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A LIVED EXPERIENCE OF BEING A FAMILY CAREGIVER FOR PEOPLE WITH SCHIZOPHRENIA IN INDONESIA; A PHENOMENOLOGICAL STUDY

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ABSTRACT

The family caregiver is significant in helping their relatives with schizophrenia by providing care support. At the same time, the long period and constant caregiving process can negatively affect the caregiver's condition physically and mentally. Understanding these phenomena is needed to create an appropriate intervention to solve the caregiving issues. Objective: This study aimed to explore family caregivers' experiences in providing care for family members with schizophrenia in Indonesia. Method: This study uses a phenomenological qualitative approach conducted from July to December 2022 in West Java, Indonesia. Fourteen primary caregivers were recruited using purposive sampling, meaning they have lived with the client for at least one year, are close relatives, and bear almost all of the care duties. An in-person face-to-face interview was driven to gather the data by following semi-structured questions as a reference. The narrative was analyzed by adopting the seven steps of Colaizzi's method. Results: Three themes and nine sub-themes were identified: lack of support in caregiving, lose yourself, and caregiving burden. Conclusions: These study findings provided a deep understanding of the experiences of Indonesian family caregivers in providing care to family members with schizophrenia at home.

Keywords: experience; family caregivers; indonesia; schizophrenia

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INTRODUCTION

Schizophrenia is a chronic disease that affects a person's perception, thoughts, and behavior. In general, people diagnosed with schizophrenia experience hallucinations and delusions (WHO, 2022). Nowadays, caring for people with schizophrenia is more emphasized by the family in society worldwide (Attepe Özden & Tuncay, 2018). This is supported by the 2013-2020 health management action plan initiated by the World Health Organization (WHO), which states that the care of schizophrenic patients is generally shifted from mental health institutions to community-based care If they are in good condition. In addition, in developing nations, besides the family obligation of the care responsibility for their ill family members, the lack of professional and mental health services seems to be the significant factor that requires the family caregiver to be considered a critical support system in the treatment process for people with Schizophrenia (Nuraini et al., 2021a). Likewise, in Indonesia, most people with schizophrenia live together and frequently depend on care support from their families in the community (Nuraini et al., 2021a).

According to the previous study in Indonesia reports that, in general, the family caregivers of people with schizophrenia do not have adequate skills and knowledge to provide care for their relatives with Schizophrenia. This condition causes many problems for the family due to caring for their ill relative (Tristiana et al., 2019). Patients with schizophrenia have a long duration of illness and severe disabilities in daily functions and social interactions (Vermeulen et al., 2019). Therefore, their family must look after them to prevent relapse. Families of someone with schizophrenia will be burdened with the responsibility of caring for their ill relatives, and mental health professionals will be unable to provide the needed assistance for families and sufferers if this issue is still ignored by society (Nuraini et al., 2021a). Western civilization has recognized attention to this issue since the early long time ago. Several studies have focused on the caregiver's emotional and physical condition as the effects of caring for people with chronic illness (Eghbalmanesh et al., 2023; Ribé et al., 2018; Martín-Carrasco et al., 2016).

In contrast, other studies have looked at the associated factors of the caregiver's burden and the correlations between various aspects (Hu et al., 2016; Ribé et al., 2018). Family caregiver burden is the extent to which caregivers perceive their emotional and physical health, social life, and financial status as a result of caring for their ill relative (Gunawan et al., 2023). The term caregiver burden is used to express any adverse consequences of caring for patients with mental disorders by family caregivers. Recently, the caregiving burden has been widened to involve the physical, psychological, social, and financial aspects experienced by family caregivers (Liu et al., 2020). Studies conducted in Western society revealed that family caregivers experience a series of conflicts and tend to show emotional responses such as fear of violence, high levels of burden, stigma, frustration, sadness, anger, and timelessness (Eghbalmanesh et al., 2023; Ribé et al., 2018). At the same time, research evidence from Hong Kong found that caring for people with schizophrenia was correlated with the low quality of life of family caregivers (Zeng et al., 2017).

Moreover, the presence of someone with schizophrenia in the home, especially after deinstitutionalization, can burden the work and social life of family members or caregivers (Lippi, 2016). Previous studies conducted in Indonesia found that caring for people with schizophrenia burdens the caregivers. A prolonged treatment, the severity of the illness, and the high cost of medication caused the burden among family caregivers of Schizophrenia (Gunawan et al., 2023; Nuraini et al., 2021a). A deeper understanding of the experience of family caregivers in caring for relatives with schizophrenia is fundamental as a basis for health policymakers and mental health workers such as nurses in planning appropriate health actions given to them according to their perceived needs in delivering care assistance to their family members with schizophrenia. However, previous studies have not explored this experience in depth. Therefore, the purpose of this current study was to explore the experience of caring for family members with schizophrenia from the perspective of family caregivers in Indonesia.

METHOD

A qualitative study design with a phenomenological approach was applied to achieve this study's aim. The main reason for using phenomenological research is to get a deeper understanding of the situation and condition of the family caregivers' point of view and how they are emotionally on their perception of delivering care for relatives with schizophrenia. The researcher achieved data saturation in this study after interviewing 14 participants. This study's participants were the family caregivers of people with schizophrenia registered in the community health center of Tamansari, Indonesia. The researcher collaborated with the community psychiatric nurse (CPN) from the community health center of Tamansari to determine the potential participants for this study. A purposive sampling technique was applied to select the family caregivers for the study participants. All the participants have met the inclusion criteria of this study: family caregiver aged 18 years old or above, being a caregiver for at least one year and bearing most of the care responsibilities, living with the patients at home, and communicating effectively.

Data collection was conducted between July to December 2022. The semi-structured interview guideline, containing several questions, was used to explore the experience of the family caregivers in providing care for their relatives with schizophrenia. The researcher interviewed each respondent for 55 to 60 minutes. The researcher also used a voice recorder to record all interview processes of each respondent with their permission. In addition, the researcher took field notes during the interview process. In this study, Colaizzi's seven steps of data analysis procedures were used, including (1) the researcher listening to and reading each interview transcription of the respondents carefully, (2) finding the significantly related statement, (3) formulating the meaning from related significant statement, (4) identified the themes from the formulated meanings, (5) validate the findings by comparing the transcription, theme, and sub-themes, (6) define description of the themes and sub-themes, (7) member checked as the final validation of the findings in this study. This study was proved by the Social and Welfare Department committee and the Department of Health of Tasikmalaya City, Indonesia, with IRB number (575.4/371/TMS/2022.)

RESULTS

In addition, most family caregivers in this study were female (n = 11), and a small proportion were male (n = 3). Meanwhile, most of the family caregivers were mothers (n=8), and some of them were grandmothers (n=3), fathers (n=2), and husbands (n=1). At the same time, the range age of the family caregiver in this study is (38 to 75 years). According to the marital status of the family caregivers, most of them (n = 8) were married, a few of them (n=5) were widowed, and one of them was divorced (n=1). Regarding their educational background, most of the caregivers had primary high school (n=5), several of them were in junior high school (n=3) and senior high school (n=3), and had no education (n=3) Table 1.

Table 1.
Characteristics of family caregivers (n= 14)

Characteristics	f	%
Gender		
Female	11	78,57
Male	3	21,43
Relationship		
Mother	8	57,14
Father	2	14,29
Grand Mother	3	21,43
Husband	1	7,14
Marital Status		
Married	8	57,14
Widowed	5	35,71
Divorce	1	7,14
Education background		
None	3	21,43
Primary school	5	35,71
Junior school	3	21,43
Senior School	3	21,43

Table 2.
Theme and Sub-theme

Theme	Sub-theme
Lack of support in caregiving	Lack of social support Lack of financial support Lack of professional support
Lose your self	Loss of professional development Loss of self-determination Losing a job
Caregiving burden	Struggle in managing client's psychotic symptoms Struggle in managing the client treatment process

Theme 1: Lack of support in caregiving

Lacking support in caregiving refers to the insufficiency of help in providing care for a family member with schizophrenia experienced by the family caregiver. This support includes a lack of social support, financial support, and professional support.

Sub-theme: Lack of social support

This study found that most family caregivers experienced difficulties getting help from other family members in providing care for their family members with schizophrenia. Family caregivers revealed that the other relatives tried to avoid them due to worrying involved in the caregiving.

> "*Aah, it is difficult, sir, especially now. Sometimes, they rarely pick up when we want to make a phone call. Moreover, they are afraid of me and avoid me because they do not want to help my husband or me. They are always told they are busy."* (P1 Mother)

The caregiving task is very demanding and burdensome. Furthermore, the family caregivers also have difficulties sharing the caregiving rules with the other family members. Therefore, sharing the caregiving task with others is very helpful for the family caregiver in providing care for their relatives with schizophrenia at home.

> *"I lived with my sister and her husband here, but when my daughter is sick again, they never help me in caring for her, just for a moment, especially when I need to go out to work."* (P2 Father)

Sub-theme: Lack of financial support

Financial difficulties were also a significant issue among family caregivers. The cost of treatment for people with schizophrenia is expensive in Indonesia, including the price of the accommodation and the drugs. Even though National health insurance covers some medicines, the family still needs to pay for some treatment with their own money.

> *" if the NHI does not cover the drug, I have to pay by my cash, and the price is costly. Sometimes, if I don't have money, I ask for money from my brothers, but they don't give me money,".* (P5 Mother)

The caregivers also have difficulties fulfilling the patient's daily expanse, and most of the family caregivers are not working to support their financial income.

> *" But her daily expenses are the most spending of money, and it is quite a burden for my family's finances. I live with my husband and two children. We depend on my husband's salary only because I don't have a job ".* (P8 Mother)

Sub-theme: Lack of professional support

Lack of professional support indicates that caregivers are not receiving adequate help that meets their care needs in caregiving from the health professional.

> "*Actually, one nurse from the community health center of Tamansari visits my daughter once a month, sometimes two months. But he only asked the question and checked my son's blood pressure, which was not helpful*". (P3 Mother)

However, in this study, other family caregivers mentioned that the family caregivers had never been informed and trained by professionals to care for the clients.

> *"No, I never got any information or training, sir. When they came to my home, they only asked me several questions about my son's condition, just like you are now asking me questions.* (P14 Mother)

Theme 2: lose yourself

Loss yourself refers to the several losses experienced by family caregivers while taking care of a family with schizophrenia, including loss of personal development, self-determination, and job loss.

Sub-theme: loss of professional development

Loss of professional development refers to family caregivers losing a chance to improve their personal growth by pursuing the best career level or enhancing their education level.

> *"Last year I had the opportunity to take a computer management training from my office which is by using the certificate I was able to get a promotion to a high position in my job. But I lost it because I couldn't leave my child for a long time".* (P12 Father)

In other cases, one family caregiver also said they quit their education program due to caregiving tasks.

> *"in 2019, I was enrolled in one university to pursue my bachelor's degree. However, several months ago, I stopped studying because I could not attend class. It was so difficult for me to leave my wife alone at home...*" (P11 Husband)

Sub-theme: loss of self-determination

Losing self-determination means that caregivers cannot pursue their way in life. Being a caregiver is not their choice but a condition that forces them.

> "*Actually, I still want to work at my school. Eventhough I am not young anymore, I love teaching my student, and I miss returning to school. However, my grandchild is sick, and his parent is not here, so I have to take care of him every day".* (P4 Grandmother)

Sub-theme: losing a job

Losing a job refers to family caregivers not having the opportunity to run their own businesses to support family income due to care responsibilities.

> *"I had a small phone shop in front of my house before, but now I can't open my little mobile phone shop anymore because my son is sick. So I don't get money to help my husband meet my family's daily needs".* (P6 Mother)

The caregivers also stated that they lost jobs and the chance to have a better career in the future.

> *"I was a kindergarten teacher before. But in 2017, I resigned from that job because it was so difficult for me to leave Rafa alone at home, even for just 3 to 4 hours…."* (P5 Mother)

Theme 3: Caregiving burden

Caregiving burden refers to the several difficulties experienced by the family caregivers in providing care for their relatives with schizophrenia, including the struggle in managing the client's psychotic symptoms and the client's treatment process.

Sub-theme: struggle in managing client's psychotic symptom

In this study, family caregivers often mentioned that helping to stabilize clients' psychotic symptoms was the most challenging support in providing care for their relatives with schizophrenia.

> "*Sometimes he is relapsed into a bad situation, such as talking alone with himself, laughing, and crying even screaming, which hard to control…"* (P10 Mother)
>
> *"I don't know how to prevent her from recurring because it is complicated to control when it has relapsed."* (P3 Mother)

Sub-theme: struggle in managing the client treatment process

Helping clients to take medication regularly is another difficulty revealed from interviews of the family caregivers' experience in caring for their relatives with schizophrenia at home.

> "*Sometimes if I can't persuade her to take medicine anymore, I ignore it. For me, that is the most challenging thing in caring for people with mental disorders*" (P3 Mother)
>
> *"I was confused and didn't know what I have to do if he doesn't want to take medication…could you teach me"* (P10 Mother)

DISCUSSION

This study aimed to explore the families' caregivers' experience in providing care support for a family member with schizophrenia. One of this study's findings is that most family caregivers of people with schizophrenia are biological mothers. This finding is also in line with results from other similar studies, which revealed that most family caregivers of people with schizophrenia are biological mothers (Bademli et al., 2018; Yazıcı et al., 2016). Like other developing countries, in Indonesia, women are seen as natural caregivers (Attepe Özden & Tuncay, 2018; Nuraini et al., 2021a). Furthermore, this study has revealed some common caregiving issues experienced by the family caregiver in providing care support for a family member with schizophrenia. In general, caregivers of family members with schizophrenia revealed that they lacked assistance in caring for their family members with schizophrenia. More specifically, the lack of care assistance includes a lack of social service, lack of financial aid, and lack of help from professional health workers. This finding is in line with previous studies, which revealed that family caregivers of patients with schizophrenia experience a lack of support in caring for their family members who have schizophrenia (Chen et al., 2019; Shiba et al., 2016).

Furthermore, financial support is a common problem experienced by family carers of someone with schizophrenia in Indonesia. It can be explained based on the findings in this study which revealed that almost all family caregivers in this study did not have a job and were old. Furthermore, this study also found that some family caregivers lost their jobs or could not continue their business ventures due to care responsibilities that required them continuously to stay home to supervise their family members with schizophrenia. The previous study supported this result and mentioned that most caregivers were widows, low-income families, unpaid people, and unemployed (Ran et al., 2017). Most families with someone who suffers from schizophrenia experience financial hardship due to high medical costs for patients and low family income (Chen et al., 2019; Nuraini et al., 2021b). The findings of this study revealed that family caregivers of people with schizophrenia were less likely to receive assistance in providing care support for their family members with schizophrenia. It could be due to the majority of the family influencers of people with schizophrenia in this study were biological mothers, whereas, in Indonesian culture, a mother is more responsible for caring for her family while her husband plays a role in earning a living to meet the needs of her family. Besides that, stigma from the surrounding environment can also be another factor that causes family caregivers to lack social support in providing care assistance to family members with schizophrenia (Subu et al., 2023). Therefore, help, in this case, is social support in providing care to someone who has schizophrenia is something vital (Yu et al., 2020). Sharing the task of providing care assistance with other family members can be an alternative to alleviating the burden of care experienced by family caregivers in people with schizophrenia (Shiba et al., 2016).

Furthermore, the caregiver's responsibilities caused the caregiver to several experienced losses in their lives. Loss is commonly expressed by caregivers while taking care of their ill relatives in Indonesia. The sadness occurred when the caregivers felt they were in isolation. The caregivers feel isolated because they have to spend much time, energy, and patience for years to deal with the caregiving process of the patient with schizophrenia (Wan & Wong, 2019). Furthermore, the care responsibilities may give the caregivers limited leisure time, limited social life, and difficulties engaging with hobbies or pursuing a better future. These restrictions can isolate caregivers from previous, current, and potential social and emotional support sources and restrict their opportunities to relax and engage in hobbies (Mandani et al., 2018). This finding is similar to the previous study that found that caring responsibilities, as well as time and energy spent in caretaking, can result in loss of social networks, loss or reduced time spent in paid work, changes in family roles, and decreased time spent in self-care and leisure activities (Rahmani et al., 2019).

Loss among caregivers increases adverse outcomes by cutting them off from potential support and assistance social participation and may lead them to poor quality of life. Medication compliance is needed to prevent the disease recurrence, although the drugs consumed by patients sometimes cause side effects that make patients uncomfortable. In this study, the caregivers revealed that helping clients take medication regularly at home is their most complicated task. Moreover, the caregivers also mentioned difficulties in helping stabilize the clients' psychotic symptoms. In line with a previous similar study, it was found that dealing with patient's aggressive behaviour, non-adherence to taking medication, difficulty communicating with patients, coping with drug side effects, and inability to handle and recognize patient's relapse symptoms were common caregiving problems experienced by family caregivers of someone living with schizophrenia (Purba, 2017). In addition in other studies found that, delays in recognizing the state of mental health conditions of family members who have schizophrenia are caused by family caregivers who do not understand the signs and symptoms of schizophrenia (Stanley & Balakrishnan, 2023).

According to the findings of this study, the researchers formulated several suggestions that could be used as a basis for health policymakers and health professionals to improve mental health services in Indonesia. First, as an effort to increase the number of visits in the utilizing of health services by patients and their families in healthcare facilities, relevant parties must expand health insurance coverage for chronic mental illness and provide more disability income support and accessible financial protection for patients with severe mental illness as an essential preventive measure. As well as mentioned in the existing literature that income support and economic security, including expanding the directory add more proportions to replace the cost of inpatient and rehabilitation, free medical fees, and simplify the application protocol effectively in promoting health professional seeking among people with schizophrenia and the family (Chen et al., 2019).

Secondly, To facilitate integrated individual treatment, from specialist institutional care to community-based care, the Indonesian government must provide more resources with sustainability (Chang et al., 2018). Our study explores caregivers' views of psychiatric community rehabilitation needs, consistent with the final result of previous studies in China society (Tsui & Tsang, 2017). Strengthening the main mental health care management system that has been running may be another critical step towards transferring mental disease care processes based on community-based rehabilitation services, which are generally lower than inpatient care costs and allow better geographical access (Lamb et al., 2015). In addition, providing more assistance for community care, such as training more community care workers and establishing an effective referral process, should be undertaken by relevant policymakers. In addition, policymakers should allocate more resources for public attention (Tsui & Tsang, 2017)

Third, the Indonesian government must carry out public mental health promotion programs through various information media, such as digital or print media, and formulate health regulations related to anti-discrimination to protect patients and their caregivers from explicit discrimination in society. In addition, providing equal opportunities to the sufferers and the families, like ordinary people, to have participated in many social agendas is a significant effort to reduce discrimination between them (Chien et al., 2014). Fourth, policymakers related to mental health must involve families in formulating healthcare plans for patients with mental disorders. In addition, health workers must be able to analyse and understand the critical role of the family in providing services to patients with mental disorders. Therefore, both must build a positive reciprocal relationship to improve the quality of mental health services. Mental health professionals and policymakers should better assist and utilize family members in managing and providing care for people with schizophrenia (Ran et al., 2017).

This study also has limitations. This study was not conducted in multiple areas, including urban or sub urban, and a small sample size of this study might not fully represent Indonesia's general views of the family caregivers experience in providing care for someone who has schizophrenia. Furthermore, further research is highly recommended to explore the critical factors that influence the attitudes and decisions of family caregivers in seeking and providing health services for family members with schizophrenia. In addition, the research area also needs to be expanded to include rural and urban areas to obtain more prosperous and more in-depth data. Therefore, research findings can be carried over to an entire representative population.

CONCLUSION

The results of this study showed that caregivers of families with long-term schizophrenia in Indonesia were experiencing several difficulties in caregiving. Our study supported the importance of Health professionals such as nurses understanding the caregiving experience of the family caregiver of someone with schizophrenia at home. Therefore, health service institutions and local health offices must pay more attention, especially in formulating health policies related to more effective and quality mental health service programs. Furthermore, related parties must ensure the sufficiency's of health professionals and medication to help family caregivers optimize their roles in providing care assistance for family members with schizophrenia in Indonesia.

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