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Original Research

Illness perception and healthcare-seeking behaviour among people with schizophrenia and their caregivers: A qualitative study

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Abstract

Objective: This study explored the perception of illness and health care-seeking behaviour from the perspective of people with schizophrenia and their caregivers in the Indonesian cultural context. **Methods:** A qualitative study was employed, using in-depth interviews, in the southern areas of Kalimantan, Indonesia. The qualitative data were analyzed using inductive content analysis. **Results:** Participants perceived schizophrenia as a result of diverse factors, including drug abuse, depression, stress, spiritual possession, black magic, and neurological disorders. These perceptions were influenced by participants' beliefs, religions, social norms, local culture, and information provided by clinicians. The patterns of healthcare-seeking behavior were similar in the first psychosis episode and during relapse. The severity of symptoms, whether classified as mild or severe, affected their healthcare-seeking behaviour. When symptoms were considered mild, they chose self-medication or alternative treatments. However, if symptoms were severe or life-threatening, patients were directed to seek assistance from healthcare centers. During relapses, the recurrent patterns of health care-seeking behaviour persisted, with the caregivers' capacity to recognize symptoms significantly influencing this continuity. **Conclusion:** participants' unfamiliarity with the term "schizophrenia" is indicative of a knowledge gap. Moreover, to manage the symptoms and provide quality care, an intervention is necessary to improve the patient and caregiver's knowledge of schizophrenia.

Keywords: schizophrenia, psychosis, perception, health care-seeking behaviour, recurrence

INTRODUCTION

Schizophrenia is a severe mental disorder characterized by disruptions in cognitive processes, perceptions, emotional responses, and social interactions that are genetically or environmentally influenced.[1,2] Globally, an estimated 24 million individuals are affected by schizophrenia, positioning it among the top 20 contributors to years lost due to disability.[3,4]

The primary therapeutic approach for managing schizophrenia involves the administration of antipsychotic medications, necessitating prolonged adherence to a medication regimen. Non-adherence to antipsychotic therapy represents a substantial challenge in people with schizophrenia.[5,6] This lack of adherence contributes to various adverse outcomes, including relapses, heightened severity of symptoms, re-hospitalization, an increased risk of mortality,[7] and an increased burden on medical expenses.[8]

Illness perceptions refer to the cognitive constructs representing patients' beliefs regarding the physiology of a disease, its symptoms, medical conditions, and associated health threats. These beliefs play an important role in their behavior and the ultimate outcomes of therapeutic interventions.[9] The adherence to prescribed medication and treatment regimens is intricately linked to individuals' illness perceptions.[7] Variations in interpreting one's illness can significantly impact emotional and behavioral responses. Individuals tend to interpret their illnesses differently, subsequently influencing their emotional and behavioral reactions. The sources of information about the disease contribute to shaping cognitive and emotional forms, culminating in the development of a particular perception. The formation of this perception serves as the first step in an individual's coping process, delineating how they manage the illness and approach seeking treatment.[10]

Healthcare-seeking behavior refers to individuals' actions to address their health concerns by actively seeking medical treatment. This behavior exhibits complexity in Indonesia, attributed to the nation's multicultural and ethnically diverse population.[11] Culture plays a pivotal role in shaping attitudes towards health and illness, influencing how individuals conceptualize illness, seek medical care, perceive healthcare providers, and accept medical interventions.[12] Given this intricate cultural backdrop, it becomes imperative to study

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the sociocultural dimensions of mental illness within local contexts. Such an investigation facilitates the development of socially and culturally relevant actions or strategies in providing mental health services. An in-depth exploration of how patients perceive their illness, coupled with understanding societal attitudes and beliefs, becomes instrumental in formulating interventions. This knowledge serves as a foundation for promoting effective treatment modalities and enhancing medication adherence among individuals grappling with schizophrenia in the Indonesian context.

METHODS

Study design

The study employed a qualitative descriptive approach, utilizing semistructured in-depth interviews. This study was conducted and reported according to the Consolidated Criteria for Reporting Qualitative Research.[13]

Participants

The study employed purposive sampling as a sampling method, and it was guided by the principle of selecting respondents most likely to provide relevant and valuable information.[14] The study respondents were recruited from Sultan Suriansyah Hospital in South Kalimantan Province. The researcher established inclusion and exclusion criteria to guide the selection process. Collaborating with a psychiatrist from the hospital, potential respondents meeting the research criteria were identified. The participants encompassed individuals diagnosed with schizophrenia themselves or, alternatively, their caregivers. The inclusion criteria specified that participants must have received a diagnosis of schizophrenia from a psychiatrist using the DSM-V criteria, possess the ability to comprehend information and respond to questions in either Indonesian or the local ethnic language, and express a willingness to participate in the study by providing informed consent.

Conversely, individuals with organic brain disorders and cognitive impairments were excluded from participation. Following the application of these criteria, the researcher (first author) explained the study's objectives to the patients or their accompanying family members during treatment at the hospital. Subsequently, eleven participants expressed their consent to partake in the study and were interviewed at their respective homes at agreed-upon times.

Study settings

The interviews were conducted at the participants' residences in Banjarmasin, in the southern province of Kalimantan, Indonesia. Banjarmasin is one of South Kalimantan's cities characterized by a diverse and multi-ethnic population, including the Banjar, Dayak, Javanese, Batak, Bugis, Madurese, Sundanese, and others. The city's context is significantly shaped by the presence of a river, serving as a cultural and civilizational focal point. The cultural tapestry and traditions of the Banjar people have evolved through centuries of assimilation, with a notable influence from Islamic beliefs introduced by Arab and Persian traders. The Banjar customs ingrained in the social fabric of the community, imbued with Islamic characteristics, endure through time. This cultural amalgamation is evident in the daily life activities of the residents, ultimately shaping their attitudes, beliefs, and understanding of health.

Ethics approval

This study received ethical approval from the Medical and Health Research Ethics Committee (MHREC), Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, as indicated by EC approval No. KE/FK/1565/EC/2022. In addition, research approval letters were issued by *Badan Kesatuan Bangsa dan Politik Kota Banjarmasin* and Sultan Suriansyah Hospital. Participants were provided with comprehensive information about the study's objectives, along with their entitlement to decline participation without any adverse impact on the care they received. To safeguard the privacy of participants, all personal information was anonymized. Following this detailed explanation, participants provided verbal consent for their involvement in the study. As a token of appreciation, each participant received an alarm pill box after completing the in-depth interview. This compensation was offered in acknowledgment of their valuable contribution to the study.

Data collection

The researchers had no direct relationship with the participants to ensure the reliability of the data collection process. Interviews were conducted at a time convenient for the participants. Before commencing the interview process, the researcher asked for background information from both patients and their caregivers, encompassing details such as age, gender, education, employment status, and the duration of the illness. Demographic data were systematically collected and summarized, with results presented in Table 2. Subsequently, the researcher, serving as the first author, conducted the interviews during the period of January to February 2023, involving three distinct meetings with the participants. The first meeting was dedicated to establishing rapport, explaining the study's objectives, and obtaining informed consent from the participants. The second meeting

Table 1: Semi-structured form for in-depth interviews (translated)

Number	Questions
1	How would you describe your condition/illness?
2	What do you think is the cause of your condition/illness?
3	Can you describe your experience managing your condition/disease the first time the symptoms of this disease appeared?

comprised the in-depth interview sessions, conducted in the local language. The interviews, guided by a semi-structured questionnaire (refer to Table 1), spanned a duration of 30 to 60 minutes, were recorded, and subsequently transcribed in Bahasa Indonesia. The transcripts were anonymised prior to analysis. Interviews continued until data saturation was reached. Throughout the interviews, the researchers diligently took field notes to document events related to the interview process, including participant-delivered observations such as non-verbal movements, environmental influences, and facial expressions. The third meeting served as an opportunity to assess the patient's condition and their family's well-being. A reminder pillbox was provided during this meeting as a gesture of appreciation for their participation. This token of appreciation acknowledged their contribution and aimed to potentially enhance medication adherence by providing a practical tool for managing their medicines.

Data analysis

The transcripts underwent qualitative inductive content analysis for analysis. In order to enhance the trustworthiness of the findings, the categories and their content were systematically reviewed by the second, third, and fourth authors. Comprehensive discussions involving all authors were conducted to finalize the coding process, ensuring a collective and thorough examination of the data.

RESULTS

Participant characteristics

Eleven people with schizophrenia, accompanied by their family members serving as caregivers, actively participated in the in-depth interviews. The socio-demographic and disease-related characteristics of these participants are detailed in Table 2. The average age of the 11 participants was 36 years, with an age range spanning from 24 to 57 years. The participant group consisted of five men and six women. In terms of educational attainment, three out of the 11 participants were high school graduates, while four out of the 11 participants were self-employed. Regarding the duration of illness, five individuals had an illness duration of less than 10 years (ranging from 3 to 9 years), while the remaining six participants had an illness duration exceeding 10 years (ranging from 12 to 25 years).

Illness perception

The content analysis of the data revealed two major themes: causes of illness and symptoms of illness. The subsequent description outlines these themes, accompanied by illustrative examples of patient responses.

Theme 1. causes of illness

The perceptions of patients and their caregivers regarding the causes of schizophrenia encompassed a spectrum of factors. Notably, both groups identified illicit drugs, spiritual influences, socioeconomic factors, infectious diseases, and individual or emotional factors as potential contributors to the onset of schizophrenia.

Among the eleven participants, two individuals, specifically Participant No. 1 and Participant No. 11, attributed drug abuse as a cause of schizophrenia. Participant No. 1 initially lacked awareness regarding the causes of their child's illness. However, upon receiving information from a healthcare professional, the family came to understand and acknowledge that their child's schizophrenia was linked to drug abuse. Participant No. 11, on the other hand, acknowledged a personal connection between his history of frequently using illegal drugs and the subsequent manifestation of schizophrenia symptoms. The participant reflected on his past engagement in drug use,

Table 2: Patient and their caregiver Characteristics

Participant No	Age	Gender	Job status	Education	Duration of illness (years)	Caregiver involved and their Relationship with patient	Caregiver's job status
1	30	Male	Unemployed	Primary school graduate	3	Mother	Unemployed
2	55	Female	Unemployed	High school graduate	25	Husband	Unemployed
						Daughter	Employed
3	24	Female	Unemployed	College dropout	5	Husband	Employed
4	57	Female	Unemployed	Primary school graduate	12	Daughter	Employed
5	26	Female	Self-employed	High school dropout	7	Mother	Self-employed
6	37	Female	Unemployed	High school dropout	15	Husband	Employed
7	29	Male	Self-employed	High school dropout	12	Mother	Unemployed
8	36	Female	Unemployed	High school dropout	15	Mother and sister	Unemployed
9	49	Male	Unemployed	High school graduate	15	Mother	Unemployed
10	27	Male	Self-employed	College dropout	9	Father	Unemployed
						Mother	Employed
						Aunt	Unemployed
11	29	Male	Self-employed	High school graduate	8	Wife	Unemployed

noting the emergence of symptoms coinciding with this period of substance abuse.

'The doctor said my brother's illness was due to drugs.' (P1)

'My illness is due to drugs; I have been a drug abuser in the past.' (P11)

The findings from the interviews revealed that four participants held the perception that their illness was attributable to spiritual causes. According to these participants, the manifestation of their illnesses was believed to be linked to supernatural forces, including spirits, witchcraft, and demonic powers.

'The disease came from my school. Sometimes, it is like a whisper. There was a supernatural being; I felt someone calling at the window, but when I opened the window, there was no one.' (P6)

'Many people said that my illness was caused by witchcraft.' (P4)

'It's easy for demons to enter her mind because she likes to daydream. Her emotions tend to intensify during full moons.' (P5)

'We initially thought that she was possessed by the spirit of an ancient pet within her body.' (P8)

Another spiritual perspective was expressed by Participant No. 10, who attributed their child's illness to the will of God. In this view, the participant perceived the onset of the illness as a divine decree.

'I am sure that my son's illness is God's will.' It is changing my pattern of life, a warning from God for me.' (P10)

The development of schizophrenia is frequently associated with socioeconomic factors, including poverty and family conflicts, which can contribute to heightened levels of interpersonal conflict.

'Due to issues with her father, we divorced, and it became a burden on her mind.' (P5)

'Since the divorce occurred in his household, he often daydreams, talks to himself, daydreams, and then his brain is disturbed.' (P9)

As reported by a participant, information provided by a doctor indicated that infection could be one of the factors contributing to the development of schizophrenia.

'The doctor once suggested that there may have been an infection during gestation.' (P10)

Several participants identified individual or emotional factors as potential causes of schizophrenia. These factors encompassed conditions such as stress, depression, anxiety, feelings of loneliness, burden of thoughts, and introverted personality traits.

'The doctor at that time said that our mother's illness was because she was experiencing depression.' (P2)

'I often feel anxious, stressed out, and lonely, particularly after the passing of my baby.' (P3)

'I am experiencing a condition where I am unable to control my thoughts, especially when I begin to overthink.' (P6)

'Overthink and an introverted personality may have caused this illness, and finally, I heard voices.' (P10)

Significantly, none of the participants, whether individuals diagnosed with schizophrenia or their caregivers, employed the term "schizophrenia" in describing their experiences. Furthermore, their perceptions of illness did not align with Western biomedical conceptualizations of schizophrenia.

Theme 2. symptoms of illness

Participants in the study define illness primarily by describing the symptoms they experience. Their understanding of their health conditions does not rely on clear identification of specific disease names; instead, they attempt to perceive and articulate their illnesses based on the symptoms they have encountered.

'Since the second pregnancy, he started behaving differently, throwing things, and even attacking me.' (P1)

'He appeared as if someone was talking to him. Sometimes, he looked out the window and in the mirror. There are many people, he said.' (P7)

'One month before I heard the sounds, I had a headache that felt like my brain was working hard.' (P10)

Help-seeking treatment behavior

The data analysis yielded two broad and interconnected themes: the course of the disease and the severity of the symptoms. Figure 1 illustrates the observed patterns of help-seeking behavior among people with schizophrenia during the first episode of psychosis and subsequent relapse episodes.

During the first episode of psychosis, distinct patterns of seeking treatment emerged, influenced by the perceived severity of the symptoms. Mild symptoms were characterized by manifestations such as difficulty sleeping and anxiety, which were deemed non-potentially harmful to the patients, their families, or others in their vicinity. Conversely, severe symptoms were defined by manifestations considered harmful to the well-being of the patients, their families, or those around them. Within the first episode of psychosis, there was variability among patients, with some exhibiting mild symptoms while others presented with more severe conditions.

During the first episode of psychosis characterized by mild symptoms, families often refrained from seeking formal treatment, either due to a lack of understanding of the patient's illness or a desire to manage the symptoms independently. In some instances, families attempted self-medication by purchasing over-the-counter medications from a pharmacy to address the patient's mild symptoms. Alternatively, seeking assistance from health workers, commonly referred to as *mantri* by the local community, was another avenue pursued. In addition, families explored alternative healing practices, consulting individuals known as *orang pintar* or *tuan guru*,

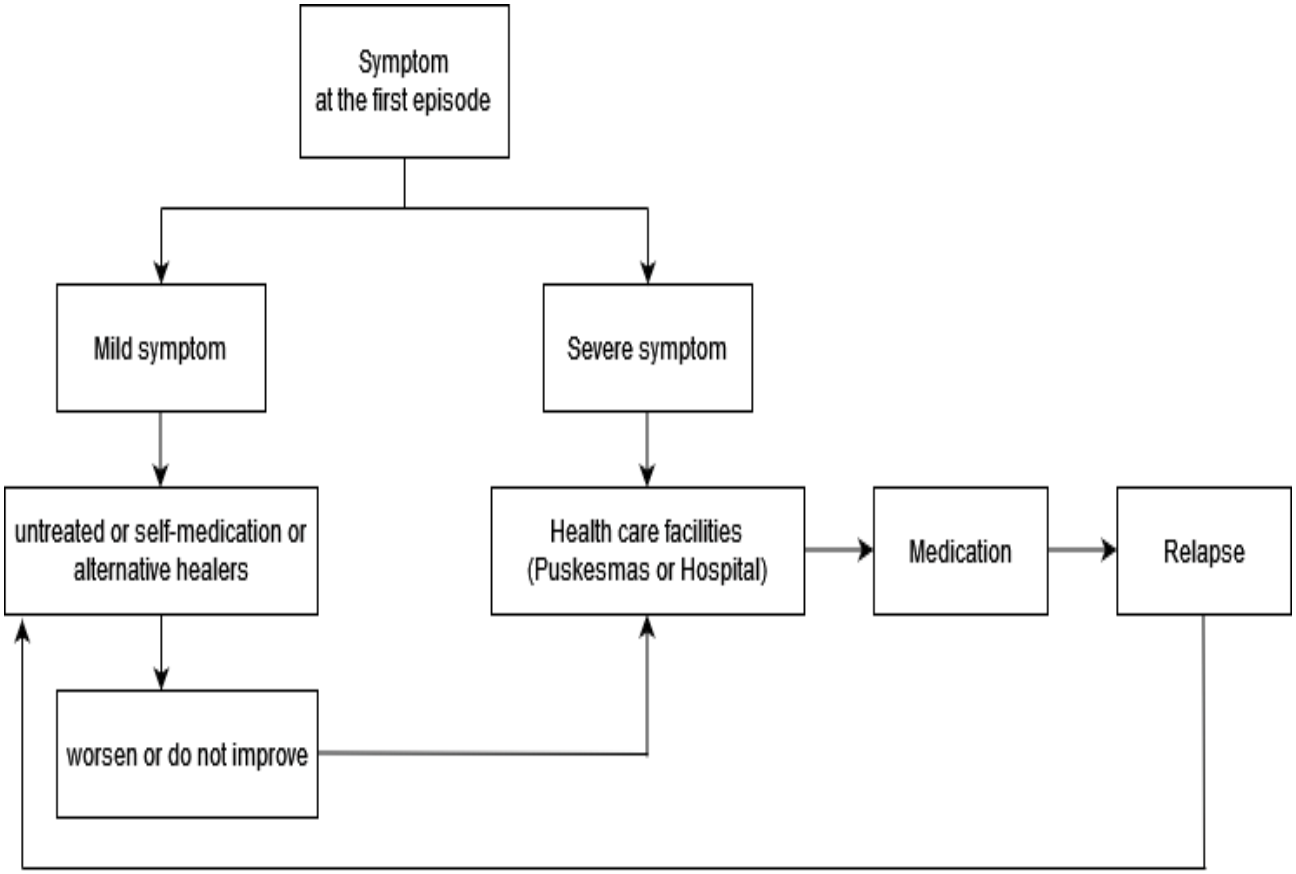

Figure 1. Pattern of help-seeking treatment behavior of people with schizophrenia

believed within the local community to possess the capability to facilitate healing.

Cultural and religious practices played a significant role in the help-seeking behavior. Some individuals turned to Islamic treatments, employing methods such as *ruqyah*, believed to be effective in expelling supernatural entities like *Jinns*, demons, or *sihr* (black magic or witchcraft) from the patient's body. Others sought treatment by visiting a temple, driven by the local belief in the supernatural powers of the temple to bring blessings and healing to those who visited.

'We did not treat her at first. We thought she was emotionally angry because we could not fulfil her wishes.' (P5)

'In the past, my mother was treated with some alternative like *ruqyah, prayed water from orang alim*, and was also taken to the 'candi agung' temple.' (P2)

'When the symptoms first appeared, I was taken for treatment by a 'tuan guru'; after a relapse, I was taken for treatment to the primary health service (Puskesmas) and finally advised to be treated in a hospital.' (P3)

'At first, my husband took me to *orang alim* and *orang pintar* for treatment.' (P4)

'Seeing and feeling strange, at first we just asked a prayered water from *tuan guru* and bought medicine at the pharmacy so he could sleep, then went to the *mantri* to treat him.' (P7)

As the symptoms of the people with schizophrenia worsened and failed to show improvement, the family's perspective on seeking formal healthcare evolved. In cases where the symptoms became more severe or posed a risk to the patient and those around them, the family took more decisive action. With input from neighbors or relatives, the family eventually opted to seek professional medical treatment at healthcare facilities such as *puskesmas* (community health centers) or hospitals.

'My brother had become violent at the moment, threw things around the house and was immediately taken to the hospital.' (P1)

'My family was advised to take me to the hospital because my condition was out of control and not like most individuals generally.' (P6)

'At first, she could not sleep and was restless; we (the family) just kept quiet, wondering what was wrong? over time, her behavior got worse until finally, she hit and kicked her Mother. Finally, we took her to the hospital. '(P8)

During relapsing episodes of psychosis, the pattern of seeking treatment continued to be contingent on the perceived severity of the symptoms experienced by the patient. In

cases characterized by mild symptoms, the family often faced challenges in identifying the indicators of relapse, leading to delayed or no immediate treatment. However, as the family began to suspect a recurrence of symptoms similar to the first episode, they initiated self-medication by purchasing drugs from a pharmacy. Only when the symptoms escalated and failed to improve did the family decide to seek professional medical care at a hospital. Conversely, when severe symptoms manifested during relapse and were readily recognized by the family, a more decisive approach was taken. In such instances, the family promptly decided to take the patient to the hospital.

'We didn't recognize the symptoms of his recurrence. So, we tried treating it ourselves by purchasing medicine from a pharmacy to help him sleep. We also tried alternative treatments, but there was no improvement. Finally, we consulted a doctor at the hospital.' (P7)

DISCUSSION

The study findings revealed that participants lacked familiarity with the term "schizophrenia" and, instead, constructed their understanding of the illness based on personal experiences. Despite efforts by doctors to provide information about the disease, the participants expressed difficulty comprehending the concept clearly. The information received from healthcare professionals often centered around symptoms and causes experienced by the patient rather than a comprehensive understanding of schizophrenia as a distinct mental health condition. Consequently, participants may not grasp the full scope of what schizophrenia entails and might perceive individuals in mental hospitals as merely experiencing stress or depression.

The study reveals that participants held diverse perceptions of schizophrenia, perceiving it as stemming from illicit drugs, spiritual causes, socioeconomic factors, infectious diseases, and individual or emotional influences. Importantly, people with schizophrenia in many local communities face stigmatization and are often labeled as individuals experiencing stress, possession by jinn, influence of black magic, lacking faith, or even referred to as 'mad.' These societal labels impact both the individuals with schizophrenia and their caregivers, influencing their perception of the condition. This finding aligns with previous studies conducted in various countries, indicating that community members, including patients and caregivers, commonly attribute the causes of schizophrenia to traditional beliefs or supernatural forces. These may include notions such as God's will, demon possessions, bewitchments, curses, and punishment for sins.[15–17]

The findings from a study conducted in Suzhou and Siping cities in Jiangsu and Jilin Provinces, China, align with the observations in the present study. Very few patients with schizophrenia or their family members in the Chinese study considered biological factors as the primary cause of schizophrenia. Instead, the majority attributed the cause of schizophrenia to social, interpersonal, and psychological problems; even when asked, none of the respondents considered schizophrenia a "brain disease".[18] This perspective resonates with another study, which reported that patients and their relatives attributed the causes of schizophrenia to factors such as life circumstances, biological or natural causes, genetics, and drugs.[16,19,20]

There are notable differences in the perceptions of schizophrenia between developing and developed countries. Generally, in countries with Eastern cultures, the signs and symptoms observed in people with schizophrenia are more frequently associated with spiritual or supernatural conditions. In contrast, Western societies tend to attribute hallucinations and delusions to mental illness that requires immediate treatment.[21] For instance, a study in Ghana revealed that a substantial majority (94%) perceived schizophrenia as being caused by witchcraft or evil spirits, and a significant portion (66%) believed it to be a result of divine punishment.[17] In Ethiopia, perceptions regarding the causes of schizophrenia included religious factors, drug misuse, poverty, and punishment for sins or wrongdoings.[15,16,22] Conversely, in Western countries, the focus often centers on biological factors such as genetics, brain disease, and infection. In addition, social risk factors, including personal weaknesses, are emphasized in the understanding of schizophrenia.[23–25]

Illness perception plays a crucial role in influencing a patient's decision to seek treatment and adherence to prescribed treatment.[26] Studies have indicated that patients' and caregivers' beliefs regarding medications and their perceptions of illness significantly impact treatment adherence and decision-making processes related to seeking treatment. The intricate interplay between these beliefs and perceptions can have a profound effect on treatment outcomes.[25]

The findings of this study highlight a delay in the treatment-seeking process during the first episode of schizophrenia. Families, initially unfamiliar with the symptoms, often refrain from seeking treatment. However, as the symptoms persist and are perceived as unusual, families or caregivers tend to opt for self-medication or alternative therapies before considering treatment at health facilities. The preference for alternative treatments is influenced more by the beliefs prevalent in the local community than by medical recognition of the disease.

This pattern aligns with studies conducted in other regions, such as southwest Ethiopia, where traditional healers were the primary choice for treating mental disorders, including schizophrenia.[22] Similarly, a qualitative study in the province of Aceh, Indonesia, revealed that families often turn to traditional healers before seeking professional help for mental illnesses.[27] The role of caregivers in deciding where to seek help is crucial. In Indonesia, caregivers commonly seek assistance from alternative healers, such as *paranormal* or *dukun* (traditional healers), or religious figures like *kyai*, *ustadz*, or through *ruqyah* (Islamic religious healing). This tendency to initially explore alternative avenues has been associated with delays in psychiatric treatment and an increased risk of poor prognosis.[28]

The reliance on traditional or religious healers as a primary treatment option for individuals with schizophrenia is not unique to Indonesia. Several studies across different regions have

reported similar patterns. In Hunan Province, China, individuals diagnosed with schizophrenia commonly turn to nonmedical options for help, including seeking support from their families, engaging in Buddhist prayers, and consulting traditional and/or religious healers.[29] Similarly, in the southeastern region of Nigeria, research has shown that individuals who attribute the occurrence of schizophrenia to supernatural and magical explanations are more inclined to seek faith healers as their primary treatment choice. This preference contrasts with those who adhere to naturalistic explanations for the condition.[30]

Previous studies have consistently identified multiple factors influencing treatment-seeking patterns in patients with schizophrenia. Key factors include a lack of knowledge about schizophrenia and its treatment, stigma and cultural beliefs, limited access to care, and financial considerations. These factors often interact with one another, creating a complex web of influences that collectively shape general perceptions and attitudes about mental illness and the decision-making process for seeking treatment.[29,31–33]

The first influencing factor identified in this study is the level of education, a variable significantly associated with help-seeking behavior.[34] The study's results indicate that individuals with a lower level of education are more inclined to seek treatment from non-healthcare professionals when symptoms first appear or during relapses. The majority of respondents in the study exhibited a relatively low level of education, and their initial choice for treatment involved non-healthcare professionals. The decision-making process for seeking treatment was also influenced by local culture and the community's understanding of the symptoms. Notably, only one patient in the study was directly taken to the hospital by their family, guided by the advice of other families with healthcare workers at a hospital. The recommendation for immediate hospital treatment prompted this family's decision to seek professional medical care for the patient.

The study by Wong et al. (2020) revealed that overt symptoms of schizophrenia did not necessarily motivate families or caregivers to seek professional help. Instead, these individuals encountered barriers that hindered their access to professional assistance, contributing to a lack of knowledge about schizophrenia. This deficiency in understanding within families and caregivers prevents them from recognizing the symptoms of schizophrenia during the first episode, as the significant behavioral changes exhibited by individuals with schizophrenia are often misconstrued or overlooked. The lack of awareness regarding these behavioral changes as symptoms of a mental disorder can lead to delays in seeking treatment.

In the case of relapse, the lack of knowledge about schizophrenia, particularly the signs and symptoms of relapse, poses a challenge for identifying these indicators in people with schizophrenia. Therefore, it becomes imperative for families or caregivers to possess adequate knowledge about schizophrenia, including a comprehensive understanding of its signs, symptoms, and appropriate treatment strategies. This knowledge serves as a critical predictor of prognosis during the first episode of psychotic disorders. The ability to recognize mental illness has significant implications, as it facilitates timely and appropriate help-seeking behaviors. This, in turn, holds the potential to enhance outcomes for individuals with mental illness.

The second influential factor identified is stigma, and its correlation with knowledge is noteworthy. A previous study explained the correlation between the adequacy of knowledge and the level of stigma. Caregivers with sufficient knowledge and a low level of stigma tend to actively facilitate professional help-seeking. Conversely, individuals are less inclined to seek professional help when they lack knowledge about mental illness, even if their level of stigma is low. The study's results also indicated that a lower tendency to seek professional help is observed when an individual has insufficient knowledge coupled with a high level of stigma. Moreover, the findings suggested that a high level of knowledge about schizophrenia does not necessarily translate to a high propensity to seek professional help if the individual still has a high level of stigma.[33]

The societal stigma that labels people with schizophrenia as 'crazy' has a profound impact, leading to resistance within families or caregivers. This resistance manifests in a reluctance to seek treatment from health professionals, as individuals may continue to hold onto the belief that schizophrenia can be cured through alternative medicine. This phenomenon is particularly pronounced in Banjarmasin, where the Islamic beliefs strongly influence the culture

Access to medical services and associated costs are the last factors influencing the decision to seek help for treatment among individuals diagnosed with schizophrenia and their caregivers, particularly in low and middle-income countries. A study conducted in China by Hu et al. (2021) highlighted that 30% of individuals diagnosed with schizophrenia in the study population refrained from seeking professional help due to limited access to medical care. This problem is also attributable to the limited understanding of family members or caregivers about how to access care for schizophrenia. In situations where families or caregivers lack knowledge about the appropriate healthcare facilities for a patient, they often rely on information provided by relatives or neighbours, seeking alternative options for therapy. The high costs of medical treatment are a substantial barrier for patients seeking immediate help at healthcare facilities. Moreover, the absence of health insurance exacerbates this issue. Consequently, families and caregivers frequently opt for alternative treatments perceived as more affordable, yet still promising a cure.

Family members play a crucial role in the therapy and support of individuals with schizophrenia. Studies conducted in various countries, including China, southern India, and Nigeria, consistently highlight the pivotal role of relatives in the initial stages of seeking help for individuals with schizophrenia. In China, relatives were identified as the primary means of support,[29] while in southern India, mothers were often the ones seeking initial treatment.[35] In addition, a study from Nigeria revealed that a substantial majority (91%) of individuals with schizophrenia received assistance from relatives during their

initial efforts to seek treatment.[30]

These studies suggest that relatives play a very important role in the help-seeking behavior of individuals with schizophrenia. Families and caregivers serve as the primary support system, providing direct care to individuals with schizophrenia. Equipping families and caregivers with knowledge related to schizophrenia and its treatment becomes paramount, as they become integral targets for interventions in the healing process of individuals with schizophrenia. Several studies consistently demonstrate that the active involvement of family members or caregivers significantly contributes to enhancing a patient's overall functioning, improving quality of life, and promoting adherence to recommended therapies. This involvement, in turn, reduces the likelihood of relapse.[36,37]

CONCLUSIONS

The findings of this study emphasize the significance of people with schizophrenia and their families constructing illness concepts within the framework of their personal narratives, influencing their treatment-seeking behavior. In light of these insights, it becomes imperative to develop effective psychoeducational interventions aimed at enhancing their understanding of schizophrenia and its treatment.

AUTHOR'S CONTRIBUTION

The roles and contributions of the authors in this study are delineated as follows: NC played a pivotal role in conceiving and designing the study, acquiring and analyzing the data, interpreting the results, and drafting the manuscript. AWW, SAK, and JG contributed significantly to the interpretation of the data, critically revised the manuscript for essential academic content, and gave their approval for the final version.

CONFLICT OF INTEREST

None

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