ORIGINAL ARTICLE

Psychological Burden Experiences and Coping Strategies of Family Who Have Family Members With Schizophrenia

Rindayati Rindayati[1,2], Ah Yusuf[1], Mundakir Mundakir[3], Abd Nasir[2], Nisa Kurnia Illahiati[4]

[1] Department of Nursing, Faculty of Nursing, Airlangga University, 60115 Surabaya, East Java, Indonesia
[2] Department of Health, Faculty of Vocational, Airlangga University, 60115 Surabaya, East Java, Indonesia
[3] Department of Nursing, Faculty of Health, Muhammadiyah Univeristy 60113 Surabaya, East Java, Indonesia
[4] Communication Department Faculty of Social and Political Sciences Airlangga University 60115 Surabaya, East Java, Indonesia

ABSTRACT

Introduction: Uncontrolled behavior of schizophrenic patients, becomes a psychological burden for other family members, so families try to find various effective coping strategies. This study aims to explore the psychological burden and coping strategies of families who have family members with schizophrenia. **Methods:** This research design uses a phenomenological qualitative approach, with a purposive sampling technique, as many as fifteen family members have schizophrenic relatives as participants. Interviews were conducted through in-depth interviews and analysis of research data using interpretive phenomenology analysis. **Results:** The themes that were found to represent the psychological burden and coping strategies families were 1) worrying about uncontrolled behavior, 2) inadequate financial responsibilities, 3) seeking help from others and 4) establishing communication between other family members. **Conclusion:** The psychological burden experienced by family members due to one family member experiencing schizophrenia can be covered by seeking the help of others and establishing effective communication with other family members.

Keywords: Psychological burden; Coping strategies; Family members; Schizophrenia

Corresponding Author:
Rindayati, M.Kep
Email: rindayati-2019@fkp.unair.ac.id
Tel: +085706304058

INTRODUCTION

Schizophrenia is a disease with behavioral disorders and causes a serious psychological burden on their families, thus requiring them to look for various alternative coping solutions. This disease affects 24 million people in the world (1). While in Indonesia, there are around 1,890,000 people with schizophrenia, of which 155,000 live in East Java (2). At home, people with schizophrenia become a fairly heavy psychological burden for their families (3). Because the families were very depressed with their behavior which sometimes showed symptoms such as smiling and talking to themselves, getting angry for no apparent reason, and being very lazy (4), so the family members would feel stressed and anxious when other people find out about their schizophrenic family and are frustrated with the patient's arbitrary behavior (5). In addition, limited mental health facilities make schizophrenic patients tend to stay at home, which can increase the family's anxiety level (6). So it is important to do research on psychological burdens and family coping strategies, as a contribution to improving the quality of nursing.

Previous studies reported various family burdens in caring for schizophrenic patients at home, including economic burdens, nursing burdens, physical burdens, psychological burdens, and social burdens (7). The occurrence of a psychological burden on families caring for schizophrenic patients was also informed by other researchers, by finding the emergence of symptoms of depression, stress, and anxiety in families with schizophrenia (8). In addition, several studies have also reported that schizophrenia is a major contributor to the psychological burden that adversely affects family health (3,9,10). Coping strategies play an important role in reducing perceived burdens, but there are still many uses for avoidance and other non-adaptive coping strategies (11). Studies inform that appropriate coping strategy are influential in overcoming family health (12,14). Thus, the identification of psychological burdens and the use of coping strategies are expected to have positive expectations in the future.

The psychological burden of family members who have relatives suffering from schizophrenia comes from various factors, namely patient behavior, environmental stigma, lack of knowledge about care, patient abuse, and lack of support (15). So that all family members feel a very heavy psychological burden, and if the coping strategies are not appropriate, they are vulnerable to stress, anxiety, and frustration with various physical, mental, and social manifestations (16). The heaviest impact of family members who experience stress and anxiety will focus on self-care and neglect sick relatives, so mentally ill relatives experience relapse more often, which in turn becomes a chain of family problems that are difficult to decide (17).

For this reason, the use of effective coping strategies is important for families as caregivers of people with schizophrenia (18). Herefore, families as informal nursing service providers need to broaden the identification of various coping strategies and be flexible in using the attributes of coping strategies according to existing situations and conditions. However, the research has not been revealed in detail. Although several studies have reported the results of research related to family burdens and coping strategies by families as informal caregivers (19, 21). These studies have not fully revealed, highlighting how the use of coping strategies is related to the problems of people with schizophrenia in the family, so this study focuses on studies of psychological burdens and coping strategies used in helping to overcome the problems of schizophrenic patients.

MATERIALS AND METHODS

Research design

The design of this study used a phenomenological qualitative approach (22), In-depth and semi-structured interviews were conducted with families of people with schizophrenia, with the hope of obtaining complete data about their experiences as caregivers, which were conducted individually with interview guidelines used as a reference. The results of the interviews were recorded using a mobile phone, which was then transcribed and confronted with nonverbal responses through field notes for data analysis to improve data accuracy (23), which were then compiled as verbatim data. The purposive sampling technique is a sampling technique with certain considerations used to recruit participants. Researchers also recruited a diverse and representative sample to reflect the family population of schizophrenic patients, so that they had a meaningful experience until they reached data saturation, and data saturation was reached at the 15th interview because no new information was found (23).

Data Collection

Data collection was carried out between April and June 2021, by visiting the participants' residences, beginning with an explanation of the research objectives, signing informed consent, and time contracts, and explaining ethics and confidentiality, followed by an hour-long interview with each informant.

Data analysis

Interpretive phenomenological analysis was used in this study (24) by reading interview transcripts and field notes carefully and repeatedly to find emerging themes, then categorizing important words that are related to each other through a selective approach. Along with this complexity, reflection on various interpretations has been carried out to maintain openness in monitoring assumptions and biases through a triangulation process with participants, then analyzing each sentence and confirming the data with field notes to find important themes to be reconstructed into a proposition. Focusing on the family experience living with schizophrenic patients (23). Furthermore, the researcher connects between categories based on the events experienced, and always pays attention to the balance of the research theme by looking at each part as a whole.

Ethics statement

Research ethics applies the principle of beneficence and respects human dignity. This research has been declared ethically feasible by the Health Research Ethics Committee (KEPK) of the Faculty of Nursing, Airlangga University with ethical approval number 2227-KEPK (26th April 2021).

RESULTS

A total of 15 family members as participants in the study, consisting of 13 women and 2 men, can be seen in full in table I below.

Themes

Four main themes describe the psychological burden and coping strategies of families with relatives with schizophrenia, namely 1) worrying about uncontrolled behavior, 2) inadequate financial responsibilities, 3) seeking help from others and 4) establishing communication between other family members.

Worrying about uncontrolled behavior

Families are worried that the behavior of a family member who suffers from schizophrenia is often uncontrolled. This theme is obtained from the behavior of being angry for no reason, quietly shutting himself in his room, not wanting to eat, not wanting to talk, talking, and smiling to himself. Families feel

Table I : Members family as participant in study

Family	Age participant	Type sex	Education	Work	Inner Status Family
Participant 1	52	Woman	School Intermediate First	Mother House Ladder	Younger brother biological
Participant 2	25	Woman	School Intermediate On	Laborer factory	Younger brother biological
Participant 3	60	Woman	School Base	Self-employed	Mother
Participant 4	56	Woman	School Base	Mother House Ladder	Mother
Participant 5	26	Woman	Bachelor	Not work	Son-in-law
Participant 6	50	Woman	School Base	Mother House Ladder	Older brother biological
Participant 7	55	Woman	School Base	Laborer farmer	Mother
Participants 8	48	Woman	School Intermediate First	Mother House Ladder	Older brother biological
Participants 9	47	Man	School Intermediate On	Private	Father
Participant 10	60	Man	Bachelor	Retired Employee Country Civil	Father
Participant 11	41	Woman	School Intermediate First	Mother House Ladder	Mother
Participant 12	22	Woman	School Intermediate First	Mother House Ladder	Older brother biological
Participant 13	46	Woman	School Intermediate First	Self-employed	Mother
Participant 14	52	Woman	School Base	Self-employed	Mother
Participant 15	71	Woman	School Intermediate First	Mother Household _	Mother

confused, worried, and afraid to face the behavior of relatives who suffer from schizophrenia disturbing others. One participant expressed concern about this behavior:
"When he relapsed, he used violence, shouted, threw things, threw anything at a nearby house, suddenly hit passersby, kicked the door … so that the family and neighbors were all afraid, worried and tense if something untoward happened" (P1).

Other participants tried to reveal families with schizophrenia who engage in other forms of violent behavior:
"When he was silent, he let go of his motorbike and then he made sounds, groaning in a very loud voice that disturbed the neighbors, but how can the wong (people) not be informed because pancene mboten (it's not) normal" (P6).

In line with the previous violent behavior, other participants attempted to state:
"It's stressful to have a sick relative like that, especially when you have a relapse. (P3).

Another participant also recounted how his relative hit him which made him worry:
"It keeps getting worse and worse, ma'am, the medicine doesn't seem to be suitable, can't sleep at night, is so restless that he beats himself on the head" (P4).

The behavior of schizophrenic patients that triggers the next stress is shutting themselves in the room. A participant tries to describe the behavior conditions of his family members as follows:
"When he was stopped as a laborer from a wood factory….coming home from work he kept quiet, the longer he kept silent….I got angry, but in the end,

he didn't want to look at me…..every time I came he covered his face with a sarong (traditional cloth) and kept quiet in his room" (P9).

Another participant told about his sick relative, kept silent and locked himself in his room, recounted:
"After work from the forest when he got home he said his body felt hot, he continued to sleep in his room like a confused person, after a long time he whimpered and kept talking to himself, smiled to himself, didn't want to eat and didn't want to leave the room" (P8).

The condition of another patient who was also silent and caused family stress was narrated by the following participants:
"Initially niku rabi (originally married) didn't do it, he wasn't greeted by his wife, at first it was like being stressed out, you know....just kept quiet, didn't want to talk to anyone...so we were confused" (P6).

Next is the behavior of the patient who does not want to eat triggers the emergence of stress for other family members, as told by participants:
"Seeing the child is silent, doesn't want to leave the room, doesn't want to eat, can't sleep, keeps crying, has been treated everywhere, it still feels like everyone's confused" (P7).

Other participants also described the condition of a sick family as follows:
"Eat no….don't want to eat at all…just keep laughing" (P12).

Another participant tried to tell about his family who did not want to eat:
"….at first he locked himself in his room, then his neck was hard and kept on mboten purun dahar (like that he kept refusing to eat)….stood loudly (once) for a year" (5).

The next patient's behavior is not wanting to talk which triggers the emergence of stress for other family members. Participants relate the following:
"…why is it still getting worse... to the point of not wanting to talk at all (P11).

The participants then shared their experiences:
"He was….silence only, invited to talk to niku mboten (it didn't) response….I gave him food, he was silent…but he ate it, he left the plate alone, later it's time to eat I'll give him another meal… he was told to take a shower, shut up only" (P8).

The next participant's exposure is as follows:
"His condition was getting worse and worse… for three months he didn't want to talk at all… kept silent in his room" (P3).

Various behaviors of family members with schizophrenia trigger the emergence of family stress with various manifestations.

Insufficient financing responsibilities

The needs for daily life and medical expenses for sick family members are fully borne by the family resulting in inadequate financing. This theme is obtained from the needs of daily life, the high cost of treatment, and the economic status of the family. Patients who are not products that the needs of daily life are the responsibility of the family resulting in inadequate financing. One of the participants recounted the needs of the daily life of a schizophrenic patient who is his dependent:
"….He used to work in Malaysia, then when he came home he was told to marry his father but he didn't want to get married yet, but he didn't dare to tell his father…. in the end, they got married, then, in the end, they couldn't work, it was like that" (P8).

Other participants also tried to share their experiences in taking care of the needs of their sick family members:
"There are a lot of siblings, ma'am… but no one wants to be with him, so we'll bring him home here… all needs are met from here, eat as we eat, if you eat well, you eat well, if you don't, you don't eat well, when we have luck, we give a little money so we can buy the cake we want" (P1).

In line with the above, this participant also revealed what happened to him:
"At first it was like stress, ma'am, but it got worse... for three months it didn't want to talk, couldn't do anything, so all its needs were borne by the family... we lived according to our abilities, participants told stories with sad faces" (P3).

The high price of drugs for mental illness and the lengthy need to take medication for patients make the family experience a psychological burden. One participant recounted:
"Up to three years of treatment there…. Menur Mental Hospital…then the nurse suggested that the control should be sent to a nearby hospital….but I took treatment to the puskesmas near my house….the medicine is sometimes not available at the puskesmas, so I have to buy it at my pharmacy, the medicine is expensive" (P3).

Another participant also told the same thing as before:
"Then he was taken to a mental hospital… Menur means his place is in Menur Mental Hospital until there he continues to be infused….because he hasn't eaten for three months, drugs that are not available are edeemed at the pharmacy with his own money" (11).

The participants then recounted their experiences as follows:
"I'm worried that the medicine is expensive. I'm trying to hold on to niki (like this)…. disuwukne means going to a dukun, but because she hasn't recovered yet, she's taken to the health center)…smart people" (P7).

The average economic status of families with schizophrenic family members is middle to lower and poor, as told by participants:
"I sell snacks at the market, ma'am, I get it for about 1-1.5 million ... to help meet household needs because her father works as little as possible, eats and needs from the sales," (P13).

As with the previous statement, the following participants also tried to express:
"The work is in the fields, ma'am, helping people in the fields, the income is uncertain if on a normal day like this you get wages to plant rice, the harvest time is quite a lot, no one helps with the work Mrs. her father has become sickly since his son was sick like that" (P14).

Seeking help from others
Families try to overcome the problem of the behavior of family members who experience schizophrenia by seeking the help of others so that the family does not fall into stressful conditions. This theme was obtained from asking for help from traditional healers, asking for help from the authorities, asking for help from medical personnel. Efforts to ask for help from traditional healers in their area, as told by one participant:
"….continues to be fished by the family, morak - marik sak unine uwong diparani (the family is looking for treatment, here and there, every time people are told they are visited) to the cleric, sometimes the cleric also asks for help so that he recovers quickly" (P6).

Other participants also tried to relate:
"Since the family asked for help from smart people for healing…. but it turned out that he had not recovered and was getting worse, in fact for three months he was getting worse….finally he was taken to the kyai who owns a hut and was treated in the hut" (P3).

Asking for help from traditional healers was also done by participants with the expression:
"Sometimes he says it looks like there is a snake.... then his brother tries again by asking for help from traditional healers, then he goes home still doesn't want to talk, sek paces back and forth .... you know, like people are confused, often forget so ask the ustad for help to be in rukyah (P3).

Furthermore, several participants described seeking help by asking the authorities for help, as the participants recounted:
"If you relapse using violence, shouting, hitting, kicking things….then, people don't dare….I didn't even dare, we finally asked the police for help to take them to a mental hospital" (P1).

Other participants also tried to share their experiences:
"Once lost in temokaken tiyang ten (found by someone in) Ngawi, continued to be treated (stayed) at the Ngawi hut instead of ucul (out of the hut) and finally brought back home by the civil service police unit (Satpol PP)" (P6).

Next, ask for help from medical personnel in health services, both mental hospitals, general hospitals, health centers, and practicing doctors. One participant tries to reveal:
"My son can work…but there are still strange thoughts that sometimes come at night. She didn't want to take the medicine because she said she wasn't sick, but eventually relapsed…couldn't sleep, was scared, her strange thoughts often came up, so her husband and family didn't want to…and was sent back to my house (the patient's mother) asking for help to get her to the hospital" (P14).

Establish communication between other family members
Efforts to relieve inadequate financial responsibilities in alleviating the psychological burden of the family are carried out by establishing communication between other family members. This theme is obtained from the communication with the nuclear family and communication with the extended family. One participant tried to express:
"My sick child lives in a small house alone…when it comes time to eat, I deliver his food, but he is not given medicine because he has never been taken to the hospital. I said to my other children…let's go, your sister is looking for medicine at the hospital, the cost is together and then the answer is…. family first, Mak (mother) how will you bring it later" (P15).

Another participant communicating with other families said:
"The patient's son never visited his father who was sick even though it was Eid Al-Fitr ... I finally called and said ......come here to visit your father, he misses you, if Eid will come here... your father wants to meet his son" (P8).

In line with the statement above, one participant tried to narrate:
"My son lives with his husband and son, he can work in a factory making instant noodles near his house, but he doesn't want to take any more medicine because he says he's not sick, he relapsed again… his mother), I gave him another medicine" (P14).

The limitation of this qualitative research is using an interpretive phenomenological approach which assumes that the research findings are not purely

descriptive but involve the researcher's interpretation. The limitation of this research is the subjectivity of the researcher. The results of the study depend on the researcher's interpretation of the implied meaning in the interview, which causes the tendency for bias to still exist. To reduce bias, researchers conducted a triangulation process. Source triangulation is done by cross-checking the data with facts from different informants and other research results. For the triangulation method, several methods were used in data collection, namely in-depth interviews and observation.

DISCUSSION

Problems in the family related to the presence of people with schizophrenia in the family are an important discussion in this study, as how they cope with their psychological burden. This study aims to understand how the psychological burden and the chosen coping strategy are related to the presence of family members who suffer from schizophrenia. The results of the study informed the participants' psychological burden and coping strategies began with worrying about uncontrolled behavior. Verbal behaviors such as talking to yourself, smiling at yourself for no reason, and not wanting to talk can create anxiety as a psychological burden on the family. This is consistent with previous research that chronic mental illness with inappropriate behavior becomes a psychological burden for caring families (25). The psychological burden can be defined as the emergence of symptoms of anxiety and or symptoms of depression experienced by families who have mentally ill relatives (26). Violent behavior that is considered the most worrying is shouting while raging and damaging to endanger oneself and others.

The patient's behavior can lead to family stress because members who experience schizophrenia have uncontrolled behavior which is found in the form of angry behavior for no reason, quietly shutting themselves in the room, not wanting to eat, not wanting to talk, talking and smiling alone which causes family worries, sadness, and fear. These results are consistent with previous research that the verbal behavior of people with mental disorders causes family shame and sadness, while nonverbal behavior causes anxiety as a form of pressure (27). The trigger for the heaviest worry is lazy behavior that causes unproductiveness, so the family has to bear the cost of care and all living expenses (28). The behavior of not wanting to eat, not being able to sleep, not wanting to talk, smiling, and talking alone greatly affects the psychological burden on the family (5). The psychological burden increases when a mentally ill relative does not want to take medication so they often experience repeated relapses with more severe conditions.

The results of further research found that families experienced inadequate financial responsibilities due to the needs of daily life, high medical costs, and the family's economic status being substandard conditions. Research informs that the factor associated with higher financing dependents is the cost of daily living needs due to unproductive patients (29). This inadequate financial coverage is by the statement that the global burden of disease due to schizophrenia is high when compared to other chronic diseases, so this result supports previous research and the World Health Organization's statement on disability-adjusted life years (DALYs) in chronic diseases (30). This long-term treatment becomes a psychological burden on the caring family and if not handled properly can lead to physical health problems (16). The psychological burden hurts the families of people with mental illness.

Family dependents that result in inadequate financing also occur due to the high cost of treatment, because the price of psychopharmaca-type drugs is relatively high and schizophrenia treatment takes a long time (30). Research reveals that people have a negative view of the notion of mental illness as a curse, suspicion of doing harm, and incurability (32). The environmental stigma is most severe when there is discrimination against other family members, making it difficult to find a mate and work can increase the psychological burden on the family.

Research informs that the psychological burden associated with uncontrolled patient behavior causes families to seek help from others as a family coping strategy by asking for help from traditional healers, asking for help from the authorities, asking for help from medical personnel (33). These results appreciate the statement of the importance of the support system in the care of schizophrenic patients to make the right decisions regarding patient care so that it takes place well (34). Family support is very important especially in seeking help for treatment by medical service standards, while the ability of the family is in limited conditions (28). Asking for help from others to overcome the behavior of schizophrenic patients by asking for help from medical personnel is the right effort.

The next coping strategy carried out by the family is to establish communication between other family members, both with the nuclear family and extended family as an effort to overcome inadequate financial responsibilities. These results are to the culture of *gotong royong* (cooperation), tepo sliro (can meaning being able to understand other people) and tolerance

in Indonesian families, who have a habit of helping to care for sick relatives (2). Previous research stated that communication in caring for the sick is very important as a form of emotional family bonding (6). Emotion-focused coping involves an effort strategy to minimize negative emotional outcomes to avoid stress by relaxing (12).

CONCLUSION

Families who have family members with schizophrenia experience a psychological burden caused by abnormal patient behavior. Patients who engage in violent behavior, talk and laugh to themselves, cause the family to be ashamed and be looked down upon by the community. Psychological burden can have a negative impact cognitively, emotionally, and physically. The coping strategy used by the family is a combination of problem-focused coping and balanced emotion-focused coping. Most of the coping used has not been adaptive, so education about the use of coping by health workers is very important.

ACKNOWLEDGMENT

The author would like to thank the Dean of the Faculty of Nursing and the Gresik Regency Government for granting the research permission.

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