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ORIGINAL RESEARCH

'It's like living in hell' – Caregivers' Experiences for Patients with Schizophrenia in a District of Probolinggo

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ABSTRACT

Background: Schizophrenia frequently results in significant distress and impairment across multiple domains, including personal, familial, social, educational, and occupational functioning. Caregiving for individuals with schizophrenia can result in substantial stress and burden for caregivers. **Objective**: This study aims to explore the experiences of caregivers in providing care for patients with schizophrenia in a district of Probolinggo. **Material and Method**: This study employed a qualitative research design, used interviews as the data collection method, and analyzed the data using inductive thematic analysis. **Results**: The objective experiences comprised three main themes: (a) caregiving activities, (b) challenges encountered in caregiving, and (c) changes in caregivers' lives following the caregiving role. The subjective experiences consisted of four main themes: (a) caregivers' emotional experiences during patient care, (b) caregivers' perceptions of the illness, (c) positive meanings derived from the caregiving experience, and (d) caregivers' expectations for the patient. **Conclusion**: Based on the findings of this study, caregivers experience a wide range of situations while caring for individuals with schizophrenia.

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Highlights

1. Caregivers experience a wide range of situations while caring for individuals with schizophrenia;
2. Two categories were identified in caregiving experience: objective and subjective experiences.

BACKGROUND

Although schizophrenia is often discussed as a single disorder, it is more accurately understood as a heterogeneous group of disorders with diverse etiologies. Patients with schizophrenia show considerable variability in clinical presentation, treatment response, and illness course. The signs and symptoms are diverse, encompassing disturbances in perception, emotion, cognition, thought, and behavior (Boland, Verduin and Ruiz, 2022).

Schizophrenia frequently results in significant distress and impairment across multiple domains, including personal, familial, social, educational, and occupational functioning (World Health Organization, 2025). Schizophrenia not only affects the individuals who experience the disorder but also has a significant impact on caregivers or family members who provide care (Shalahuddin *et al.*, 2025). Due to the various clinical manifestations exhibited by individuals with schizophrenia, patients are often unable to live independently (Samuel, Thomas and Jacob, 2018). When a person is diagnosed with schizophrenia, family members or caregivers play a crucial role in supporting the patient's daily functioning, as several aspects of life are disrupted by the illness (Bademli and Lök, 2020). For families already facing various daily challenges that affect all aspects of their lives, having a family member with severe mental illness can have a substantial impact on the entire family system (Khatimah *et al.*, 2022; Gagiu *et al.*, 2025).

Caregiving for individuals with schizophrenia can result in substantial stress and burden for caregivers. Recent studies have shown that caregivers experience multidimensional challenges while providing care, including physical, psychological, social, and economic difficulties (Sustrami *et al.*, 2024; Shalahuddin *et al.*, 2025). It has been observed that the majority of caregivers experience emotional exhaustion like feelings of sadness, hopelessness, helplessness, discomfort, uncertainty, anxiety, anger, despair, and fear (Bademli and Lök, 2020; Syarif *et al.*, 2025). From an economic perspective, as many individuals with schizophrenia are unable to work to meet their living needs, they often depend on their caregivers for financial support. A substantial portion of the economic burden borne by caregivers is allocated to treatment-related expenses (Makanjuola and Ngcobo, 2025b). A large proportion of caregivers indicated that they personally financed unreimbursed care-related expenses for individuals with schizophrenia, particularly food, transportation, and clothing. (Krasa *et al.*, 2025). Some caregivers reported difficulties in convincing other family members that the patient was ill, leading to family conflicts, reduced family involvement in care, and strained relationships, which negatively affected family cooperation and future planning (Pan *et al.*, 2024). Several caregivers reported significant changes in their own lives, including feelings of being 'trapped' in the caregiving role, experiencing social isolation, and perceiving their standard of living to be lower than that of others (Makanjuola and Ngcobo, 2025a). Many caregivers also described experiencing physical exhaustion, fatigue, burnout, and psychological pressure related to the continuous demands of caregiving (Sánchez-Martínez, Cauli and Corchón, 2024). A significant proportion reported disrupted and poor-quality sleep, often attributable to being awakened during the night to attend to the patient's needs, which is associated with increased caregiver burden and distress (Tumanggor and Marhamah, 2021).

In this context, this qualitative study aimed to explore caregivers' perceptions of schizophrenia and their roles as caregivers, as well as to provide in-depth insights into their feelings, thoughts, and experiences.

To achieve this aim, the study sought to address the following research questions:
a. How do caregivers perceive the patient's illness?
b. What has been the experience of being a caregiver for a person with schizophrenia?
c. What challenges have caregivers encountered while caring for the patient?

Surabaya Medical Journal (SMJ IDI SBY)
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d. What feelings or emotions have caregivers experienced while providing care?
e. How has caregivers' life changed since beginning to care for a person with schizophrenia?
f. What positive meanings or lessons have caregivers gained from caring for a person with schizophrenia?
g. What are the hopes and expectations for the patient with schizophrenia under your care?

OBJECTIVE

This study aims to explore the experiences of caregivers in providing care for patients with schizophrenia in a district of Probolinggo

MATERIAL AND METHODS

Study design

This study employed a qualitative research method because the researcher aimed to understand the experiences of individuals who care for patients with schizophrenia. This study employed a phenomenological research design, in which the researcher describes individuals' lived experiences of a particular phenomenon as conveyed by the participants (Creswell and Creswell, 2018).

Data collection

This study used interviews as the data collection method. The interviews were conducted with informants to obtain descriptions of their experiences in caring for patients with schizophrenia. This study employed a semi-structured interview approach, which allows greater flexibility than structured interviews (Sugiyono, 2013). The purpose of this approach is to openly explore emerging issues and enable informants to express their views freely

Data analysis

The data analysis technique used in this study was inductive thematic analysis. A study is considered inductive when the researcher does not limit the investigation to confirming or rejecting predetermined assumptions, but instead seeks to understand how a situation comes to occur (Poerwandari, 2007)

Ethical consideration

Ethical approval for this study was obtained from the National Unity and Political Agency of Probolinggo Regency (Badan Kesatuan Bangsa dan Politik Kabupaten Probolinggo), ensuring that the processes of data collection and analysis were conducted in accordance with ethical standards for the use of primary data

RESULTS

In reference to the 4 participants in this study, the majority of the respondents were aged 30 - 55 years old. The majority of the participants have been treating for more than 1 year. In this study, two overarching categories were identified: objective and subjective experiences. The objective experiences comprised three main themes: (a) caregiving activities, (b) challenges encountered in caregiving, and (c) changes in caregivers' lives following the caregiving role. The subjective experiences consisted of four main themes: (a) caregivers' emotional experiences during patient care, (b) caregivers' perceptions of the illness, (c) positive meanings derived from the caregiving experience, and (d) caregivers' expectations for the patient.

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Objective Experience

Caregiving Activities

Practice of physical restraint

Some caregivers decided to physically restrain or confine the patient (*pasung*) due to concerns for both the patient's safety and their own, as the patient frequently displayed anger and engaged in destructive behavior toward the surrounding environment.

> "Eventually, my younger sibling (the patient) was beaten. It was like this in the past—as if he had been done something wrong. Because he is my sibling, I could not bear to see him treated that way by outsiders, so I restrained him with chains." (C1)
>
> "When he began to lash out, restraint was applied. He physically assaulted the family" (C3)

Seeking spiritual treatment or a religious leader (*Kiai*)

Several caregivers reported seeking spiritual or religious treatment, including consultation with a religious leader (*kiai*), as part of the patient's care.

> "Initially, we relied solely on spiritual treatment..." (C2)
>
> "We frequently consulted a *kiai*..." (C3)
>
> "Initially, the patient complained of stomach pain, after which he was taken to consult a kiai. He stayed there at the kiai's place. When we came to pick him up, his condition had already become like that..." (C4)

Seeking medical treatment

Several caregivers reported seeking medical help from a village nurse or obtaining medication from the local primary health care center (*Puskesmas*).

> "Then we went for treatment at the *Puskesmas Kuripan*. We pursued both medical treatment and visits to a *kiai*. He improved for about four months; after receiving medication, he stopped talking excessively." (C3)
>
> "After 27 days of being ill, I took him to seek treatment from Mr. E, the village nurse." (C4)

Challenges Encountered in Caregiving

Patient's Bath

Some caregivers reported difficulties in assisting patients with bathing. In some cases, caregivers struggled to persuade patients to bathe, as the patients tended to wander around and spend a long time during the activity, while in other cases, patients refused to be bathed altogether.

> "Asking him to bathe was also difficult. When I told him to do so, he would go to the bathroom, but he appeared restless and kept moving around, taking quite a long time" (C2)
>
> "He had to be bathed, because he was unwilling to be bathed" (C3)

Feeding Patient

Some caregivers experienced difficulties in feeding the patient, as the patient tended to eat excessively and would become physically aggressive if leftover food was taken away.

> "In the past, he never seemed to be full. He would eat, feel hungry again, and eat repeatedly. There was no sense of satiety. If food was available and then taken away, he became angry and would immediately hit others. Nothing seemed to work." (C3)

Complying with the Patient's Demands

The caregiver admitted the difficulties in complying with patients' frequent requests to go outside or leave the house.

> "For me, the most difficult part is when the patient insists on going out or walking somewhere; in such situations, I have to give in to their wishes. That is what I find most confusing." (C4)

Changes in Life Following the Caregiving Role

Informants' lives changed after assuming caregiving responsibilities; some had to work to meet their family's financial needs, while others made efforts to continue working despite the patient's condition being difficult to leave unattended.

> "Our daily needs were supported by Mr. M (the patient). I was not permitted to work and was expected to take care of my mother and the household" (C3)

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> "Yes, if I did not work, how could we manage? I was so busy that I did not have time to bathe, only to perform ablution (*wudhu*). Yes, that's right—I sometimes did not even have time to eat." (C4)

Subjective Experience

Caregivers' Emotional Experiences during Patient Care

A wide range of emotions characterized caregivers' daily experiences while providing care, including fear, feeling burdened, a sense of affection, compassion, and acceptance, annoyance, sadness, discomfort, and sometimes emotional numbness. One caregiver described experiencing significant emotional distress, characterized by deep sadness and discomfort because of the aggressiveness.

> "I felt like crying; he was constantly aggressive, and it made me feel deeply sad. Being at home felt like living in hell. Once, at night while we were sleeping, stones were thrown through the window. My husband was extremely frightened. He was so afraid that he eventually decided to divorce me." (C3)

Caregivers feared that the patient might harm other people and the surrounding environment.

> "The main fear was that he might harm other people, or take other people's motorbike" (C1)
>
> "My former husband was often scolded and physically abused. Eventually, he became fearful, felt unable to endure the situation, and asked for a divorce." (C3)

Caregivers also reported initially being afraid to administer medication to the patient because they had heard rumors that the medication could have harmful side effects.

> "People here said that there were others with similar conditions, and that they were given such medication. They said the medication could cause paralysis or make a person unable to see. That is why I was afraid." (C4)

Caregivers expressed a sense of burden associated with managing the patient's care.

> "It does feel like a burden, but there is nothing else to be done. Perhaps this is a trial I must endure" (C1)

In some cases, caregiving responsibilities were shared among family members, which gave rise to feelings of compassion toward other relatives who were also involved in providing care.

> "Cigarettes and daily food were already provided by my husband and me, so those were not a problem. What I felt sorry for was my mother—her sleep was not normal because she was frequently called by the patient" (C1)

Feelings of acceptance and sincerity were evident among caregivers as they continued to care for the patient and sought ways to facilitate recovery.

> "Perhaps because we are caring for my younger sibling and my father-in-law, my husband and I have learned to accept this sincerely. Maybe God has blessed us with improved economic conditions. So my husband and I never complain; instead, we truly want to help him recover—however that may be possible." (C1)

The informant felt irritated by the way other people perceived the patient's condition.

> "Sometimes I feel irritated by certain people in the neighborhood. I already understand their attitudes. They say things like, 'Why do you let him out?' or 'He shouldn't be allowed to go out.' I tell them that he is not being let loose. Even when he goes out, he is still restrained. But if he were kept inside the house all the time, I would feel sorry for him"

Caregivers' Perceptions of The Illness

One perceived that the patient's illness was caused by cough syrup addiction that later developed into depression.

> "It started with an addiction to cough syrup. In my view, it was depression—stemming from uncontrolled desires. It was truly depression." (C1)

One stated that the caregiver did not know the cause or origin of the patient's illness

> " I do not really understand the illness; I do not have any idea. I only know how it initially began" (C2)

The patient's illness was believed to be caused by environmental pressures, including the presence of spirits and amulets (*jimat*) attached to a tree

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> "Pressure from environmental, perhaps. He would talk about it. According to our neighbors, whenever there were 'spiritual winds,' he became aggressive. They said that if there was an amulet (*jimat*) attached to a tree, he would become agitated. After it was searched for and found, and the amulet was removed, he no longer became aggressive. That is how strongly it was believed. After the amulet was removed, the aggressive behavior stopped." (C3)
>
> "The amulet was hanging from the tops of the trees behind the house. Eventually, all of the trees were cut down, and since then, the patient has never been aggressive and started calming down" (C3)

One perceived the patient's illness as being caused by weak mental resilience and possession by *jinn*, which it was believed could ultimately damage the nervous system

> "His mental strength was weak, and then he was possessed by *jinn*, which, when severe, would to affect the nerve, wouldn't?" (C4)

Positive Meanings Derived from the Caregiving Experience

Caregivers felt that caring for a person with schizophrenia helped them become more patient, sincere, and psychologically resilient.

> "The lesson I have learned is that I must become a more patient person and more resilient." (C1)
>
> "At first, I was impatient, but now I am learning to be patient. At first, I was not sincere, but eventually I became accepting." (C3)

Caregivers also learned to develop a deeper understanding of the patient's condition.

> "I came to understand the situation; at first I did not understand the problem, but over time I gained an understanding of it." (C3)

Several caregivers interpreted their caregiving experience as a form of life trial or spiritual test.

> "There must be wisdom behind this experience. I see this as a test in my life. When others ask how I can remain strong, I tell them that this is simply the trial I have been given." (C4)

Expectations for the Patient

Several caregivers expressed expectations for the patient's complete recovery.

> "My hope is that if the patient recovers, the recovery will be complete, so that they can return to and live again with their family" (C2)
>
> "Someday he can fully recover and return to their previous condition as before" (C4)

One stated the expectation for the patient's work.

> "I really hope he can do his job again, including returning to Jakarta, because financial resources are currently needed." (C3)

The caregiver expressed hope that the patient would eventually recover fully, be able to marry, and have offspring.

> "Who knows, someday he may truly recover, get married, and have children." (C1)

One sees the patient as someone who has potential, so she hopes the patient can help the family business.

> "I think he has some hidden qualities; perhaps he can achieve those potentials. He can help our business and store. I know he was diligent and neat before he got sick" (C1)

DISCUSSION

Based on the data obtained, it can be concluded that being a caregiver for individuals with schizophrenia involves a wide range of life experiences. In general, caregivers' experiences in providing care can be categorized into objective experiences and subjective experiences. According to the *Great Dictionary of the Indonesian Language* (Kamus Besar Bahasa Indonesia), experience refers to events or situations that have been personally encountered. The term *objective* refers to conditions that reflect actual circumstances and are not influenced by personal opinions or viewpoints, whereas *subjective* refers to perspectives or feelings that are personal in nature and not directly related to the factual aspects of a situation (Pusat Bahasa Departemen Pendidikan Nasional, 2008)

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Objective Experience

Objective experiences consisted of patient care practices, the challenges encountered during caregiving, and changes in caregivers' lives after assuming the caregiving role. The care provided by all informants included restraining the patient, seeking spiritual treatment from religious leaders (*kiai*), and accessing medical care through primary health centers or community nurses. In providing care, informants reported difficulties related to bathing the patient, feeding the patient, and complying with the patient's demands. Several informants described changes in their lives after beginning to care for the patient. Some reported that they were previously responsible for managing household duties, but after the onset of the patient's illness, they became the primary income earners. Others reported being able to continue working as usual while simultaneously providing care for the patient.

Based on the data obtained, informants employed various approaches in caring for individuals with schizophrenia. Physical restraint was applied by participants C1 and C3. C1 restrained the patient because the patient frequently wandered around and caused disturbances within the community. The patient had also been physically assaulted by community members, which led C1 to restrain the patient out of compassion. Meanwhile, C3 restrained the patient because the patient frequently caused disturbances and had physically harmed both the informant and the informant's former spouse. This practice is similar to what has been reported in rural areas of Ethiopia, where physical restraint is also used as a means of protecting both the individual and the surrounding community (Asher *et al.*, 2017) In seeking treatment, some informants reported bringing the patient to spiritual healers, such as *kiai*, traditional healers, or religious figures. This practice is closely related to local cultural beliefs, which often interpret such illnesses as being difficult to explain through medical causes alone (Basumatary, Ali and Daimari, 2020). As a result, these beliefs may delay access to formal medical treatment (Aktaş and Ayhan, 2025). Families typically seek biomedical care only after spiritual treatment fails to produce the expected improvement. Although spiritual treatment does not lead to the desired clinical outcomes, these cultural beliefs remain deeply rooted and are not easily changed within a short period of time (Darban *et al.*, 2023)

Caregivers experience various challenges when caring for individuals with schizophrenia. For example, informants reported difficulties in assisting patients with bowel care, bathing, and feeding. Such tasks may increase the overall burden experienced by caregivers (Kamil and Velligan, 2019; Vadher *et al.*, 2020). In addition, informants reported difficulties in complying with patients' requests, particularly due to patients' unstable behaviors. These challenges become more burdensome because caregiving activities are carried out over a prolonged period and require substantial physical and emotional energy from caregivers (Tamizi *et al.*, 2020).

Since caring for a family member with schizophrenia, informants reported experiencing significant changes in their lives, particularly in economic conditions and in the role of the main income earner within the family. One informant stated that they had taken over the patient's role as the primary breadwinner in order to meet the family's financial needs. Other studies have similarly reported that the illness of a family member requires families to manage their finances independently and strive to meet their own needs without relying on external assistance. Informants who reported continuing to work while simultaneously providing care described this as an effort to fulfill the family's economic demands (Darban *et al.*, 2021). Nevertheless, other studies indicate that economic conditions may deteriorate due to reduced work productivity while caring for a person with schizophrenia, which constitutes an indirect economic burden of caregiving (Xu *et al.*, 2019). A recent comparative study reported that caregivers of patients with schizophrenia experience reduced work productivity, lower health-related quality of life, and significant burden relative to non-caregivers, including impacts on work and finances (Kojima *et al.*, 2024)

Subjective Experience

Subjective experiences refer to experiences that are shaped by an individual's personal perspectives, feelings, or opinions, rather than by objectively measurable facts. In this study, subjective experiences comprise four main themes: (1) emotions experienced while caring for the patient, (2) informants'

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perceptions of the patient's illness, (3) positive meanings or lessons derived from the caregiving experience, and (4) expectations toward individuals with schizophrenia.
A wide range of emotions emerged as informants cared for individuals with schizophrenia. Informants reported experiencing fear, feelings of burden, compassion, acceptance, irritation, sadness, discomfort, confusion in providing care, feelings of being a burdened caregiver, and at times emotional numbness. These emotions arose as a result of the burdens associated with caregiving and are commonly experienced by other family members who share responsibility for caring for individuals with schizophrenia. Feelings of loneliness, suffering, and fear have been reported when caregiving responsibilities are assumed by family members (Lima and De Andrade Lima, 2017). Other studies have similarly shown that most caregivers of individuals with schizophrenia experience negative emotions such as feeling overwhelmed, stressed, chronically fatigued, burdened, frustrated, angry, depressed, or anxious (Brain *et al.*, 2018).

Informants held diverse perspectives regarding the condition of patients with schizophrenia. This variation is presumed to stem from the persistence of cultural beliefs within the community that associate mental illness with local customs and traditional explanations. Some informants believed that the patient's illness was caused by addiction to cough medicine and depression, while others attributed it to environmental factors, the presence of talismans, weak mental resilience, or possession by jinn that eventually damaged the patient's nerves. Additionally, some informants demonstrated limited understanding of the patient's illness. Research conducted by Igberase and colleagues indicates that many communities continue to believe that schizophrenia is caused by supernatural factors such as curses or witchcraft, sorcery, reincarnation, divine will, or the work of evil spirits (Igberase and Okogbenin, 2017). Similarly, other studies report that mental illnesses such as schizophrenia are often perceived as being caused by spirit possession, jinn, or evil forces (Subu *et al.*, 2022). These beliefs subsequently influence help-seeking behavior, leading families to seek spiritual or traditional treatment before accessing medical services (Darban *et al.*, 2023). However, some scholars argue that such community perceptions may arise because individuals with schizophrenia do not receive appropriate medical treatment at an early stage (Kurihara *et al.*, 2006; Negash *et al.*, 2023; Tyagi *et al.*, 2023)
Informants reported gaining meaningful insights (*hikmah*) through the process of caring for patients with schizophrenia. Various forms of positive meaning were described, such as having opportunities to develop patience, learning to become more resilient and sincere, perceiving the patient's illness as a form of life trial, and gaining a deeper understanding of the patient's condition and illness. Other studies have shown that in difficult circumstances, families caring for individuals with schizophrenia are able to become more patient, courageous, and surrendered to God. Beginning with more positive perceptions, families may develop more positive behaviors. The formation of meaning or positive aspects in caregiving is important, as it serves as a foundation for building resilience, personal strength, and positive cognitive changes (Fitryasari *et al.*, 2019; Asgari *et al.*, 2025; Tailaiti *et al.*, 2025).
Each informant expressed specific hopes for the person with schizophrenia under their care. Some caregivers hoped that the patient would recover, be able to marry and have a family, maximize their abilities and potential, return to work as they had before the illness, and regain their former productive life. Caregivers' expectations toward patients with schizophrenia tend to be modest and realistic. Such expectations are often adopted as a strategy to reduce the level of stress experienced during caregiving (Pan *et al.*, 2024). Various forms of hope also function as coping mechanisms that help caregivers manage the burden associated with providing long-term care for individuals with schizophrenia and help reduce the negative emotion induced by caregiving (Issac, Yesodharan and Sequira, 2023; Liu *et al.*, 2025).

Limitations

This study did not explore in detail how psychosocial, environmental, and cultural contexts interact in shaping caregivers' experiences. Future research may seek to examine these dimensions more comprehensively to provide a deeper understanding of caregiving dynamics.

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CONCLUSION

Schizophrenia is a complex disorder that profoundly affects the lives of those who experience it. In their daily lives, individuals with schizophrenia are often highly dependent on caregivers who live with them. Based on the findings of this study, caregivers experience a wide range of situations while caring for individuals with schizophrenia. Caregivers experienced diverse emotional responses, including fear, burden, sadness, discomfort, irritation, compassion, acceptance, and emotional numbness. Their perceptions of schizophrenia were also influenced by varying levels of understanding and cultural and spiritual beliefs regarding the causes of mental illness. Objective experiences may subsequently shape and give rise to subjective experiences. By understanding both the objective and subjective experiences of caregivers of individuals with schizophrenia, this study is expected to contribute to improving knowledge and caregiving practices for patients with schizophrenia.

Conflict of Interest

The author declares no conflict of interest

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None

Ethical Clearance

This study received ethical approval from the National Unity and Political Agency of Probolinggo Regency (Badan Kesatuan Bangsa dan Politik Pemerintah Kabupaten Probolinggo) with the certificate number: 000.9.4/319/426.102.03/2025

Author Contribution

TMAM : draft preparation, editing, data curation, translating, data analysis. SA : data analysis

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