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Family Experiences in Caring for People with Schizophrenia: A Qualitative Study

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ABSTRACT

Background: Schizophrenia is a chronic mental disorder that leads to significant suffering and the inability to maintain relationships with family members. Families have had meaningful experiences during their care, as this mental disorder requires long-term care and increases the burden on the family. This family's role is crucial to the healing process for people with schizophrenia. The purpose of this study is to describe family experiences with schizophrenia treatment. **Methods:** This study is qualitative descriptive research. Participants were divided into three family groups, each consisting of 4 to 8 people, with a total of 16 families participating. The participant-taking technique used is purposive sampling. Researchers collect data through focus group discussions (FGD). Researchers employ framework analysis as a data analysis technique. **Results:** The research found five themes: negative emotions, positive emotions, family burdens, stigma, and coping strategies. Families can experience negative emotions of anger, frustration, and fear when treating people with schizophrenia. The family also feels positive emotions of hope, patience, and gratitude. Long-term care and high dependence increase the burden on the family. There's still family stigma and public stigma. As time passed, the family developed a coping strategy to adapt to the existing stressors. **Conclusion:** The family has valuable experience in providing care to people with schizophrenia. Nurses need to provide family intervention to deal with the stress and stigma perceived by the family.

Keywords: Care; Experiences; Family; People with Schizophrenia; Qualitative

INTRODUCTION

Schizophrenia is the most stigmatising psychotic disorder and most commonly causes a series of severe and chronic symptoms, such as vaginism, hallucinations, chaotic speech and behaviour, as well as cognitive impairment. This chronic mental disorder causes a disability or incapacity that significantly affects the quality of life of the patient and his family (Jauhar, Johnstone, & Mckenna, 2022). In Asia, more than 70% of patients with schizophrenia depend on the family, compared to about 25–50% in Western countries. Schizophrenia is also considered one of the most serious mental illnesses. Many people with schizophrenia are unable to fully recover (Marutani *et al*., 2022) and even experience social isolation, stigma, and difficulty finding a husband or wife (Jauhar, Johnstone, & Mckenna, 2022).

Treatment of people with schizophrenia has shifted from institutional to community based. This shift is in line with the view that community-based care improves outcomes for patients. Community-based care promotes an increased role for the informal carer, which is largely made up of close family members (Montenegro *et al.*, 2023). These roles can have their own impact on carers, including mental, physical, financial, social, and emotional impacts (Cleary *et al*., 2020).

The family is crucial in providing care and social and financial support for people with schizophrenia.

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They provide support for taking the drugs, incentives, and guarantees for obtaining independence. Not only parents, but spouses, brothers and sisters, and large families have been involved in supporting the care of people with schizophrenia (Huang *et al*., 2021; Naamara *et al*., 2023; Stanley & Balakrishnan, 2023a; Susanti *et al*., 2024). The role of treating people with schizophrenia can create feelings of sadness, loss, depression, and stigma, as well as put pressure on other family relationships (Cleary *et al.*, 2020). During the first episode of schizophrenia, members of the family who suffer from schizophrenia tend to experience a series of traumatic events. Furthermore, they face a continuing cycle of parenting and begin to adapt in terms of uncertainty, loss of life expectancy and health, lack of personal and social resources, difficulties in understanding, stigma and descent, family disturbances, and conflicts in interpersonal relationships. In addition to having a negative impact, treating relatives with schizophrenia also has a positive impact, such as rewarding feelings, family solidarity, self-confidence, personal growth, learning knowledge and skills, affirmation, and appreciation (Shiraishi & Reilly, 2019; Mardhiyah *et al*., 2020; Liu *et al*., 2022).

Research that studies positive experiences and emotions in families when treating people with schizophrenia is still limited, especially in Indonesia. Most studies reveal the negative impact of schizophrenia treatment on the family (Yulianto, Mubin, & Novitasari, 2024), the burden (Peristianto, Subandi, & Utami, 2022), and the coping strategies used by the family (Lestari *et al*., 2021). Thus, it is important to explore the experiences of families so that it can help to understand that treating family members with schizophrenia does not necessarily have a negative impact on the family. This study aims to explore carers' experiences of taking care of family members who have been diagnosed with schizophrenia.

METHODOLOGY

Design

This research was a descriptive-qualitative study that uses inductive strategies to interpret the characteristics of complex clinical phenomena. Interpretation is the search for truth, explanation, understanding, and meaning in the relationship of cause and effect (Adams, Hooker, & Taft, 2023).

Study Population and Location

There was a total of 16 families across the 3 family groups that made up the participant pool. Each group included 4–8 members. Purposive sampling was the participatory sampling method employed in the qualitative design. Ages 19 to 59, good communication skills, physical health, and living with people with schizophrenia and giving face-to-face care for at least 10 hours a day are the requirements for family participants (Susanti *et al*., 2024).

The Community Health Centre's mental health coordinator recruits' participants by first sending out a list of people with schizophrenia in the area who fit the inclusion and exclusion criteria and then following up with potential volunteers to explain the study details. Researchers get informed consent, invite them for FGD, and give them a full day to think over their decisions. The research was conducted in Sukoharjo district and the city of Surakarta, Central Java, Indonesia.

Data Collection

The study was carried out over the course of four months, beginning with the administrative procedure and ending with the execution of data collection (October 2022–January 2023), in Sukoharjo Regency (one group of families) and Surakarta City (two groups of families). Division of FGD groups based on location affordability. Focus groups (FGDs) are used to collect data. The researchers used a focus group discussion guide that asked about family experiences during the treatment of family members suffering from schizophrenia. The experience included positive and negative experiences. The researchers questioned how people perceive family members suffering from schizophrenia. At last, the authors asked what families did when faced with difficulties during the treatment of schizophrenia. In 45 to 60 minutes, FGDs were completed. Minutes and facilitators were used to record and guide the discussion and take notes on significant occurrences.

Instruments

The instrument in this study was the researchers themselves. The researchers used the Focus Group Discussion (FGD) technique to obtain data from the participants. They used FGD guides that were structured around the purposes of the research to guide the data collection process. Researchers also used voice recorders and writing tools to document data and important things during the process of data collection.

Data Analysis

Researchers used framework analysis as a method of data analysis because it generates highly structured outputs of summarised data and offers easy-to-follow instructions. It is useful for managing large data sets and needing to obtain a detailed, descriptive overview of the entire data collection, as well as when multiple researchers are working together on a project. The seven steps of framework analysis are: transcribing, familiarisation, coding, creation of a functional framework, application of the framework to all transcripts using pre-existing codes and categories, data charting into the framework matrix, and data interpretation (Gale *et al*., 2013). The researcher recorded the conversation and turned it into a transcript in the first step, transcription. The researcher read the transcript multiple times in the second step to improve understanding. Coding is the third step, where the researcher codes the transcripts. The fourth step was for the researcher to draft an analytical framework. Every code that was acquired during the third phase has been categorized. In the fifth step, every transcript is subjected to an analytical framework that makes use of pre-existing codes and categories. Data mapping into the framework matrix is the sixth step, which involves the researcher creating a matrix and mapping the data into it. The data from each transcript is categorised and summarised through charts. The interpretation of the data is the seventh step.

Ethical Consideration

The ethical agreement for this study was obtained from the Ethical Committee of The University of Indonesia, Indonesia, with approval number KET-236/UN2.F12. D1.2.1/PPM.00.02/2022 on 5th September 2022.

RESULTS

The study was conducted on 16 families of people with schizophrenia in Sukoharjo district and Surakarta City. The characteristics of the participants are shown in Table 1.

Table 1: Characteristics of the Participants

Characteristics	F	%
Gender		
Male	6	37.5
Female	10	62.5
Education		
Not completed Elementary School	6	37.5
Middle School	1	6.3
High School	7	43.8
University	1	6.3
Job		
Teacher	1	6.3
Housewife	5	31.3
Private	2	12.5
Seller	3	18.8
Housemaid	1	6.3

Retiree	1	6.3
Guide	1	6.3
Driver	1	6.3
Laborer	1	6.3
Marital Status		
Married	11	68.8
Unmarried	4	25.0
Widow/Widower	1	6.3
Relationship with Patients		
Parent	6	37.5
Husband/wife	1	6.3
Sibling	5	31.3
Uncle/Aunt	1	6.3
Child	2	12.5
Nephew	1	6.3
Total	**16**	**100**

The family participants were predominantly female (62.5%), high school graduates (43.8%), housewives (31.3%), married (68.8%), and had a relationship with people with schizophrenia as a parent (37.5%). The age of family participants ranged from 19 to 74 years, with an average of 51 years (SD = 18.8).

The family experience of treating people with schizophrenia consists of five themes: negative emotions, positive emotions, family burden, community stigma, and coping strategy.

Negative Emotions

Anger emotions are often experienced by families when treating people with schizophrenia. It's because people with schizophrenia hang most of their lives on their families; for example, self-care like eating, bathing, cleaning their homes, and so on. Sometimes, families get annoyed when helping people with schizophrenia because they cannot cooperate. The participant's statement in favour of the issue was as follows:

"It means, wake up, take a shower, drink, eat, and clean the room; it has recovered well; be grateful. Sometimes not causing dizziness." (K15)

"But my daughter is so annoying; for example, when I'm busy, I ask her to eat by herself, but she spills the meal." (K12)

Some families feel frustrated and think that treating people with schizophrenia can affect their mental health. The supportive statement of the participants was:

"If I think about it, it makes me crazy, then I'll just leave it." (K16)

Families sometimes feel scared if people with schizophrenia get upset because they can't control their anger.

"We're afraid he gets out of control with his anger." (K1)

Thus, the findings of this study suggest that families can experience negative emotions of anger, frustration, and fear when treating people with schizophrenia.

Positive Emotions

In addition to feeling negative emotions, families also experience positive emotions: hope, patience, and gratitude. Although schizophrenia is a chronic mental disorder and requires long-term treatment, the family still hopes they can recover. It's in line with the participant's statement.

"Yes, may it be, ma'am. May God give pleasure to my children. I also know there's someone who can heal, hopefully." (K2)

"Yes, but the hope in the heart remains for the people with schizophrenia—how to get healed so quickly." (K1)

Amid the difficulty of treating family members with schizophrenia, the families must be patient.

"Yeah, it's true; patience is the most important thing when dealing with people with mental disorders." (K1)

"Mr. S was originally selling newspapers in the neighbourhood; now it's not. Suddenly, during the night of prayer in the mosque, he cried. Then I transferred to Ustadz, and then I was taken to the hospital for treatment. Yes, I have to be patient." (K8)

The family is also grateful for the progress experienced by family members with schizophrenia.

"There, all praise to God, is progress. She didn't want to take a shower or get out of bed when her menstrual blood was flowing to bed, but all praise to God, now that she's menstruating, she can wipe her own pants." (K11)

"All praise to God; my three children already have a family, but I still have someone to accompany; my psychotic daughter can accompany me to this day." (K6)

So, in addition to negative emotions, the family also feels positive emotions of hope, patience, and gratitude.

The Burden of the Family

Taking care of people with schizophrenia brings a special burden to the family. Subjective burden is the mental burden that a family feels because of the treatment of people with schizophrenia. The participant's statement supports the existence of a subjective burden.

"Well, in my mother's case, I keep thinking about her because she likes to go alone on foot. I don't know where she went, but she was already in that condition when she was home." (K13)

"I'm tired of saying, 'Please take a bath'. I just told her to take a shower again and again. My neighbour said, 'Cut your hair; I'll give you 200', but she didn't want to do it." (K16)

The objective burden is also felt by the family when giving treatment to people with schizophrenia. It was the time they spent treating people with schizophrenia. The family treated people with schizophrenia for years, even up to a lifetime; moreover, people's care requires full supervision.

"She's home alone. As if I stayed an hour or a day, because I need to go outside, I didn't come in soon; she said nothing; she didn't want to eat; even when I prepare the meal, she won't have the meal and drink; she only wants me to keep accompanying her; but how do I treat her well if she keeps asking me to accompany her?" (K15)

If it were me, I'd cut my sister's hair myself. *"Wi, tomorrow you'll go to heaven. Wi, you take care of your sister with your big effort. You helped her take a shower and wash her clothes for years'. My brother, my sister, nobody cares, just me."* (K12)

The burden of the family will increase when family members have other responsibilities, for instance, taking care of the elderly, children, or family members who suffer from diseases.

"Yeah, you're already too old—not a six-year-old kid—and still asking me to feed you. How would I let it be? I'm the one who helps you take a bath. You need to make it fast. Come here. I want to take care of my grandchildren. Let's hurry. Furthermore, I'm not only taking care of her but also taking care of my grandchildren too. 'Grandma, please, Grandma'." (K12)

Thus, the results of this study showed that the burden on families increased as a result of treating people with schizophrenia, especially if families also have responsibility for caring for children or the elderly.

Stigma

People with schizophrenia often receive stigma from the local community. Stigma is experienced by

mocking, insulting, and laughing. This phenomenon supported the statements of several participants.

"It just happened yesterday when there was an event. She spoke by herself, and people laughed at her. Well, maybe society does not understand what a patient with a mental disorder is. So, maybe the academics can facilitate the counselling so that if there is a patient with a mental disorder, people already know what to do, what to ask, not laugh at them, and where action should be taken if there is any problem. In fact, sometimes they laughed at... it was... that's a joke." (K4)

"We hope that society realizes it. Don't make fun of the patient with a mental disorder... 'Go away from us'... not even invited. I hope society realizes it. Come here and have a conversation with patients with mental disorders. Sometimes she reported that she had been mocked and humiliated". (K2)

People's stigma is not just words, but even an act of excluding them, even sending them home when the person with schizophrenia is out of the house.

"There. If he wants to be in society, he'll be sent home like that." (K1) "Yes, it's isolated. Sometimes there's a show that's being sent back.... It's a joke; it's not tied up. Don't say that; don't talk about it; that's what it's about—that his son's reporting to me. Yeah, expelled like that, because maybe it's because you think someone like that can't be hired like that. And then, with that weird nickname, you know, someone said, 'That's a psycho, crazy, or something." (K2)

The behaviour shown by people with schizophrenia sometimes also makes the family feel ashamed of the neighbours around them.

"When the person with schizophrenia is recovered, he can recognize their parent. He acts normal in the neighbourhood, but when I'm in the same house, he's always angry and emotional. I'm really ashamed of my neighbours." (K6)

Based on the data, it can be concluded that people with schizophrenia still feel the stigma of humiliation, isolation, and expulsion.

Coping Strategy

The family tried to sincerely accept the condition of people with schizophrenia and face it patiently.

"Yes, there is. I used to be angry, but when I thought deeper, we'd fight after all. That's the condition. Yeah, we support him as much as we can, and we honestly help him when... it's a matter of patience to call someone like that if you're impatient or even fighting. Yes, hopefully later he will also wake up and be on the way to recovery." (K5)

The family also tried to not always think about the condition of people with schizophrenia, so the family would not get stressed.

"The benefits, first of all, make me feel happy and somehow make the burden lighter. It relaxes my mind. I used to overthink it, but now it's better. Pray to the Lord". (K11)

"If I overthink it, it makes me crazy, but now I let it be." (K16)

The family can take the positive side of his child, whose people with schizophrenia can accompany the parent until they are old, while his siblings are already having their new family.

"Yes, thank God, my other three children have been a good family, have made friends, and have given friends to her mother." (K6)

Family members can proclaim the people with schizophrenia condition and give support to the caregiver.

"Especially me, I myself, sometimes I give support for his siblings, that they can understand, but sometimes his brother is so emotional until they fight, we already understand the situation, have nothing to say, and we just surrender to God." (K11)

Thus, families developed a variety of coping strategies to cope with the difficulties of caring for people

with schizophrenia, i.e., acceptance, positive aspects, and social support.

The overall results of the study can be presented in Figure 1.

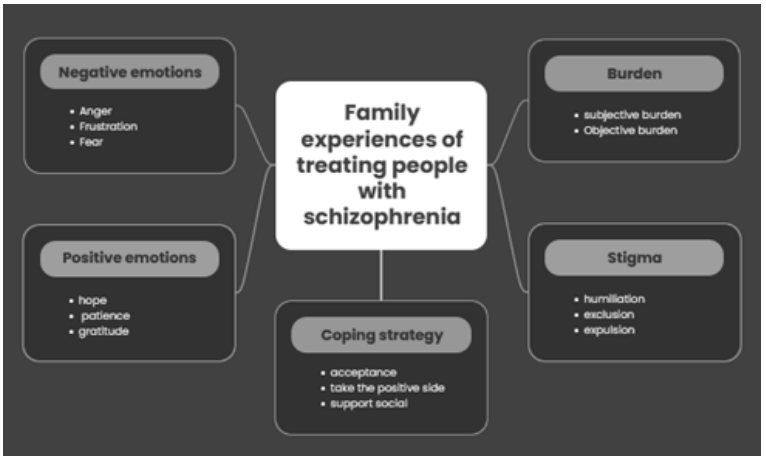

Figure 1: Scheme of Family Experiences of Treating People with Schizophrenia

DISCUSSION

Negative Emotions

Negative emotions like anger and frustration are often experienced by families when treating people with schizophrenia, especially when people with schizophrenia are not cooperative and the family is busy. The findings are in line with research showing that after caregivers suffer shock and are not ready for long-term treatment of schizophrenia, they often feel negative emotions like guilt and shame (Pan *et al*., 2024). The research showed that the difficulty of treating people with schizophrenia leads to an obstacle to family acceptance of the condition of people with schizophrenia (Priasmoro *et al*., 2023). The primary family caregivers face difficulties while dealing with individuals diagnosed with schizophrenia (Can Oz, Duran, & Incedere, 2022). This can lead to caregiver mental health problems and impaired family functioning (Kochhar *et al.*, 2024). In order to provide long-term support and enable therapeutic improvements to overcome obstacles, family functioning is essential to each member's well-being as well as that of the family unit (Hsiao *et al*., 2023).

Positive Emotions

The results show that families experience positive emotions when treating people with schizophrenia, namely hope, patience, and gratitude. The findings are in line with research that shows that families have positive experiences of treating people with schizophrenia, which includes sincerity of care, satisfaction of being cared for, and a sense of love (Liu, 2024; Liu *et al*., 2022). Thus, the findings in this study add to the literature about the positive experiences of families in treating people with schizophrenia, in particular in Indonesian culture. Further research is needed to explore other positive experiences that need to be enhanced to optimize the function of health care and family psychological well-being.

Family Burden

The burden perceived by the family increases due to frequent thinking about people with schizophrenia or due to the amount of time spent treating people with schizophrenia. This finding is consistent with the theory that people with schizophrenia often put a burden on the family because they have to help them in their daily activities, such as bathing, dressing, eating, taking medication, and discharging. The burdens precepted by family members also include subjective elements, like concerns about the health status of people with schizophrenia, poor financial conditions, and difficulty meeting daily needs (Sustrami *et al*., 2023).

The findings are consistent with studies showing that family burdens are linked to psychosocial and financial burdens. Schizophrenia is a mental illness that requires a lot of nursing resources and can lead to

depression, social isolation, and physical illness (Benallel *et al*., 2023). Research finds that 90% of families are burdened in terms of treatment costs, time spent to treat people with schizophrenia, stigma associated with having family members with mental disorders, emotional problems, disruption at work, and reduced productivity (Amaresha & Venkatasubramanian, 2012). Family burden is also linked to hope and social support (Guan *et al*., 2023). Intervention to reduce the burden on the family is essential so that no saturation or exhaustion occurs, and they can provide optimal care to the people with schizophrenia.

Stigma

Stigma is often inherent in people with schizophrenia. They're often laughed at, bitten, kicked out, or mocked. The findings are in line with a study that suggests that nineteen percent of the sample reported moderate-to-severe levels of internalized stigma, out of the 102 participants (50.5%) that exhibited internalized stigma. Value negation received the highest score out of the five categories, followed by discrimination experience and social disengagement (Liu *et al*., 2024).

Stigma can also be experienced by families of people with schizophrenia. The findings are in line with a study that suggests that families often feel discriminated against by society because of the presence of people with schizophrenia in their families (Balang *et al*., 2023). The findings are also consistent with the theory that families can feel embarrassed and burdened by their members having schizophrenia (Blanthorn-Hazell *et al*., 2018; Park & Lee, 2017). The stigma faced by a family associated with having a member of a family with schizophrenia leads to several consequences, including affecting self-esteem, obtaining a job or a home, and acceptance by others. Stigma can also affect the quality of care and encourage families to use negative coping strategies (Wang *et al*., 2023).

Coping Strategy

The family explained that in order to deal with the situation related to their schizophrenic members, they tried to accept the condition of people with schizophrenia with sincerity, patience, positive thinking, and using social support from family and neighbors. This is in line with Lazarus and Folkman's theory that coping is defined as the strategy that an individual performs in responding to and acting when undergoing stress or when the level of exposure to stress increases (Rahmani *et al*., 2019). Coping strategies can be classified as focused on emotions and focusing on problems; in addition, the individual can react to stressful situations using an adaptive or maladaptive coping strategy (Stuart, 2021). Research showed that the coping strategies used by caregivers of people with schizophrenia vary. Parents used more information support, positive communication, and involvement of patients in daily activities; siblings used the coping strategy more for social interest and avoidance (Plessis *et al*., 2022).

The findings of this study are in line with other studies showing that having people with schizophrenia can strengthen relationships because of family reunification, especially during the acute phase of the disease or recurrence period. The family is also closer to God. When families are stressed by people with schizophrenia's care and worried about their condition, they get motivation from friends, relatives, and neighbours (Mbadugha *et al.*, 2023).

The findings of this research support a study that showed that the majority of families of patients with schizophrenia had a good quality of life (39.4%) and excellent quality of life (41.3%) (Sustrami *et al*., 2022). Families that have successfully developed a positive coping strategy will show a better quality of life than families that have not yet been able to accept the condition of the patient. Other research suggests that in order to be resilient, caregivers of people with schizophrenia need preparedness and life satisfaction (Stanley & Balakrishnan, 2023b).

Limitations

This research has its limitations because it has a relatively small number of participants and comes from two districts/cities in Central Java Province. Future researchers can be conducted in different regions of Indonesia, thereby making it more representative. Researchers can also develop mixed methods to obtain more complex and rich data.

CONCLUSION

The family has valuable experience in providing care to people with schizophrenia. Initially, the family faced significant stressors, including the burden and high stigma. Nurses need to provide family intervention to address the stress and stigma perceived by the family. Future research should explore the effectiveness of targeted family interventions and develop comprehensive support systems to improve the well-being of both caregivers and patients, potentially leading to better treatment outcomes. Additionally, policy implications must include the need for mental health education programs to reduce stigma and enhance community support networks for families.

Conflict of Interest

The authors declared no conflict of interest.

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