia is also a chronic disease disorder that is quite high in prevalence. The prevalence of schizophrenia in the world from the median of schizophrenia is 4.6 / 1,000 for the prevalence of points, 4.0 / 1,000 for lifetime prevalence and 7.2 / 1,000 for morality risk.

As a chronic illness of mental illness, the treatment of schizophrenia takes a long time. Therefore, it takes an active role of the family, especially caregiver to treat schizophrenia at home. Caring for a family member with disabilities such as schizophrenia is a major role for women in Asian countries such as Japan, Taiwan, Malaysia, Philippines and Indonesia (Talwar & Matheiken, 2010).

A caregiver or other family member is important in the healing process for

schizophrenic patients. In the course of treating patients, due to this disorder being chronic or relapse, a caregiver must have sufficient knowledge in treating patients with schizophrenia and is able to recognize the needs that are met in caring for patients with schizophrenia ([Rafiyah, 2011](#)).

The results of Agiananda ([2006](#)) study indicates that the unmet needs are the need for improved health (changes or improvements in symptoms of schizophrenia), the need for mental health services (group meetings and vocational training, sharing groups for caregiver, cheap /generic, continuous care, friendly and friendly service from health workers at the site), and the need for active action from health workers (information about schizophrenia, the involvement of patients in treatment planning, therapists plan therapy according to the needs of the patient and always evaluate the results of the treatment, and help bridge the family's issues related to patient care) ([Agiananda, 2006](#)).

Therefore, this study needs to be done to explore what needs should be met by caregivers in treating schizophrenia at home. Nurses does not only focus on schizophrenia alone, but also pays special attention to the needs of the caregivers, so nurses can assist caregivers in meeting the needs associated with treatment and care of schizophrenic patients. Thus, the family, especially caregivers can optimally perform home care on sick family members.

METHODS

Study Design

The design of this study used the phenomenology design which aims to explore the ability of caregivers in identifying the needs of caring for family members suffering from schizophrenia. This phenomenology study can provide a deep understanding of the caregiver's needs in caring for family members who are experiencing schizophrenia.

Sample

A total of 10 participants participated in the study. The purposive sampling method was used in selecting research participants. The inclusion criteria of the study participants

were: 1) having a family member diagnosed with schizophrenia, 2) being directly involved in home care, 3) taking care of schizophrenia patients for more than a year, 4) being willing to participate by signing informed consent, and 4) able to identify the things needed in treating schizophrenia.

Data Collection

We used in-depth interviews using interview guides to gather information. The interview was conducted for approximately 60 minutes for each meeting. The probing technique was used to ask questions and record interview results. After that, we transcribed the interview result. Furthermore, we grouped the data and narrated it into the form of themes, sub themes and main categories. The interview guideline consisted of 10 open-ended questions developed by the researcher herself and has been validated by three psychiatrists. Triangulation was used to check the validity of research data.

Data Analysis

We used the Colaizzi's method ([Polit & Beck, 2008](#)). The process of data analysis included 1) reading interview transcripts repeatedly and identifying the meaning of the statement, 2) reviewing the interview results by focusing on phrases and sentences related to caregiver needs in treating schizophrenia, 3) finding meaning words of transcripts, 4) re-reading transcripts and grouping similar themes and writing them into a description related to caregiver caring for schizophrenia, 5) describing the complete phenomenon, 6) identifying the essence of the transcript, and 7) conducting member checks to participants to validate some of the existing themes. The principles of trustworthiness of Guba and Lincoln (1989) were applied to ensure the rigor of the study. A member checking was done with primary caregivers of persons with schizophrenia. Findings were also reanalyzed with an experienced researcher, called as peer checking ([Gunawan, 2015](#)).

RESULTS

Four themes emerged from data: 1) seeking information about schizophrenia, 2) sought healing through regular treatment, 3) the need for group support, 4) looking for appropriate

rehabilitation for relatives with schizophrenia patients, and 5) the need for easy mental health facilities that are affordable.

Theme 1. Seeking for information about schizophrenia

Information about the disease is needed by caregivers in caring for schizophrenic patients at home. The information they get from health workers and other sources helps them to take care of their sick family.

"... I asked the doctor about my son's illness, he said his mentality was disturbed, I asked another doctor, he said it was chronic, probably schizophrenia..." (Participant 1)

Participant's need for information on the cause of schizophrenia.

"... suddenly came home from work angry ... yelled ... held the phone ... talked to people ... but no ... strange behavior ... silence ... showered at night ... played music loudly." (Participant 7)

"... the Doctor explained there was a disturbance in my sibling's brain ... had to take medicine for my sibling to calm down, that's it, I'm curious, sometimes I googled to find out the cause of my sibling's pain." (Participant 3)

Drug compliance is needed to prevent the recurrence of the disease, although the drugs consumed by patients sometimes cause side effects that makes patients uncomfortable. This condition makes caregivers worried, because they do not know the side effects of the treatment of schizophrenia. This is expressed by the participants as follows:

"... my son's eyes glared upwards, he complained his neck was tense, I was confused, I stopped the medication, took him for medication again, the doctor changed the medicine without explanation ..." (Participant 6)

"... my mother complained her feelings were all over the place, hair is pulled after taking the medicine, the next day we went for check up again and the doctor changed the medicine, he said it didn't fit ..." (Participant 4)

"... a few moments ago, the medication was replaced by the doctor, it wasn't suitable, my child was restless, and the medication was changed again, then it fit him ..." (Participant 8)

Theme 2. Sought healing through regular treatment

Participants expressed their curiosity about the mental state of sick family members.

"... already been hospitalized three times ... healed ... his girlfriend relapsed again ... it confused us ... my child is still taking medication ..." (Participant 2)

The patient's healing is the participants' main desire, so caregiver seeks to bring patients regularly treated every month.

"... hope to recover ... the medicine is taken regularly ... there's only two left ... came to the poly to continue treatment ..." (Participant 1)

Caregiver assured himself that by taking medication on a regular basis the patient's illness can heal.

"... when my sibling was severely sick-the medication was not taken regularly ...always restless... difficult to sleep ... disturbing others ... currently calm ... sometimes help clean the house, that's it, taking medicine regularly ..." (Participant 5)

Group support is needed by participants in caring for family members who have schizophrenia. Caregiver is very happy to accompany family members to the outpatient medical treatment because they can meet other families.

"... it feels good to meet with others ... we vent ... if there is a problem in taking care of the child ... we exchange opinions ... persuade to take medicine" (Participant 3)

Participants expressed their opinion that they needed a meeting with members of the family who suffered the same illness as their family members. They usually discuss with other families while waiting for nurse calls in the outpatient poly.

"... we like to exchange ideas, share experiences with others ... waiting to be called ... so we share stories with others." (Participant 7)

"... the good thing is this, there's a place where we gather, help each other, we both have family members who suffer from schizophrenia" (Participant 9)

Theme 3. Looking for appropriate rehabilitation for schizophrenia patients

Caregiver is in dire need of rehabilitation for family members with schizophrenia, because with rehabilitation the patient has the skills so that the patient can adjust to the environment.

"... there should be a place for my child to learn skills, so they can work, sew, cook, whatever it is, as long as my child is kept busy ..." (Participant 8)

"... if there is any kind of workshop for my sick sibling, I'd be happy, I'd be willing to pay, let him have work, not kept at home, eat and sleep, let him have friends because there are others together ..." (Participant 5)

Theme 4. Utilizing mental health facilities

Problems in accessible mental health services were felt by participants who accompanied family members who went to an outpatient clinic. Mental health services that were located far from the family members' home becomes a big problem for them.

"... my home is far... we change transportation three times ... not to mention taking my child ... the fare is expensive; I also have to work and sell..." (Participant 10)

"... traffic on the way ... far away, my husband is not healthy, the child still have to go to the hospital, why is there no medicine for my child, not to mention queuing, because there are many others wanting treatment, every month I come with my child ..." (Participant 8)

DISCUSSION

The results of this study indicated that the participants need information about schizophrenia, its causes and treatment. This information is important for them to assist in caring for family members who are schizophrenic. This information will facilitate the caregivers in recognizing signs and symptoms of schizophrenia, drug types, benefits and actions to be taken to overcome the side effects of taking medication. In this study, participants received information from health workers such as doctors and nurses. In addition, one participant looked for information about schizophrenia from the internet. The results of this study were in line with previous research suggested that the caregivers get information about mental illness experienced by family members from doctors, nurses and the Internet ([Sabanciogullari & Tel, 2015](#)). In addition, the caregivers also need information related to the actions to be taken when facing the aggressiveness of the patient, overcoming medication non-compliance, coping with drug side effects, communicating with patients, information on illness, symptoms, how and where to seek help in the event of a crisis, recognize the signs and symptoms of recurrence, and who can help them when they

need help. The family's lack of understanding, especially caregivers about the symptoms of schizophrenia resulted in delays in realizing the mental state of a family member experiencing schizophrenia ([Cahyono & Asrap, 2017](#)).

Group support received by caregivers in this study was obtained from families with schizophrenia. A caregiver requires group support as a forum to share experiences in caring for family members with schizophrenia. The support of this group can help caregivers develop adaptive coping and be able to reduce their tension. In addition, nurses can also provide support to caregivers and patients. The nurse can provide health education about the actions the family can take to control the signs and symptoms of schizophrenia. Nurses can also give family therapy ([Attendance, 2010](#)). A systematic review showed that caregivers need to receive caregiving support from others including professional health care providers, other family members, friends as well as self-help groups to help them to live with and care for their family member diagnosed with schizophrenia effectively, thus those group resources need to be made available at the community level ([Tungpunkom, Napa, Chaniang, & Srikhachin, 2013](#)). Magliano adds that adequate supportive support received by families can improve the family's ability to deal with any challenges in care so that they can overcome the difficulties encountered while treating schizophrenic patients at home ([Magliano, 2008](#)).

Rehabilitation of patients with schizophrenia is another requirement of caregivers that have not been achieved optimally. Participants revealed that rehabilitation can improve a patient's ability to adapt to his environment. They have confidence that patients will get better quality of life by following the rehabilitation program. Research conducted by Purba showed that schizophrenia patients who were given rehabilitation intervention had better social skills than schizophrenia patients who were not given rehabilitation intervention ([Purba, 2013](#)). The provision of this rehabilitation program can improve and maintain its health and social skills and can also prevent recurrence. Rehabilitation

programs in the form of occupational therapies, vocational training and social skills training can also improve social skills and work skills of the patient, so it is expected that they already have enough social skills when returning to their family and society ([Friedrich & Wancata, 2015](#)).

In this study, caregivers want an accessible mental health service. In fact, most caregivers complained that mental health service is far from their house. Therefore, they did not have time to bring relatives to see the psychiatrist and other mental health professional regularly. Consequently, incidents of relapse rate are higher. A previous study showed that mental health care professional should involve all family members in the care plan for the relatives with schizophrenia ([Yang, Hsieh, Lee, & Chen, 2017](#)). The accessible mental health service is very important for both caregivers and schizophrenia persons. They tended to accept the helpfulness of professional help from health professional such as psychiatrist and mental health nurse. This is because caregivers would like to seek professional help for their loved one ([Chen et al., 2017](#)).

CONCLUSION

The result of this study indicated that caregivers have several needs that must be met in caring for family members who experience schizophrenia. Caregiver seeks to meet those needs by seeking information about diseases from health workers and the internet. In addition, caregivers also identify the need for healing guarantees by asking health workers. Caregiver efforts to meet the needs of group support through discussions with other caregivers. Caregiver also needs a place to train patients to work and not become a family burden. An easily accessible health facility is an unmet caregiver requirement. Therefore, special attention is needed from health service institutions and local health departments to enable mental health services so that the availability of health workers and medications can help caregivers in optimizing their ability to care for family members who experience schizophrenia at home.

Declaration of Conflicting Interest

None declared.

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Author Contribution

This is the original work of the corresponding author.

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