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Navigating care: family information needs and responsibilities in the context of schizophrenia caregiving

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ABSTRACT

Introduction: : Families of schizophrenia patients need to obtain information from health services about how to care for them. Limited information and understanding of responsibilities in caring are still obstacles to becoming an empowered family in caring for patients with schizophrenia. The study aimed to explore family needs regarding information from health services and family responsibilities when caring for patients with schizophrenia.

Methods: This study used a descriptive qualitative design. The study involved families who cared for patients with schizophrenia in Surabaya, Indonesia. Twenty participants were obtained using purposive sampling techniques and the sample size was determined by data saturation. Data were collected using in-depth interviews, field notes and interview question guides. The data were processed with content analysis.

Results: The results showed eight themes. Families need information about patient conditions, medication, routine control, and counseling for patient conditions as well as for families. The family describes the responsibilities carried out for the patient as providing support for patient treatment, fulfilling daily needs, helping with social skills, and providing activities in spare time.

Conclusions: Adequate information from health services regarding both the patient's condition and family counseling can help to meet the demands of care, which stimulates families to be more empowered to carry out care responsibilities and has an impact on the ability to care better

Keywords: counseling, empowerment, family, mental disorder, responsibility, schizophrenia

Introduction

Schizophrenia is a serious mental illness characterized by incoherent thoughts, strange behavior, strange speech, and hallucinations, such as hearing voices, that cause functional disorders in carrying out daily activities (APA, 2020). Schizophrenia is a severe mental illness which continues to increase. The prevalence of serious mental disorders in Indonesia increased from 1.3 cases per mile to seven cases per mile in 2018 (Ministry of Health, 2018). The increase of prevalence rate is related to high recurrence in Indonesia, about 60% in the first year after discharge from hospital (Rahmawati, Maryanto and Apriliyani, 2022). The patient recurrence is caused by the

insufficient family roles and functions, limited information, and family responsibilities during care, which have an impact on the family's powerlessness specifically in being unsure about how to treat patients at home (Fitryasari, Nursalam, Yusuf, Hargono, & Chan, 2018; Iswanti, 2023; Jessica, Fithriyah, & Ardani, 2021). Powerlessness was influenced by various things. However, fluctuations in the patient's condition, the negative stigma that is still high from society, the ability to manage burdens and stress in dealing with problems, and lacking knowledge to need information support cause helplessness in the family and have an impact on the ability to care for patients with schizophrenia every day and when a relapse occurs (Aass, Moen, Kletthagen, Lundqvist, & Schröder, 2021; Dehbozorg, Moghadam, Shahriari, & Sarani, 2022; Fitryasari, Yusuf, Dian, & Nihayati, 2018). The family requires to be empowered and able to care for them well (Sejong, 2021). Family empowerment can be done by giving the right information about schizophrenia, training the family in how to care for the patient, and showing the right attitude when accompanying the patient (Izibeloko *et al.*, 2016; Tehangga, Sunarsih and Supodo, 2021). Families need support from health workers in the form of continuous and consistent care and treatment information (Fitryasari et al., 2020; Leggatt, 2002; Tristiana, Yusuf, Fitryasari, Wahyuni, & Nihayati, 2018). Health workers, especially nurses in outpatient installations or mental health service clinics, have provided support in the form of health education to families of patients with schizophrenia.

Innovation in providing information in health education in mental health services needs to be emphasized in the aspect of empowering the potential of families (Iswanti *et al.*, 2023). Families have care demands in the form of patient care information needs that can foster a sense of responsibility in caring for and optimizing the abilities of family members to be more effective in caring for family members and maintaining their lives (Hulme, 1999). This research wants to explore in depth based on the Caregiver Empowerment Model (CEM) perspective in how to increase families' knowledge, skills and confidence in caring for patients, so that they are better able to manage the care of patients. This model defines family empowerment as increasing the family's ability to assess, influence, and manage situations by using family resources to achieve desired outcomes (Barnes *et al.*, 2020). The CEM model can be used to improve and promote families' abilities in caring for patients by considering the need of care (Sya'diyah *et al.*, 2023). Family empowerment explains that each family member has the power to meet their needs by activating the family's social support system and trying to apply skills and competencies to overcome the problems they face (Graves and Shelton, 2007). This research aims to explore the information needed to meet the demands of care and foster responsibility so that families become more empowered in caring for patients with schizophrenia.

Materials and Methods

Research design

This research uses a descriptive qualitative design by describing the family's information need from mental health services and the family's responsibilities in caring for patients with schizophrenia.

Participant and recruitment

The population was families who cared for patients with schizophrenia at the Menur Mental Hospital and the mental ward of Dr. Ramelan Naval Central Hospital Surabaya, Indonesia. This research involved 20 participants who were obtained using purposive sampling techniques, in which the number was determined based on data saturation; it means the results of the interview with the 20th participant showed data that had been told by the previous 19 participants. Inclusion criteria were family members who care for patients with a diagnosis of schizophrenia for at least 1 year, have experienced a recurrence at least once, age at least 20 years old, and live in the same house with the patient. Participants involved received an explanation of the objectives, research procedures, rights and obligations as well as the benefits of participating in the research and signed an informed consent in the consultation room.

Data collection and analysis

Data were collected using in-depth interviews and field notes. Before data collection began, the research instrument was first tested. The in-depth interview question guide and field notes were tested by conducting interviews with three participants who were not selected as research participants. The results of the pilot test were used to improve the interview questions so they were easier for participants to understand. In-depth interviews were conducted once with each participant with duration between 35 to 55 minutes. The interview location was in a consultation room at the outpatient clinic, a closed room and there were no other people in the room. Participants were asked to answer two main questions: "According to the family, what

Table 1 Participant characteristics

N	Age (Year)	Gender	Education	Occupation	Relationship	Duration of care (Year)
P1	52	Male	Senior High	Soldier	Father	7
P2	52	Male	Senior High	Self-employment	Father	10
P3	62	Male	University	Self-employment	Sibling	3
P4	44	Female	Senior High	No Work	Wife	21
P5	44	Female	Senior High	No Work	Mother	2
P6	50	Female	Junior High	No Work	Wife	22
P7	44	Female	Senior High	No Work	Child	20
P8	48	Female	University	Teacher	Wife	21
P9	28	Female	Senior High	Self-employment	Sibling	3
P10	53	Female	Junior High	Self-employment	Mother	4
P11	71	Female	Senior High	No Work	Mother	10
P12	67	Female	Junior High	No Work	Mother	23
P13	44	Female	University	No Work	Sibling	12
P14	56	Female	University	No Work	Mother	5
P15	63	Female	Elementary	Self-employment	Mother	18
P16	47	Female	Elementary	No Work	Sibling	2
P17	59	Female	Senior High	No Work	Child	3
P18	65	Male	University	Civil-government	Husband	2
P19	40	Male	University	Civil-government	Child	10
P20	46	Female	Senior High	No Work	Child	2

information is needed from mental health services when caring for patients with schizophrenia?" and "What are the family's responsibilities in caring for patients with schizophrenia at home?" The questions were open-ended and during the interview process they were recorded using a voice recorder. Interviews were conducted until the 20th participant and the researcher did not add any more participants, because the data told by the participant had already been mentioned by the previous 19 participants. Interviews were conducted by six researchers, namely RF, IM, and GAA at Menur Mental Hospital while LL, RFD and HS at Dr. Ramelan Naval Central Hospital. All interviewers had experience in conducting in-depth interviews and had previously conducted qualitative research. The recording results and notes in the field notes were then transcribed in verbatim form after each interview was completed with each participant. Discussion of interview results was carried out regularly among the four interviewers and also with other research teams to integrate research findings.

The data were analyzed and interpreted based on five steps of content analysis techniques: unitizing (data collecting), sampling (determining the sample), recording (recording and creating verbatim), reducing (select meaningful words in sentences and clustering in sub-theme), inferring (make conclusion as a theme), and narrating (describing the result) (Krippendorff, 2018). Data analysis was carried out simultaneously with data collection until data saturation was obtained. Demographic data are presented in detail in the form of a table of participant characteristics.

Rigor in this research was carried out by involving several researchers in the analysis process to check and reduce individual bias. Apart from that, member checking was also carried out, by involving research participants to read the verbatim conversations one week after the interview process to ensure that the data were correct.

Participants were recruited based on ethical principles and there was no coercion. During the recruitment, there were two potential participants who refused to be interviewed because they had to hold the patient and another had to immediately move to the pharmacy room. This research was approved by the Ethical Committee of Menur Mental Hospital with number 0009.2/5586/102.8/2023 and the Ethical Committee of Dr. Ramelan Naval Central Hospital with number 110/EC/KEP/2023.

Results

Participant characteristics

Descriptive participant characteristics are explained in Table 1. This study involved 20 family members who cared for patients with schizophrenia. The participants were aged between 28-71 years. Participants consisted of 15 women and five men with varying levels of education, from no school to university, most of them ware in senior high school. The majority, 11 participants, did not work, and the others were self-employed (n=5) or worked as civil government officer (n=2), teacher (n=1) and soldier (n=1). The relationships with the patients were as mother (6), father (2), spouse (3 as wife and 1 as husband), four children and four siblings. All participants have been involved in the process of treating the patient for at least two years and the longest was 23 years.

Table 2 Identified theme and exemplary significant statement of information needed for the family from health services for caring for the patient with a mental disorder.

Theme	Sub-theme	Significant Statement
Patient condition	type of schizophrenia signs and symptoms	"… he suddenly got angry or screaming for no reason" (P5, P11, P20)
		"...often daydreaming then talking himself, no one with him… like a hallucination?" (P2, P8)
		"… She doesn't want to talk to anyone, … stays in the bedroom all day and often smiling alone " (P7, P9, P19)
	cause of schizophrenia	"… She is sick like this (mental disorder) because she is insecure… since she was at school" (P9, P13, P15, P18)
		"… because he's quiet and doesn't want to talk about problems, he ends up getting sick (mental disorder)" (P1, P3, P9)
		"… could it be hereditary? Her uncle was also sick like this (mental disorder), the same condition" (P4, P6)
Medication for patient	accuracy of taking medication	"… we (family) want to know,.. What medicine it is? What it is for?... How long to take it?" (P1, P2, P4, P8, P10, P15)
		"… Should the medicine be taken at any time? Before or after a meal?" (P6, P17)
	how to give medicine	"… we asked the nurse, whether the medicine was oral only or perhaps some were injected" (P5, P20)
	treatment effect	" Is this medicine addictive? You know… She has to take medicine for all her life?" (P3, P15)
		" …He was sleepy after taking the medicine, his body was stiff as wood, and slept a lot" (P8, P13)
		"… She gets better talking with others after regularly taking medicine, but if she forgets to take it, she seems restless" (P10)
	medicine availability	"… medicine is very important and hospitals have complete medicine as prescribed" (P6, P16)
	persuade patients to take medication	" It's not easy to keep him from taking medicine, we have to teach (by nurses) strategies to persuade him (patient) to keep taking the medicine" (P2, P8, P15)
		" Sometimes I mix it (medicine) into food, but if he (patient) finds out, he'll be angry to me and I'll let him (P6, P11)
Routine control information	control time	" We have to know when he (patient) should brought back for next treatment here (hospital) because I have to go to work every day" (P3, P8, P14)
	equipment carried during control	"… what kind of letter must be prepared? Do we need a referral letter from the community health center or any else, we have to prepare it before the time (for routing control)" (P13, P12)
Counseling for patient condition and family	caring for patients at home	"… we are overwhelmed when he (patient) angry and out of control, what we should do?... Doctor or nurses must tell us something" (P1, P15)
		"… when he (patient) talks slurredly, we only pretend not to hear it, but it does not work and makes him angry, what should I do?" (P9, P12)
	prevent patient recurrently	"… After being treated and getting better, in less than a week he had a recurrence, why is it always like that?, we need an explanation, why?" (P5, P10)
		"...If she recurs, we (family) are confused about what to do, it's very difficult for us" (P7, P17, P20)
	stress management for caregivers	"... We (family) feel like going crazy too, We need to be checked (mental condition) too" (P15)
		"… I want to be taught, how not to be tense when caring for him… I'm stressed every day" (P8, P18)

Information that families need from mental health services when caring for patients with schizophrenia.

Based on the results, four themes were found: information about patient condition, medication for patients, information for routine control and counseling for patient conditions, and also for families (Table 2).

Patient condition

Most families want to know about the patient's condition. The information which they want to know is grouped into the type of schizophrenia, signs and symptoms and the cause of the schizophrenia. Families often report that the patient's behavior at home is abnormal and changing. According to the family, patients can become angry for no reason, talk to themselves, refuse to carry out self-care, and even stay in their room for days. Three participants (P7, P9 and P19) said that *"… She (patient) doesn't want to talk to anyone, … stays in the bedroom all day and often smiling alone…"* The family also asked why the patient was experiencing schizophrenia. Some families think that this illness is caused by the patient's closed personality, and not discussing the problems he is facing with other people. Statements from three participants (P1, P3 and P9) describe this situation: *"… because he's quiet and doesn't want to talk about problems, he ends up getting sick (mental disorder)…*" However, some families predict that the patient's illness is decreasing. The family needs an explanation from health workers about why the patient's behavior is abnormal and what caused this to happen.

Medication for patient

Families who accompany patients during treatment at home want to know good information about medication for patients; this is divided into five groups.

Table 3 Identified theme and exemplary significant statement of family responsibility for caring for the patient with a mental disorder.

Theme	Sub-theme	Significant Statement
Giving support for patient treatment	accompany the patient for routine control	"Yes, you have to, bringing control is certain, otherwise it can be dangerous" (P1, P5, P15, P19) "The control date must be recorded, prepared the day before, someone must accompany it, me or someone" (P6, P8, P17)
	monitor patients to take medication regularly	"Every morning before going to work I wait for him to take his medicine until he swallows it, sometimes it takes time, but you know that must be" (P9, P13) " I made a schedule on my cell phone calendar, to remind him to take his medicine, he likes to forget, if he forgets it can relapse, we're all the ones in trouble" (P4, P16) "I have to check on my husband, make sure whether he has taken medicine, whether the medicine is correct or not, well, that's my obligation" (P4, P8)
Fulfill daily needs	basic need	" prepare all the food needs, every day, I also increase the amount, she needs more sometimes" (P7, P15) " I provide everything, like food, drink, snacks, it must be there" (P8, P13)
	personal hygiene	"Reminding him to shower is the most difficult, if he pees and forgets to flush, he has to be reminded" (P3, P16) " she wants to wear the same clothes, I have to change them to new ones, sometimes she looks for the clothes she wore earlier, she gets angry because of it" (P7, P11) "he doesn't want to brush his teeth, I don't give him food if his teeth aren't clean, it's not easy for me and him" (P1, P18)
	individual need	" He often cuts his clothes and tears them, I buy them new ones but he cut them again, what should I do?" (P8) "always asking for pocket money, even though I have prepared snacks, but he always asks for it or he sulks" (P19, P20)
Helps social skill	engage in interaction at home	"Take turns with his father every day to talk to him, anything about food or what he's watching on TV" (P5, P11, P12) "While eating, breakfast or dinner, we always talk to each other like normal people" (P9, P15)
	teach how to speak well to other people	"I taught him, speak well, call the name of the person you are talking to, smile, don't get angry or yell, just talk to neighbors as needed" (P10, P17) "His brother likes to shout, I told him to be patient, keep calm, just take it slow and the answer to the point, don't fight" (P7, P13) "When you speak, don't rush, think about what you want to say so that other people don't get offended" (P3, P8)
	invite interaction with the community	" I invited her to go to a social gathering at the neighbor's, she wanted to come, she liked it, she got extra snack" (P4) "When there is community service at the mosque, I bring him, ask him to help, but I monitor, so he doesn't get too tired" (P15, P17)
Provide activities in spare time	provide art activity	"I bought a guitar he liked, took lessons with a neighbor" (P8, P9, P13) "he likes painting, there is a studio near the house, he goes there diligently, so I said to the studio owner, let him join if he wants to join in" (P11)
	inviting worship activity	"Our whole family reads the Bible every morning, he wants it instead of just lying down" (P17) "pray together at the mosque, sometimes at home with us, always on time" (P6, P17, P20)
	involve in routine household activities	"I ask her to help clean the house, sweep the floor, mop, wash clothes if she's in the mood, she will do" (P1, P17, P19) "he wants and likes to wash cars, if his brother comes home when the car is dirty, he is given money and he is even happier" (P8, P12) "she likes to cook, but she feels confused but it's okay if I help because she likes to cook and clean up the kitchen" (P13, P14)
	modification of activity outside the home	"We take her to the mall, to the market, to exhibitions, out on picnics so she doesn't stay at home all the time" (P1, P3, P7) "I like gardening, he wants to help buy plants, buy fertilizer, water, so he won't keep watching TV all day" (P5, P8)
	find a job	"I once asked him to work, looking after the shop, but he still had to accompany him, because sometimes he was confused too" (P11) "He wants to be a letter delivery boy at his brother's office, and he can earn good money" (P10)

Families feel the need to know the accuracy of taking medication, how to give medication, treatment effect, medication availability, and how to persuade patients to take medication. The family has a strong desire to know the name of each drug consumed by the patient, the function of each drug, the frequency of taking the drug, and how long the patient must always take the drug. Some families also ask whether medication is given only

orally and whether there are other ways to administer medication. Families often ask this because the family needs information about the treatment effect if the patient has to continue consuming it in the same way (oral administration). Some families say that the patient's condition has improved after taking medication regularly, but, on the other hand, the family is worried that the patient will become dependent if he continues to take medication orally for a long time. Families also often find it difficult because some of the patients being treated refuse to take medication orally. Families need information regarding strategies for administering medication to persuade patients to take medication regularly. Five participants expressed the situation by saying *"…It's not easy to keep him from taking medicine, we have to teach (by nurses) strategies to persuade him (patient) to keep taking the medicine…"* (P2, P8 and P15) and *"…Sometimes I mix it (medicine) into food, but if he (patient) finds out, he'll be angry to me and I'll let him…"* (P6 and P11). Knowledge about the medication that the patient must take is information that is needed by the family because medication is one way to prevent relapse in the patient.

Information for routine control

Taking patients for regular check-ups at health services is an obligation for families who care for patients with mental disorders. Families need clear and definite information regarding control time and equipment must be carried during routine control. The family said they had to set aside special time amidst their busy family schedule, so that ensuring control time would help the family to be able to take the patient to health services. Apart from that, the preparation of letters and administration that must be brought during the control must also be informed to the family. Two participants conveyed this in the following conversation, they (P13 and P12) said *"…what kind of letter must be prepared? Do we need a referral letter from the community health center or any else, we have to prepare it before the time (for routing control)…"* This will be very helpful so that the family can prepare before the control time arrives.

Counseling for patient condition and family

When families meet with health workers at health services, they need good counseling services related to how to care for patients at home, preventing recurrence as well and managing the stress experienced by the family. Some families complain of feeling overwhelmed when the patient cannot be controlled, such as when the patient becomes extremely angry, refuses to take medication, or relapses a few days after returning from the hospital. Apart from the patient's condition, the family also needs information regarding the stressful situation they are feeling. Families need counseling to manage the stress that occurs due to physical and psychological fatigue while still having to care for patients well at home. Three participants complained about the situation by saying *"...We (family) feel like going crazy too, we need to be checked (mental condition) too…"* (P15) and also *"… I want to be taught, how not to be tense when caring for him… I'm stressed every day…"* (P8 and P18). Information and special counseling services for families in health services will be very helpful in being able to survive and successfully provide good care for mental disorders patients at home.

Family responsibility for caring for the patient with a mental disorder

The results of the analysis show that there are four themes according to families related to responsibilities when caring for patients with schizophrenia, namely giving support for patient treatment, fulfilling daily needs, helping patients to have social skills, and providing patients with activities in spare time (Table 3).

Giving support for patient treatment

The family said that they always try to support the patient's treatment process because it can prevent recurrence. The support provided by the family is mainly in two ways, namely taking the patient for control to mental health services regularly and monitoring the patient to always take medication regularly. It is not uncommon for families to have to postpone activities they are going to do because they have to wait for the patient to take medication. Four participants confirmed that the control schedule was important as they said *"…Yes, you have to, bringing control is certain, otherwise it can be dangerous…"* (P1, P5, P15 and P19). For families, treatment is very important and primary because it can prevent patient recurrence.

Fulfill daily needs

The family feels that they are the ones who must be responsible for meeting the patient's needs every day because the patient is sick and needs help. Patient needs are grouped into three: basic daily needs such as eating, drinking, and snacks; patient self-care, such as bathing and changing clothes, which must be continuously reminded by the family; and personal needs such as

clothing and daily pocket money. This was represented by two participants who said *"… I provide everything, like food, drink, snacks, it must be there…"* (P8 and P13). The family realizes that fulfilling the patient's daily needs is not easy, but the family must fulfill these needs so that the patient is not neglected.

Helping with social skills

To several families, mental disorder patients have difficulty socializing with other people, so the family must help gradually so that the patient can interact well with the family and neighbors. The family helps the patient to engage in interaction at home, teaches him how to speak well to other people, and invites interaction with the community. Two participants said *"…I taught him, speak well, call the name of the person you are talking to, smile, don't get angry or yell, just talk to neighbors as needed…"* (P10 and P17). The family tries to understand that the patient's socialization abilities have decreased due to the disease process so they feel they have a responsibility to help the patient by practicing their communication skills.

Provide activities in spare time

The family said they wanted to provide activities for the patient in his free time. Every day the patient must be active to avoid experiencing a recurrence. Some families try to facilitate patients who enjoy artistic activities by buying musical instruments or painting tools and taking art lessons. The family also involves the patient in doing routine household tasks such as cleaning the house, cooking, and washing clothes. The family realizes that if the patient is too bored at home it will be easy for him to relapse, so some families take the patient to the mall or market to modify the atmosphere. There are even families who find light work that the patient can do, such as tending a shop or delivering letters. Five participants stated *"…We take her to the mall, to the market, to exhibitions, out on picnics so she doesn't stay at home all the time…"* (P1, P3 and P7) and *"…I like gardening, he wants to help buy plants, buy fertilizer, water, so he won't keep watching TV all day…"* (P5 and P8). However, the family also pays attention to ensure that activities involving the patient both inside and outside the home are not too tiring so as not to result in a relapse in the patient.

Discussions

The research results are explained in the form of four themes related to the need for care information and four themes related to responsibility in caring for patients so that they become more empowered families, which will be explained in the following discussion.

Patient condition

Families when caring for patients with schizophrenia need information from health services regarding the types or symptoms and causes of schizophrenia. Types of schizophrenia based on the symptoms that appear in patients often make families confused and not knowing what to do. The symptoms can be divided into positive and negative symptoms (Hawari, 2009). Positive symptoms show an excess of normal function, such as hallucinations, delusions, and aggressive behavior (Correll and Schooler, 2021). Meanwhile, negative symptoms are explained as the absence of normal behavior, and patients have deficiencies in motivation, communication, and social functioning (Galderisi *et al.*, 2018). The families in this study had cared for the patient for at least two years; however, they were still confused about why the patient showed changing symptoms. Patients can become angry for no reason, talk to themselves, refuse to carry out self-care, and even stay in their rooms for days. The family needs continuous explanation that the symptoms displayed by the patient are a process of mental disorders experienced by the patient.

It is not easy for families to understand the causes of schizophrenia. The research results show that families need information about the causes of their family members experiencing schizophrenia. Families often ask because the patient felt insecure in the past and did not want to talk about the problems they were experiencing, and some families even still think that mental disorders are a hereditary disease. This family's thinking is in line with the opinion of Gilmore (2010) who explains that serious mental disorders, including schizophrenia, can be caused by the interaction of genetic risk factors and environmental exposure since the fetus is developing in the womb. The family is worried because they see that another family member is also experiencing schizophrenia. However, families also think that individuals who tend to hide problems and do not tell others also have a big role in causing schizophrenia. Cadge (2019) explains that personal characteristics such as a closed or introverted personality contribute to the occurrence of serious mental disorders. Each individual will try to solve their problems, but inadequate abilities and utilization of social support around them will also affect a person's mental resilience. The behavior of each patient varies

greatly and requires the family to accept this condition (Fitryasari, Yusuf, et al., 2018). Family knowledge about the patient's condition, especially the type, symptoms, and causes of mental disorders, is very important because it is the basis for the family to understand that the behavior displayed by the patient is due to the disease process. The family's acceptance that the patient's condition is a demand in providing care at home will be a positive aspect that supports the family empowerment process. Sufficient information from health workers regarding the condition of patients with chronic mental disorders can increase family tolerance in dealing with the patient's symptoms, reduce family stress and negative emotional expressions, increase hope that the patient will be able to recover, and increase the family's strength to become more empowered in caring for patients at home (Suryani, Ningsih and Nur'aeni, 2019; Lohrasbi *et al.*, 2023).

Medication for patient

The research results explain that families need information about the drugs consumed by patients. Families feel the need to know the accuracy of taking medication, how to give medication, treatment effect, medication availability, and how to persuade patients to take medication. The families are concerned with the drug names, dosage, side effects, and reasons why each medication is prescribed (Izibeloko *et al.*, 2016).The family believes that patients who take medication according to the instructions of health workers will recover quickly and prevent recurrence (Haddad, Brain and Scott, 2014). The family will try to help the patient take medication regularly in various ways. The long-term treatment that patients must undergo causes a tendency to refuse to take medication or can be said to have a low level of compliance (Ngui, Vasiliadis and Tempier, 2015). The family as the closest people in the patient's life will always try to help the patient to take medication in various ways. Information on the types of drugs that can be provided by mental health services is needed by families (Hendryx, Green and Perrin, 2009). Some families ask about non-oral medication administration or using injections because. according to the family, this is easier than asking the patient to take medication every day regularly. Adequate information regarding medication will help families find solutions to ensure that the patient correctly takes medication.

Information for routine control

Research data show that families need clear and definite information regarding control time and equipment must be carried during routine control. Routine control is a systematic examination carried out in a clinic or hospital to assess the success of the therapy that has been instructed (Noorden *et al.*, 2013). All research participants stated that patients always had routine check-ups every month at the hospital. Families feel the need to prepare time and administrative requirements at least one week before the control time arrives. Insufficient information will be an obstacle when the control process arrives; on the other hand, the family has taken the time between work to accompany the patient for routine control. Families always ask health workers when they have to go back for control and whether they have to get a new referral letter. Several families said that accompanying the patient during routine check-ups is a requirement for patient care that must be carried out to maintain the patient's psychological condition and prevent recurrence.

Counseling for patient condition and family

The results showed that families when taking control patients want to have the opportunity to consult with health workers about the patient's current health condition, prevent recurrence, and also to manage the stress experienced by the family. The family plays a core role in patient care, being the main persons responsible and experiencing many challenges during care, including various tensions as a result of patient care (Ong, Fernandez and Lim, 2021). Families need to get instructions from health workers on how to care for patients at home according to the problems and symptoms of the disease that arise. Several participants expressed the difficulty of treating patients when they were experiencing an uncontrollable relapse, such as suddenly getting angry for no reason, leaving the house, or wandering around people's houses. The patient's changing behavior causes the family to feel depressed and even unable to control their emotions and the family's anger is directed at the patient. Families experience various burdens and these have an impact on the care provided to patients (Chadda, 2014).

The stressful situation faced by families is as a result of providing care to patients with schizophrenia. Families experience emotional strain and a series of changes in their family functioning (Anuradha, 2003). Families also need counseling from health workers to be able to free their thoughts and feelings from uncomfortable situations. The availability of

psychological counseling for families is very useful for relieving pressure (Chen *et al.*, 2019). Professionals should assess the emotional status of the family as a caregiver, provide services on stress management, and suggest including in peer support groups to reduce the discomfort and enhance their well-being (Chang *et al.*, 2018). Several families expressed a desire to have their psychological conditions checked so that they do not develop into serious mental health problems. However, not all hospitals provide counseling facilities for families. Several health workers tried to find out what the families were feeling, but, due to time constraints, not all families received special treatment. Existing programs in hospitals still focus heavily on treating patients with schizophrenia.

Giving support for patient treatment

This research found that one of the family's responsibilities in caring is providing support for patient treatment by taking patients for routine check-ups to mental health services and monitoring patients to always take medication regularly. Patients need family support to be able to comply with treatment, as Siregar (2021) argued, which states that families who live in the same area or house need to help patients carry out treatment, such as regular control and compliance with the correct use of medication. Several families in this study always confirmed the date of the patient's return to the hospital and arranged work schedules so they could accompany and support the patient. The family views routine control as very important and must be assisted by the family.

The family is very concerned about the patient's regularity in taking medication. All research participants stated that medication was one way for patients not to relapse. The family has an understanding regarding the impact if the patient does not take medication regularly, which will cause relapse in the patient (Dirik. The consequences of a patient's recurrence require the family to provide more time, thought, energy, and even funds. The family tries to reduce this burden by maintaining the patient's condition so that it does not recur, by monitoring the patient to take medication regularly. This situation is reinforced by Kikkert and Scene (2006) that treatment compliance is influenced by positive perceptions of treatment and the family's desire to avoid the patient being readmitted to the hospital. Some research participants also used various methods to persuade patients to take medication, such as accompanying them every time they took medication, entering cell phone reminders, and monitoring by asking patients whether they had taken their medication on time.

The family's desire to help patients adhere to treatment in this study fostered high commitment among family members. Wardhani (2009) strengthens the results of this research, saying that the family agrees to accept responsibility as the main care provider with patience and continues to maintain treatment routines and adhere to treatment. Family commitment is a form of family acceptance of the patient's condition and allocating a certain amount of energy to stand tall in living life with the patients. Family involvement in the treatment process for patients can help the patient's condition improve, such as reducing relapses, increasing the duration of time between relapses, and reducing the rate of readmission to the hospital (Ong, Fernandez and Lim, 2021). A family situation that is highly committed and full of motivation makes the family stronger and more empowered and is very necessary to support treatment compliance in patients with schizophrenia.

Fulfill daily needs

The patient with schizophrenia requires the family to help meet all of their daily needs. Daily needs are basic activities related to basic human needs, such as eating and drinking, dressing, carrying out personal care (bathing and going to the toilet), and moving around (Brunner and Suddarth, 2002; Hardywinoto, 2005). The research results show that the family tries to fulfill daily needs, which include basic needs, self-care, and the patient's personal needs. Mentally disordered patients have limitations in interacting with the surrounding environment, so the family must help with all the patient's needs. The family provides food, drink, and snacks every day as the patient's basic needs. The family also tirelessly motivates and even helps patients to bathe regularly, brush their teeth, and change clothes after bathing. The families realized that this was not an easy thing because the patient's motivation to maintain personal hygiene had greatly decreased. The findings of this research are in line with Iseselo (2020), who explains that patients with chronic mental disorders experience difficulties and a reduced ability to care for themselves as before they were sick due to the influence of the drugs they consume. Several research participants stated that patients were able to shower and change clothes, but ensuring that they showered cleanly and changed into clean clothes after showering still required family help. The family must be able to provide support and assistance to the patient in carrying out self-care (Lucock *et al.*, 2011). The family's sense of

responsibility to maintain the health of patients with schizophrenia creates a special motivation within the family to always remind and help the patient's hygiene every day. The family also meets the patient's personal needs such as buying new clothes and giving pocket money every day. Even though the family situation is full of tension, burdens, and busyness, the family always tries to focus on fulfilling basic needs. Several families stated that they felt relieved because they had made efforts to meet the patient's food, clothing, and personal hygiene needs.

Helping with social skills

Research data show that families help patients with schizophrenia to socialize with the environment. The family helps the patient to engage in interaction at home, teaches him how to speak well to other people, and invites interaction with the community. Patients experience problems in carrying out their social functions and tend to withdraw from interacting with the community around where they live (Hunter and Barry, 2012; Ulfseth, Josephsson and Alsaker, 2013). Several participants complained about negative symptoms experienced by patients such as not wanting to interact and communicate. Families who live with patients every day have a great opportunity to help patients improve their social skills. The family invites the patient to chat every day when doing activities at home or when eating with the family. The family also teaches how to communicate with other people in a good way, keep smiling, and not get angry when saying or asking for something. Apart from interactions at home with the nuclear family, some families try to invite patients to engage in interactions outside the home, such as with neighbors. Patient involvement in a supportive and conducive home environment will help patients improve their social function (Hunter and Barry, 2012). However, families limit their ability to invite mental disorder patients to socialize in the community, because there are still concerns that the surrounding environment does not provide enough support for patients (Harandi, Taghinasab and Nayeri, 2017). Patients who are not yet stable and interact too much with the environment outside the home will cause problems and cause the patient to relapse. However, several families who tried to take the patient out had a positive impact related to increasing the patient's communication and interaction skills. Even the neighbors want to greet him, give him food, and invite him to play at home. This situation increasingly has a positive impact on the patient's social abilities. Patients are willing to answer questions, return greetings, and begin to dare to start a conversation. However, patients must still be accompanied by a family member. A conducive environment, full of initiative and creativity to dare to make adjustments to existing problems has a positive impact on the return of the patient's function socially (Fitryasari et al., 2020).

Provide activities in spare time

The results of the analysis explained that the family looked for activities to fill the patient's free time, such as taking part in artistic activities, spiritual activities, doing household tasks, taking activities outside the home, and finding work. Efforts to prevent relapse that can be carried out by families, apart from routine and regular treatment, also need to be made to create a conducive environment by involving them in family activities and helping patients face serious life problems. Filling your free time with activities you like can improve personal relationships, happiness, and satisfaction and have an impact on increasing self-esteem (Ngamaba *et al.*, 2023). Some participants realized that the patient had an interest and talent in art, so they involved the patient in art activities and bought them musical instruments. The family also invites patients to carry out routine household activities such as preparing family meals every day for patients who like to cook. Patient involvement in family activities makes patients feel happy and appreciated and has a good impact on their emotional calm. Meanwhile, some families still consider the patient's psychological condition. If they are given heavy responsibilities, it could cause a relapse. So the family tends to limit and choose the types of activities that the patient can do. Depending on the severity of the patient's condition, some caregivers expressed a different experience (Iseselo and Ambikile, 2020).

Research data show that families also try to reduce patient boredom while at home by inviting them to do relaxing activities outside the home or finding work. Working can speed up patient recovery (Fakhrou *et al.*, 2023). The family finds light work that the patient can do, such as tending a shop or delivering letters. The family said that the patient felt happy with the work that suited his abilities and became even happier because he could earn money from his work. There is a significant relationship between the involvement of mental disorder patients in a job they like and improvements in the psychosocial symptoms they experience. The family supports the patient in doing light household work and provides praise for the patient's success as a form of motivation. The patient feels that he has increased self-esteem because he can make or earn money, and the

patient even feels satisfied with life as a normal human being. Family support in finding activities for patients to fill their free time shows the family's ability to empower patients with schizophrenia.

The limitation of this research is that the interviews were conducted at the hospital outpatient clinic and not at the patient's family home, so the researchers were unable to obtain additional data related to the real situation of the patient's living environment, which could reflect the care information needed by the family. However, researchers have tried to anticipate this by asking questions that can describe the patient's home situation related to care needs.

Based on research findings, it can be identified that nurses in outpatient mental hospital units should also prepare special services that do not only focus on patients with schizophrenia but also for the families who accompany the patients, such as stress management training for families, family therapy and health education which help family to manage the burden of care.

Conclusion

This research can explain that families need information regarding the condition and treatment of patients as well as counseling for families as a demand for caring for patients with schizophrenia which fosters care responsibility as a form of family attachment so that families become more empowered and optimize the family's abilities in caring for patients well and prevent relapse in patients with schizophrenia.

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Conflicts of Interest

We declare we have no conflict of interest

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