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Original Research

Navigating Survival: A Phenomenological Exploration of Families Caring for Schizophrenia Patients during Pandemic

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A B S T R A C T

The role of the family in caring for individuals with schizophrenia is crucial, particularly in providing emotional support, monitoring treatment, and assisting with daily activities. This involvement inevitably leads to care burden, which can result in inadequate care during the pandemic. This study aimed to explore how families adapted to caring for a family member with schizophrenia during the pandemic. This qualitative study employed a phenomenological approach and was conducted in East Java, Indonesia. The participants included seven family members who provided care for individuals with schizophrenia within their households; none of the participants were related to each other. Data were collected through semi-structured, in-depth interviews and analyzed using interpretative phenomenological analysis (IPA). Four main themes were found by the thematic analysis, including: 1) Feeling an excessive burden of caring; 2) Hoping for the recovery of schizophrenia patient; 3) A sense of responsibility to continue caring for schizophrenia patient (core theme); 4) Trying to survive in caring for schizophrenia patient during the pandemic. The findings suggest that nurses can help alleviate family caregiving burdens through targeted interventions such as Community Mental Health Nursing and Psychosocial Mental Health Support, crucial strategies for maintaining family well-being and preventing patient relapse.

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INTRODUCTION

Schizophrenia is a heterogeneous global problem, having different impacts depending on age group, type, and management of incidents in each country (Crespo-Facorro et al., 2021). It is a chronic mental disorder characterized by distortions in thinking, perception, emotion, language, sense of self, and behavior, affecting approximately 24 million people worldwide, or 1 in every 300 individuals (0.32%). People living with schizophrenia often

experience significant functional impairments, making the role of the family vital in supporting their recovery, improving productivity, and preventing stigma and discrimination. (World Health Organization, 2022). The role of the family in caring for schizophrenia patients is importance, particularly in providing emotional support, monitoring treatment, and assisting with daily activities (Caqueo-Urízar, Rus-Calafell, Urzúa, Escudero, & Gutiérrez-Maldonado, 2015; Hu et al., 2025). This involvement inevitably leads to care burden, which can result in inadequate care (Ilmy, Noorhamdani, & Windarwati, 2020; Setiawati, Sawitri, & Lesmana, 2021). Numerous studies emphasize that families are not only the primary source of emotional and instrumental support for individuals with mental health conditions but also serve as the largest group of informal care providers in the community (Gutiérrez-Maldonado & Caqueo-Urízar, 2007; Stuart, Keliat, & Pasaribu, 2016). Moreover, patients and their families are classified as a group that is vulnerable to psychological problems during the current pandemic (Keliat et al., 2020).

One of the most pressing challenges for families of individuals with schizophrenia is the ability to maintain continuity of care and treatment adherence in times of crisis (Kalayci, Uzunaslan, & Uzunaslan, 2023). The difficulties encountered during such periods often require families to adapt, which in turn affects their functioning and the patient's recovery (Chien et al., 2006; Darban, Mehdipour- Rabori, Farokhzadian, Nouhi, & Sabzevari, 2021). The subjective experiences of both patients and their families are closely tied to how they adapt to challenges, which is shaped by the various social determinants of mental health they encounter. These determinants include factors such as income, employment status, socioeconomic background, education, food security, housing quality, social support networks, experiences of discrimination, childhood adversities, and the characteristics of the neighborhoods in which they live (Kirkbride et al., 2024). The pandemic directly disrupted many of these determinants, thereby indirectly impacting the quality of care provided by families.

Although the pandemic has ended, it significantly altered family dynamics, requiring families to profoundly adapt and strengthen their resilience in response to the changes they experienced (Gayatri & Irawaty, 2022). In Indonesia, the collectivist culture places a strong emphasis on the family's role in providing care for members who are ill, which exemplifies culturally sensitive patient-centered care. (Cipta et al., 2024). Families are therefore expected to be adaptable to varying and often sudden changes in circumstances, including the transition from wellness to illness and the recurrence of symptoms associated with relapse (Fitryasari, Yusuf, Nursalam, Tristiana, & Nihayati, 2018). Previous research has demonstrated that a comprehensive under-standing of schizophrenia, encompassing its prognosis and treatment, can enhance family management during the caregiving process. This knowledge can alleviate the burden of care, even amidst changing global conditions (Ilmy, Windarwati, Noorhamdani, & Wijaya, 2022).

This study aims to explore how families in East Java adapt to caring for a family member with schizophrenia during the COVID-19 pandemic. The results of this study are expected to provide insights into the needs and support required by families, as well as provide information for policymakers and mental health professionals in designing appropriate interventions for them. Additionally, by grounding research in the cultural context of East Java, this study contributes to the global understanding of schizophrenia care in times of crisis. These findings can help in developing more effective and culturally sensitive strategies to support families in their role as primary caregivers for individuals with schizophrenia, especially in crisis situations such as the COVID-19 pandemic.

METHOD

Study Design

This qualitative research uses a phenomenological approach to understand how different people perceive and interpret life experiences (Creswell, 2015). This study was conducted in the East Java Provincial Health Office's jurisdiction from November 2020 to February 2021. According to the 2018 National Health Research data, the prevalence of households with members diagnosed with schizophrenia/psychosis in East Java was 6.4 per thousand, which is lower than the national prevalence (Badan Litbangkes Kemenkes RI, 2018).

Study Participants

The study involved seven family members who served as caregivers to individuals diagnosed with schizophrenia (see Table 1). Inclusion criteria were: 1) Aged 26 – 65 years; 2) Family members who provide care for schizophrenia patients, reside in the same household, and share a familial relationship through blood ties; 3) Having a family member diagnosed with schizophrenia (F.20) exhibiting positive symptoms; 4) Healthy physically and mentally; and 5) Able to communicate well in two directions with researchers. Participants were selected using a snowball sampling technique, beginning with recommendations from the mental health program's nurse manager. Initial participants then referred other eligible caregivers who met the inclusion criteria. Prospective participants who meet the inclusion criteria may be excluded (exclusion) if they resign during the research process. Participant criteria were confirmed with data from the primary care facilities in the area where the prospective participant resided.

Table 1. Demographic Characteristics of Family Caregivers of Patients with Schizophrenia

Participant	Age	Sex	Marital Status	Relationship with Patient	Patient		
					Age	Sex	Duration of illness (year)
P1	65	Female	Married	Mother	34	Male	5
P2	61	Female	Widower	Mother	28	Female	3
P3	65	Male	Married	Father	39	Male	4
P4	58	Male	Married	Father	25	Male	3
P5	60	Female	Widower	Mother	32	Male	6
P6	59	Female	Married	Mother	28	Female	4
P7	63	Female	Married	Mother	27	Male	3

Data Collection

The first author conducted data collection using a semi-structured in-depth interview approach, serving as the main instrument in the study. The validity of the researchers (two researchers as interviewers) was supported by their educational background, mental health expertise, and familiarity with the research setting. Additionally, the reliability of the researcher was ensured through the use of detailed field notes and high-quality recording equipment (voice recorder in smartphone). Maintaining both validity and reliability is essential to minimize potential bias in research findings, as the data collection process involves formulating questions, actively listening, and observing participants' behaviors throughout the interviews.

Interviews were conducted in participants' neighborhoods in a setting made as conducive and comfortable as possible. The interviews was carried outwith interview guidelines and use Indonesian (participants are allowed to answer in Javanese if they have difficulty expressing themselves in Indonesian), which included a) The ability and process of families caring for schizophrenia patients before the pandemic; b) Family efforts in caring for patients during the pandemic, both to meet basic needs and treatment; c). The role of community leaders, cadres, and community leaders in caring for schizophrenia patients; d) social, economic, and emotional conditions felt by families during the pandemic; and e) Family expectations during caring for schizophrenia patients during the pandemic. The researcher met with the participants in two meetings, namely 1) The first meeting was to build relationships, explain the purpose of the study, and give informed consent; 2) The second meeting was in-depth interviews (one meeting without additional interviews), followed by giving appreciation to participants who have been willing and taken the time to be interviewed (recommendations for fulfilling the respect for persons aspect in research ethics). The interview lasted 30-40 minutes. Before interviewing family members, the interviewer asked for background information about the patients and their caregivers (age, gender, marital status, type and duration of illness). During the interview process, researchers utilized field notes to document events pertinent to the interview, based on observations (such as nonverbal movements, environmental influences, and facial expressions). Interviews were transcribed and analyzed on the same day.

Data Analysis

Data analysis employed Interpretative Phenomenological Analysis (IPA), a qualitative methodology designed to explore how individuals make sense of their experiences (Smith, Flowers, & Larkin, 2009). The interview transcripts were reviewed, coded, and organized into emergent themes aligned with the study's objectives. Initial coding was carried out by the primary researcher, followed by collaborative discussions among the research team to refine interpretive validity. Regarding translation, the original verbatim quotes were carefully translated into Indonesian by bilingual researchers proficient in both languages. To enhance the credibility of findings, *data source triangulation* was conducted by involving nurses from primary care facilities and relevant community stakeholders in validating and confirming the emerging themes. In this manuscript, selected participant quotes are presented to illustrate each theme and have been translated into English for clarity.

Ethical Clearance

This study has been declared ethically feasible by the Health Research Ethics Committee, Faculty of Medicine, Universitas Brawijaya, with the number 120/EC/KEPK-S2/06/2020. The researchers adhered to key ethical principles, including respect for human dignity, beneficence, non-maleficence, and justice throughout the study.

RESULT

Based on the results of data analysis conducted through in-depth interviews with families who provide care for schizophrenia patients, four distinct themes have been identified, namely: 1) Feeling an excessive burden in caring during the pandemic; 2) Hoping for the recovery of schizophrenia patients; 3) A sense of responsibility to continue caring for schizophrenia patients; and 4) Trying to survive in caring for schizophrenia patients during the pandemic. Each theme is described as follows:

Theme 1: Feeling an excessive burden of caring

This theme is compiled based on family statements regarding the burden felt to be increasing during the COVID-19 pandemic. This theme is compiled based on two conditions, namely feeling anxious during the pandemic and increasing financial burden during the

pandemic. In the context of anxiety, families experience anxiety due to various situations. The primary concern is the lack of understanding regarding the COVID-19 virus. Furthermore, the anxiety stems from the apprehension associated with the various signs and symptoms of COVID-19, which may result from infection.
"Sure thing, but I'm not sure what the corona virus is all about. It seems like no one here has gotten it. They just told me to be careful and take care of myself. Well, it's not really visible." (P3)
"Yes, actually I'm worried, there was an appeal from the village officials, like a runny nose, shortness of breath, fever, cough, shortness of breath due to corona. Yesterday I had a fever, sir. I was confused but fortunately now I'm healthy, sir, maybe I was tired yesterday" (P6)

The anxiety experienced by the family causes the family not to travel outside the home. The statement that shows this is as follows.
"During the pandemic like this, I'm worried about going anywhere, I'm afraid that I'll get infected and it will be a burden on my family later" (P4)
"Hopefully the corona pandemic can be finished soon, so that you are not afraid to go anywhere. Yes, hopefully you don't get infected, because if you get infected, it will add to the burden" (P5)

This can be interpreted as the family's desire for the COVID-19 pandemic to conclude swiftly, compounded by anxiety stemming from their apprehension of contracting the virus and exacerbating their existing burden. Furthermore, the family experienced anxiety related to the schizophrenia patient's condition during the COVID-19 pandemic, as elucidated in the following quote:
"We are worried that if corona is like this, we won't be able to survive. Everything is difficult. Moreover, my child needs treatment." (P4)
"Yes, I'm afraid that my child will suddenly relapse during a corona pandemic like this, who will help" (P3)

In addition to the psychological impact of anxiety, families are also experiencing the growing economic strain caused by the pandemic. Researchers interpret this subtheme as negative feelings resulting from the economic burden, primarily attributed to the implementation of restrictions that have led to a decrease in family income.

"The family income decreased, there was little work because of the pandemic. We had to borrow money from our neighbors to meet our daily needs" (P1)
"If it continues like this, we will definitely run out of money. Yes, expenses continue but there is no income. So where does the income come from? In a pandemic like this, we can't work" (P2)

Theme 2: Hoping for the recovery of schizophrenia patients
This theme is compiled based on several family statements in expressing family expectations for schizophrenia patients. Families want schizophrenia patients to recover as before even though it takes a long time. Shown by the following statements:
"Yes, my hope is that the child can recover and work again. If he recovers, it can improve the family's economy. I want to work again to help out my former employer. (P1)
"I hope my child gets better, sir. Yes, I totally get it if the condition is like this… I understand, sir, that mental illness can take a while to heal. (P5)

Families want schizophrenia patients to recover. When the patient recovers, the family has the hope of being able to live normally, as before having a family member with a mental disorder.

"I used to think it was wrong to have a child with a mental disorder, sir. I was really hurt when I found out that my son was the same age as his friends. I often felt jealous of the neighbors who seemed to have normal lives." (P6)
"Yes, I hope he can recover and work again. If he recovers like before, it can lift the family's economy. I will work again like before." (P7)

Theme 3: A sense of responsibility to continue caring for schizophrenia patients
This theme is formed based on family statements that lead to a sense of responsibility that the family has to continue caring for schizophrenia patients. Being responsible means being obliged to bear everything as a form of the role of the caregiver family. The family stated that they maintain a sense of patience in meeting basic daily needs. Shown by the following statements:
"Of course, the most important thing is to take care of him every day. His needs are met, because he's our precious child and we're his parents." (P3)
"Yes, I provide food and drinks every day.." (P1)
"But we do have to be patient, the hard part is that the child gets hungry easily. So the child keeps asking for food, until sometimes the food runs out. When he is hungry, he often screams. Especially during the pandemic, it was difficult for me to get my daily needs." (P5)
"Yes, if he wants to urinate or defecate, I will tell him to leave the room, rather than being careless. I unlocked it so I wouldn't do it in the room." (P7)

The family also considers that the treatment given is given every day. The statement shows the following:
"Yes, I gave him the medicine, he just had to wait patiently, if the medicine doesn't work, the child won't be able to sleep." (P2)
Families feel a sense of responsibility to safeguard schizophrenia patients and those in their vicinity. In this context, protection entails mitigating changes in patient behavior that may occasionally become uncontrollable.
"I tag along with him when he's out and about in front of the house. Sometimes, I can't help but worry about his little one, instead of him throwing a tantrum later. So, I guess I'll just have to keep an eye on him." (P2)
"So that it doesn't get worse, I put him in a room, so he doesn't wander everywhere and doesn't disturb the surrounding environment." (P4)
"I decided to talk to the neighbors, who might understand. Basically, I told everyone, especially those close to me, that my son was still mentally ill." (P3)

The family tries to adjust to the condition and treatment of schizophrenia patients. Adjusting is a family effort to successfully overcome the needs of conflict, tension, and frustration experienced. The family also states sincerity in carrying out treatment and forgives all mistakes that have been made. Shown by the following statements:
"Of course, sir. While I was taking care of him, I couldn't help but think about him. I forgave his mistakes as long as I was treating him with genuine care.

Yes, he's also family, sir. He deserves to be treated with sincerity." (P6)
"When I feel angry, I try to calm down because I don't want to let my emotions get the best of me and cause my child to act out." (P5)
The statement proves that the family adapts by not scolding and being patient in caring for them. The family realizes that scolding schizophrenia patients can reduce the mental health of schizophrenia patients.

Theme 4: Trying to survive in caring for schizophrenia patients during the pandemic

This theme is based on family statements regarding their efforts to survive in caring for schizophrenia patients during the COVID-19 pandemic. This theme is based on three situation, namely trying to maintain the health of family members during the pandemic, continuing to seek care and treatment for schizophrenia patients, and struggling to meet daily needs during the pandemic. First, families are trying to maintain the physical health of family members during the COVID-19 pandemic so that they do not get infected by the coronavirus, as evidenced by the following statements:

"For me, I try to be careful, because yesterday there was a socialization that it was mandatory to wear a mask when leaving the house. So, every time we leave the house we wear a mask. Rather than getting infected. Luckily, there was a distribution of masks yesterday, so we didn't buy them" (P3)

"*Well, basically the effort is to maintain health, me and my child... by eating and drinking enough, getting enough rest. So that we don't get sick easily, sir. Especially during this corona period. Even though it's a bit difficult for me, but it's my duty*" (P5)

Furthermore, the family endeavors to maintain psychological well-being by minimizing excessive stress levels.

"Yes, the same thing, the main thing is not to get stressed, it must be done... they say that if you are stressed, you will easily catch a virus. If the cadre spoke yesterday, if you are stressed, your immune system will easily drop like that" (P1)

Second, their experiences necessitate ongoing care and treatment for schizophrenia patients. Furthermore, families attempt to safeguard schizophrenia patients by instilling fear in them regarding the coronavirus. Furthermore, during the pandemic families have been actively involved in supervising and providing care for schizophrenia patients. These situations are evidenced by the following statements:
"Yes, I told the child that there was a corona virus. I scared him, that if he died from the corona virus, he could die" (P1*)*
"*Yes, whether I like it or not, I have to keep an eye on him at home, I'm afraid of relapsing. Because if I don't take my medication for 10 days, I'm not allowed to go anywhere. But luckily I can still get it from the puskesmas"* (P4)
"Alhamdulillah no, sir. Yesterday I told the posyandu cadre that we needed the medicine. Fortunately, the medicine was delivered by the nurse yesterday, so he didn't stop taking the medicine" (P3)

Third, families struggle to meet daily needs, both for the whole family and for schizophrenia patients. The family showed that the family was in debt and scavenged to get money to meet daily needs. In addition, the family received help from people around them. The help was received considering that the family had to survive during the COVID-19 pandemic.

"Yes, there is, yesterday the market was quiet because of corona, so I had no income, so I had to look for loans, so I had time to scavenge, to eat" (P2)
"Yes, what is surprising is that the neighbors still remember us. Yes, they helped us, we were given masks and food. Yes, everyone is feeling the hardship during this corona, so maybe it's a form of mutual assistance" (P3)
"Yes, Alhamdulüilah, I'm happy, I received the assistance yesterday, I was given basic necessities, yes money. Hopefully it can help, it's really hard during this pandemic" (P4).

The researchers concluded that the core theme of this phenomenon is "a sense of responsibility to continue caring for schizophrenia patients." This theme reflects how the family's sense of duty serves as the foundation for their ability to adapt while providing care during the COVID-19 pandemic. All participants expressed hope for the recovery of their family members with schizophrenia, highlighting the mental resilience of caregivers. Given that schizophrenia is a chronic condition that can persist for many years, families tend to develop a deeper understanding of the caregiving process and have long held hope for some degree of recovery.

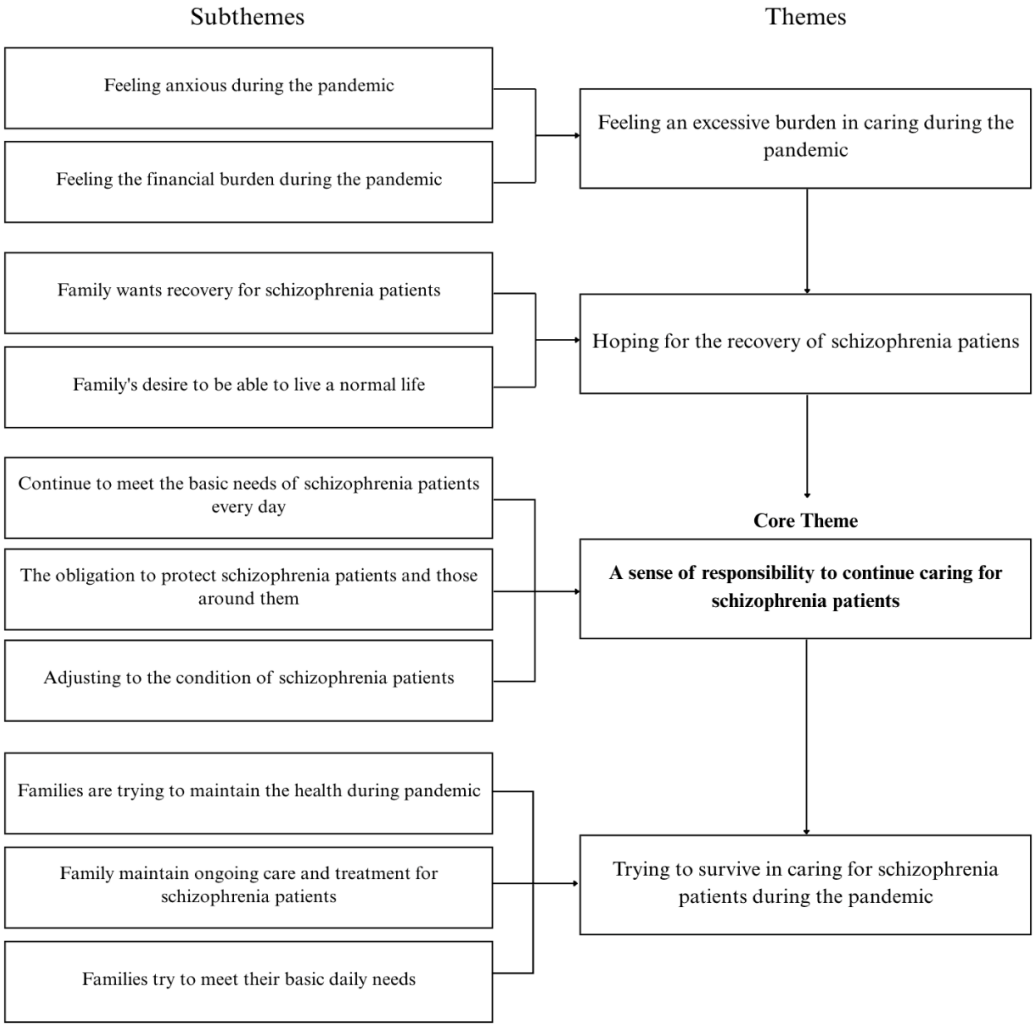

Figure 1. The development of themes and the connections between these themes in the phenomena

DISCUSSION

The primary theme identified in this study was "A sense of responsibility to continue caring for schizophrenia patients," which emerged as the most dominant theme across participant narratives. Through analyzing how families fulfilled their caregiving responsibilities during the pandemic, we found that this sense of responsibility encompassed providing for patients' basic needs, protecting both the patient and the family, and adapting to the specific challenges of caring for individuals with schizophrenia. This sense of duty often motivates caregivers to persist despite emotional and physical exhaustion, highlighting their resilience in managing complex care demands. Resilience, in this context, emerges as a multifaceted response to the burdens of caregiving, shaped by a variety of interrelated psychological, social, and environmental factors (Teahan et al., 2018). Families often develop coping strategies, such as seeking emotional support, relying on religious or cultural beliefs, and accessing community-based resources to manage their stress (Awad & Voruganti, 2008). The COVID-19 pandemic exacerbated these challenges by limiting access to mental health services and social support systems, thus increasing the reliance on family caregivers as the main source of care (Ali & Kumar, 2023). A thorough understanding of these dynamics is essential for healthcare professionals in designing interventions that effectively support both patients and their caregivers.

The unprecedented challenges posed by the pandemic have necessitated diverse strategies employed by families to ensure their survival and continued care for schizophrenia patients, maintaining the pre-pandemic level of support and assistance. In this study, families reported maintaining their physical and psychological health, continuing treatment despite limitations, and striving to meet daily needs under difficult economic conditions. This demonstrated their psychological resilience, a key factor in their ability to withstand sustained stress and adversity (Teahan et al., 2018). Resilience empowered them to manage emotional strain and physical fatigue, allowing them to continue caregiving despite limited resources and increased isolation (Geschke, Steinmetz, Fellgiebel, & Wuttke-Linnemann, 2024; Yates & Mantler, 2023). Moreover, social support and accessible mental health services were cited as critical to enhancing their adaptive capacity during the crisis (Bjorlykhaug, Karlsson, Hesook, & Kleppe, 2022; Snoubar & Zengin, 2022).

Based on these findings, we recommend the development of targeted interventions to foster psychological resilience among caregivers, regardless of professional background or sector.

Mental health nurses play a central role in building the capacity of families to care for individuals with schizophrenia. The implementation of Community Mental Health Nursing (CMHN) is a crucial component in enhancing the family's capacity to provide care for individuals with schizophrenia. Mental health nurses implement early detection activities, direct care, counseling, and education to address the challenges faced by families caring for schizophrenia. Related to family adjustments to the pandemic situations, two themes related to the experience of families caring for schizophrenia patients during the COVID-19 pandemic (feeling an excessive burden during the pandemic and trying to survive in caring for schizophrenia patients during the pandemic) have proven that families feel an additional burden that can lead to a relapse in schizophrenia patients. The findings of this study can serve as a foundation for mental health nurses to provide Psychosocial Mental Health Support (PMHS) to families caring for schizophrenia patients, such as providing counseling and establishing mutual support groups (Lohrasbi, Alavi, Akbari, & Maghsoudi, 2023). This activity seeks to enhance both physical and mental resilience within the community, making it of paramount importance for nurses at the primary care mental health service to provide PMHS and reduced demands on secondary care services (Kenwright, Fairclough, McDonald, & Pickford, 2024; Thongsalab, Yunibhand, & Uthis, 2023).

This study has limitations. It focuses exclusively on the perspectives of parents caring for children with schizophrenia, which frames caregiving within a traditional parent-child dynamic. While this viewpoint captures an important caregiving context, it does not reflect the broader diversity of caregiving relationships, such as those involving spouses, siblings, or adult children. These alternative dynamics could influence role shifts and familial relationships in different ways (Kaakinen, Coehlo, Steele, & Robinson, 2018). Future research should therefore consider a wider range of caregiver roles to better understand how family structures and responsibilities impact caregiving experiences.

CONCLUSION

Based on the findings of this study, a sense of responsibility to continue caring for schizophrenia patients emerged as the core phenomenon enabling families to navigate the caregiving experience during the pandemic. Researchers have discovered that families in Indonesia cultivate a culture of responsible care, regardless of the health status of their sick relatives. Clearly defined expectations and intentions in providing care for schizophrenia patients contribute to more effective family management and help mitigate the perceived burden of caregiving.

It is crucial for nurse to provide comprehensive education regarding the disease and appropriate care guidelines, particularly when families are responsible for the patient's care within their home environment. In addition, the establishment of support groups can facilitate the exchange of experiences among families, empowering them to cope with the psychological stressors associated with caregiving and ultimately improving the overall quality of care. The findings obtained can serve as a foundation for conducting further research on the adaptation of families in caring for schizophrenia patients, both quantitatively and qualitatively. Moreover, the Health Office is encouraged to offer comprehensive community-based mental health training to nurses at primary care facilities, ensuring that schizophrenia cases are appropriately identified and managed across the province.

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CONFLICT OF INTEREST

There is no conflict of interest

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