Family Experiences in Caring for People with Mental Disorders

Mardiangra Defrilianda¹, Dewi Kurnia Putri², Eka Wisanti³

Hang Tuah University, Nursing Study Program, Riau, Indonesia

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CORRESPONDENCE
E-mail: dewikurniaputri@htp.ac.id

ABSTRACT
Family has an important role as the main care provider for people with mental disorders. This study was to explore more deeply about the experience of families in caring for people with severe mental disorders. This research was qualitative research with a phenomenology method. The participants of this study were 3 people with more than 5 years of care for patients. Sampling technique using accidental sampling. The data collection method used in-depth interviews with Colaizzi data analysis techniques. The results obtained 6 themes. First, there was a family response in caring for ODGJ. Second there were changes in family activities. Third, problems experienced by families while caring for ODGJ consist of barriers to families experiencing mental disorders and barriers to seeking treatment from health services. Fourth, how to solved the problems experienced. The fifth theme is family expectations in caring for ODGJ. The last theme was treatment of ODGJ by the family consisting of differences in treatment of ODGJ and reasons for choosing treatment for ODGJ. This research can be used as a basic data for researchers to conduct further research to identify psychological problems experienced by families in caring for ODGJ.

INTRODUCTION
Mental disorder is one of the serious health problems that must be treated immediately because the number continues to increase and is accompanied by a collection of symptoms of abnormal conditions in a person which is not only in the relationship between the person himself but also in his relationship with society. A person is said to suffer from a mental disorder if there is interference with mental functions, such as emotions, thoughts, behaviors, feelings, self-view, desires, and perceptions that interfere with life in society (Asriani, et al., 2020; Nasriati, 2017). Data from the global health agency the World Health Organization (WHO) in 2017 found that around 264 million people suffer from depression, 20 million people suffer from schizophrenia and other psychics, 45 million people suffer from bipolar and 50 million people suffer from dementia. According to the results of the 2018 Riskesdas there was a significant increase compared to the 2013 Riskesdas results, namely 1.7 per mile to 7 per mile in people with severe schizophrenia and psychic disorders, 6.1 per mile suffered from depression,
and 9.8 per mile suffered from emotional disorders. Meanwhile, based on the province with the highest number of sufferers of severe mental disorders, it was Bali Province with 11.1 per mil, followed by DI Yogyakarta and West Nusa Tenggara Provinces. Based on the results of the 2018 Riskesdas, people with mental disorders in Riau Province were around 6.1 per mile and ranked 21st. In addition, according to the 2019 Healthy Family Indicator dashboard data, the percentage of people with mental disorders (ODGJ) in Riau Province who received treatment and not abandoned is 35.96%.

Mental health for ODGJ can be achieved with family support. Family assistance is very important to support the healing process for people with mental disorders (Dulay, 2021). Having a family member who suffers from mental disorders is the duty and responsibility of the family to care for their family members while living with the family. The high costs of treatment and recovery in mental health services, as well as long distances, result in families having to provide time, energy, and costs to undergo treatment (Pangandaheng, 2018).

The results of a preliminary study by researchers at the Pekanbaru City Health Office found data on patients with severe mental disorders in Pekanbaru City in 2020, namely 659 people or 37.58%. Meanwhile, the highest data for sufferers of severe mental disorders was in the Umban Sari Health Center with 57 people. Then the researchers conducted a preliminary study at the Umban Sari Health Center and found that the health center had implemented a mental health program in the community. In addition, the results of interviews with the puskesmas said that some of the ODGJ families were cooperative and people with mental disorders were aged 25 years and over and this was due to the use of dangerous substances or drugs and a divorce. Researchers also conducted interviews with 4 families with ODGJ, 2 of whom complained about economic constraints to treat and care for clients. This is in line with what was conveyed by the puskesmas staff that most families are constrained by the problem of medical expenses. In addition, the family said that while caring for family members who experienced ODGJ, there were neighbors who are supportive and paying attention when their family roamed outside the house. The family also accepts the conditions of their family members and continues to provide care for family members who suffers from mental disorders. The purpose of this research is to explore the experience of families in caring for people with mental disorders.

METHOD

The research used is qualitative research with descriptive phenomenological approach. The participants in this study consist of 3 people who is selected using the accidental sampling method. Data collection in this study using in-
depth interview method. This method was conducted with families who cares for family members with ODGJ. During the interview, the researcher used voice recorder namely digital voice recorder, field notes to document events or the environment before and during the interview process, as well as an interview guide as a researcher's guide. Researchers use data analysis by Colaizzi.

RESULTS

Table 1. Key Participant Data

<table>
<thead>
<tr>
<th>Number</th>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Long cared for</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>P1 (Ny. H)</td>
<td>51 years old</td>
<td>Woman</td>
<td>22 years</td>
</tr>
<tr>
<td>2</td>
<td>P2 (Nn. D)</td>
<td>28 years old</td>
<td>Woman</td>
<td>10 years</td>
</tr>
<tr>
<td>3</td>
<td>P3 (Tn. Y)</td>
<td>68 years old</td>
<td>Man</td>
<td>6 years</td>
</tr>
</tbody>
</table>

Participants were in the age range of 28-68 years with 2 female and 1 male. All participants had cared for ODGJ for more than 5 years. Participants are families who care for ODGJ from 3 sub-districts in Pekanbaru City.

Theme 1: Family Response in Caring for ODGJ

The results of the study showed that the family feels a physical and psychological response while caring for ODGJ. Some participants said about physical responses such as:

"...the upset maybe because we're tired. It's normal to be tired..." (P1).

"...sometimes I'm tired I can't tell..." (P2).

The following are participants' expressions regarding psychological responses:

"...where is it sad, other parents are normal, can be free to go anywhere, then can not be confined like that. How come this mother... sad too... from year to year just stay at home. Of course we feel the same way, right..." (P1).

"...Yeah, it's sad... it's my brother... and it's been a long time..." (P2).

"...eeeee, this is sad... it's a child's name..." this is a disease that has not healed for so long, so of course we as parents are sad..." (P3).

"...it's just that we get annoyed when we get angry like that, right, but how about that... ""...sometimes when you get angry, you regret it too..."" ...but there's just that you get annoyed..." (P1).

"...sometimes you get angry, sometimes you get angry...""...if you take a shower it's a bit difficult for some reason, until you get angry first, until you get emotional first, you don't want him to do it..." (P2).

"Sometimes we get angry too, but if we get angry, what does he add..." (P3).

Theme 2: Changes in Family Activities

The results showed that there were differences before and after caring for family and limited social relations. Following are the expressions conveyed by the participants:

"...from year to year just stayed at home. Of course we feel that way, right..." "...finally going back to the village in turns. So we can't go back to our hometown together..." (P1).

"...if you want to go out it's difficult, of course you have to take turns with papa..." (P2).

"...In the past, when the neighbor came home, it was okay, right? He immediately “Get out of here! go you!” So a bit scared..." (P1).

"... this brother is often in people's shops, so he doesn't do anything, but um, if people don't know, they might be afraid of that. Sometimes yesterday someone from the shop came to the house to tell Papa, I'm afraid the shopping people are afraid..." (P2).

Theme 3: Problems Experienced by Families While Caring for People with Mental Disorders

The results of the study indicated that there were barriers to families with mental disorders and barriers to medical treatment. Following are the expressions conveyed by participants regarding obstacles to ODGJ:

"...but he's the one who can't be managed like that, the problem is mom there...""...how come you can't be neat like that, can't be clean, why can't you be like this. That's where the mother's real obstacle is." "...it's really hard to manage, that means because her soul is disturbed..." (P1).

"...in the past, I couldn't tell him. Then, sometimes in the past, he really did pee in his pants, he held it for a long time..." (P2).

As for the participants' expressions regarding barriers to seeking treatment at health services such as:

"...Well, for treatment, you usually go to the hospital for treatment. It's a mental hospital right? There's a sedative. Well, it's just that now it's because I'm old right... the medicine doesn't work anymore. It doesn't work. Maybe the dose was too high for him maybe. Because the age factor is already too old..." (P1).

"...Hmm, queue up.

"...Natural medicine until now. So if it's because of you, just be patient. People say be patient, sir, because someone comes to him after so many years, he said, after so many years he has
an awareness. Ha, that's an alternative person…” “…But if he gets angry, he has to go to a mental hospital, right?” (P3).

Theme 4: How to Solve Problems in the Treatment of ODGJ
The results of the study show that there are several ways to do this, namely worship, trying to be sincere, following the wishes of ODGJ, trying to be firm and working with families in caring for ODGJ. Following are some of the expressions conveyed by participants:

"Most mothers pray, sometimes when they pray, they recite the Koran. Sometimes murottal lives at home like that…” (P1).

"...yes, we live in this world, we must be balanced, don't just pray, father, just pray for him…” (P3).

Expressions about God's decrees such as:

"...our responsibility as in-laws, it's our destiny to have in-laws like that, right…” (P1).

"Don't give up, don't be discouraged. We only plan, we know we will fail on the way, yes Allah's permission is also alive. We just live it, we implement it.” “... when will it heal, God is the one who will do it…” (P3).

Expressions are forced to follow the wishes of ODGJ such as:

"He can't do that, he has his own heart, has his own thoughts, he has his own things so we can't control him like that. We are forced to follow what he wants. If he says he doesn't want to, then he doesn't want to, we will eventually follow him…” (P1).

"...Even if we force him to be angry with us… so we treat him differently, we know he won't be normal, not the same as us who are healthy, right…” “... still don't want him to just go away he…” (P2).

"...sometimes he doesn't want to be taken for treatment and doesn't want to be taken anywhere. Ride the car already in front of the house, just go to the village, don't want him to do it. Only of course we have to be patient. Want to be forced? Add to that, right… he bought cigarettes, bought clothes…” (P3).

Expressions of being firm with ODGJ were conveyed by participants as follows:

"...he was sick like that, eeeeee for 3 4 days that he didn't want to move from his seat, finally found out that this was already there mom, already peed on the mattress all wet... Finally we found out, we were cutting the clothes while sitting down and cutting them all the way to Under all circumstances, gentlemen, right at home, cut it out, buy pempes, wipe it, force it a little hard, you have to do it hard, you have to force it. Usually he slowly doesn’t listen, he has to say the father (slightly loud voice) ha that's what he wants. We replaced all the scissors, after that we just buried the clothes again, right? It's been 4 days since I peed, I don't want to pee, I don’t even want to eat…” (P1).

"...at least if you haven't taken a bath for two days then you will be threatened like this 'don't want to give money, don't want to buy food if you haven't taken a bath', he gets angry when he hears that…” (P2).

Expressions of working with families were conveyed by participants as follows:

"...Well, at least we're alone with you, if the other family isn't around it's the uncle, the uncle's wife who helped pick him up to the hospital. Maybe it's because it's too far away, maybe if it's close, the uncle will help. Because it's far away…” (P1).

“…He's sleeping at home too, when he wakes up he'll wash his face or clean or wash his face at least. Because there's daddy at home too, right.. eat.. it's not just my brother who takes care of it, daddy's there too…” (P2).

“…You're just being naughty, that's all, if there is, for example, younger siblings 2 or 3, a little or a little. We're busy. Ha, so we work together, togetherness must be lived…” (P3).

Theme 5: Family Expectations in Caring for ODGJ
The results of the study found that family expectations consisted of future expectations for ODGJ and expectations for oneself. The expressions conveyed by the participants are as follows:

"...I want mother to recover, right? Recovered, eee.. healthy as usual. So he can do those activities by himself…” (P1).

"Well, the hope is that you want to get better, you can be like a normal person like usual, right...” “...even though he can't be normal, at least he's okay, he used to be good himself.. ha I'm looking forward to it for other people... well, the hope is that he can recover.. he can be like first again…” (P2).

"...waiting for the time to recover, yes, if we can get treatment, we will try too…” If he recovers quickly, thank God. If it's slow, that's fate that we have to accept, we can't force ourselves…” (P3).

Participants' expressions about expectations for themselves:

“… well, I hope you're patient…” “...if you tell people, just be patient, they say that, maybe it's fate, that's our way, we just have to take care of it…” (P2).

“…Yes, being a whip for fathers, yes, a life experience for other children, don't let it be like that, this is an example. That's why I hope you are patient… just be patient until now…” (P3).

Theme 6: Treatment of ODGJ by the Family
The results of the study found differences in the treatment of ODGJ and the reasons for choosing treatment by the family. Following are the expressions conveyed by the participants:

“…Well, for treatment, you usually go to the hospital for treatment. It's a mental hospital right? There's a sedative. Well, for treatment, you usually go to the hospital for treatment. It's a mental hospital right?” (P1).

“......these brothers and sisters are in control every month at the hospital…” (P2).

"Did you try village medicine, right? Haa eee, that's an alternative, there's an influx.. so it's okay…” (P3).
Expressions regarding reasons for choosing treatment were conveyed by participants such as: 
“...That's all, if he takes medicine he still wants to...” (P2).

“...So do you give up, it's just that the important thing is for you not to get angry, he doesn't harm other people, he doesn't disturb him, so you just calm down... okay, just natural medicine now...” (P3).

**DISCUSSION**

**Theme 1: Family Response in Caring for ODGJ**

Families that pay less attention to ODGJ such as being isolated and neglected can result in recurrence of ODGJ. The family's response will determine the possibility of the family's attitude towards individuals with mental disorders, namely accepting or rejecting them. This response will later explain whether the family really accepts or rejects certain behaviors about how a family's pattern can adjust to the presence of family members who experience ODGJ (Wati, Subu, & Nedtrida, 2018).

The results of research conducted by researchers found that there were two responses to participants while treating ODGJ, namely physical and psychological. Participants said the feelings they felt while caring for ODGJ varied and changed, ranging from tired, sad and angry. Participants felt tired/tired because ODGJ was very difficult to manage, sometimes participants also felt like they wanted to be angry because ODGJ had been directed many times but didn't listen to their family. In addition, participants also felt sad because their family members did not recover even though they had had mental disorders for a long time. The family looks teary eyed and pensive when telling this.

Fatigue is a physical response due to events that the body cannot control. Fatigue is a natural physiological response of the body that occurs due to excessive workload, lack of quality sleep, and many activities carried out by a person (Rahayu, Sulistiwati, & Swedarma, 2019). Meanwhile, sadness is a negative emotional response to a person's psychology. Feelings of sadness generally appear as a normal reaction, for example when someone experiences stress, loss, and helplessness (Suryaningsih & Imelisa, 2018).

This is in line with Muryani & Sri's research (2019) which found that the family as a caregiver bears the physical burden experienced related to physical conditions. Participants said they felt tired and thinner while caring for ODGJ. The physical burden is felt by the family due to having to take care of it on an ongoing basis starting from medical needs, daily needs such as eating, bathing and personal hygiene, as well as supervision from the family.

**Theme 2: Changes in Family Activities**

Caring for family members with severe mental disorders is associated with a negative impact on mental health. ODGJ care has an impact on a greater burden on caregivers. This will increase family responsibility and become a
stressor for caregivers. The more family tasks in caring for ODGJ, the more burden it will show. Families will spend more time caring for ODGJ so they will lose their personal time and it can have an impact on their well-being (Nafiah, 2019).

The results of research conducted by researchers found that there were changes in family activities while caring for ODGJ. It is difficult for participants to return to their hometown if there are family events or holidays, because if the ODGJ is brought later it will be difficult for the family if at any time the ODGJ wants to return home. In addition, participants also said that it was difficult to leave the house and had to take turns with other family members to care for PLWJ because PLWH could not be left alone. In this study there were also cultural differences according to the research location. The participants in this study are Malay and Minang, this influences how the nature and way of caring for their family members.

This is in line with Nafiah's research (2019) which found that caregivers who provide care to schizophrenic patients have an impact on their well-being. Caregivers feel worried about the condition of ODGJ and themselves. While caring for schizophrenic patients also has an impact on family relationships that care for others. Families sometimes experience obstacles in interaction and have limited time for themselves. In addition, the majority of caregivers have cared for schizophrenic patients for more than 5 years. Caregivers spend a lot of time on ODGJ so they have limited time for themselves. The length of time caring for the caregiver also has an impact on the burden felt by caregivers.

Theme 3: Problems Experienced by Families While Caring for People with Mental Disorders

In general, the impact felt by families who care for ODGJ is the high economic burden, the emotional burden on the family, the stress on the patient's disturbed behavior. The role of the family in providing treatment efforts to patients is generally in accordance with the capabilities of the family. While providing care, there are limitations to the ability of the family which results in the family only providing what is considered right for them. The problems experienced by families can be caused by disrupted ODGJ behavior and this will determine the family's attitude towards ODGJ (Mislianti, Yanti, & Sari, 2021).

Mental health services for severe ODGJ are health services provided in accordance with standards for all severe ODGJ such as acute psychosis and schizophrenia as secondary prevention efforts, including mental health examinations and education. Stakeholders in mental health services are direct and indirect parties who benefit or impact from the implementation of development. Stakeholders can be groups, organizations and individuals.
who have an interest or influence in the decision-making process for implementing development (Ministry of Health, 2020).

The results of research conducted by researchers found that the problems experienced by families while caring for ODGJ were obstacles to ODGJ which were difficult to direct. The family said that ODGJ could not be managed, such as not wanting to eat, wandering outside the house, urinating in the open, not wanting to get a haircut, and not wanting to take a bath. Besides that, another obstacle that the family felt was the treatment of ODGJ. There are participants who take advantage of health services but don't want to be taken to the doctor, families think drugs don't work anymore, and there are also families who only take to alternative medicine while the conditions of their family members are not too severe.

This is in line with the research of Halida, Dewi, and Rasni (2016) which found that according to some participants, the most important need for ODGJ is to eat. There are some ODGJ who want to eat alone, there are those who don't want to eat, and there are also those who always have leftover food. In addition, ODGJ have no desire to take a shower and don't want to shave their hair so that ODGJ's hair becomes dirty and tangled. Humans need food to survive and bathing as part of personal hygiene to maintain personal hygiene.

### Theme 4: How to Solve Problems in the Treatment of ODGJ

Problem solving solutions can be done by using coping mechanisms on individuals. A coping mechanism is something that is done by individuals to overcome situations that are considered as a challenge, wound, loss, or threat. Coping mechanisms are more geared towards coping with stressful and emotional demands. In addition, coping mechanisms are also used by individuals to deal with changes received. If the coping mechanism is successful, the person will be able to adapt to the changes that occur (Nursalam, 2018).

The results of the research that has been carried out by the researchers found that the solutions made to the problems experienced by the family varied, such as praying by always praying for the recovery of sick family members, trying to be sincere patiently and accepting destiny, following the wishes of the ODGJ which could not be directed, trying to be firm against ODGJ by forcing ODGJ to bathe or eat, and working with other families in caring for ODGJ.

This is in line with Pangandaeng's research (2018) which found that family support was provided such as praying for one another so that ODGJ would recover soon by praying together with the family as a daily ritual. In addition, the family also sincerely accepts family members who experience mental disorders and considers this a test that the family faces. Participants accept God's
provision for ODGJ and live it patiently. In addition, according to Nihayati (2017) the experience of families who cared for ODGJ after pasung said that what ODGJ experienced was a trial from God and they had to live it with patience.

**Theme 5: Family Expectations in Caring for ODGJ**

The hope of the ODGJ family is how the family will realize future wishes for people with mental disorders. Support provided by the family can realize family expectations, provide strength to the family, increase self-esteem, and be used as a primary prevention strategy for families to face daily challenges. Families as caregivers use various strategies while caring for patients with mental disorders, namely with positive emotions such as love and hope for a better future (Muryani & Sri, 2019).

The results of the research conducted by the researchers found that all participants hoped their families would recover and be able to carry out normal activities as before. In addition, the participants also hoped that they would always be given patience while caring for their family members who have mental disorders. This is in line with Pangandaeng's research (2018) which found that families hope that ODGJ can recover and carry out activities like normal individuals.

This is also in line with the research of Konadi, Nauli, and Erwin (2017) which found that participants who treat schizophrenia patients have hopes that in the future ODGJ will get better and not have relapses. Participants also have hopes for other family members to be able to help care for ODGJ. In addition, research by Yusuf (2016) found that family expectations are that they want their family members to recover and be able to carry out normal activities, carry out roles according to the family structure, and be able to realize the family's wishes for a better future.

**Theme 6: Treatment of ODGJ by the Family**

The recovery of people with mental disorders is influenced by adherence to treatment programs where ODGJ who adhere to control during the outpatient period are greatly influenced by the support of family members because it can minimize anxiety due to certain diseases and prevent non-compliance. Family instrumental support can be provided such as by taking the ODGJ for control to the hospital and preparing administrative documents for outpatient purposes, as well as informational support such as recording the time of the next visit and reminding the ODGJ regarding the visit schedule (Ernia, Indriastuti, & Risnawati, 2020).

The results of research conducted by researchers found that each participant had a different way of treating ODGJ. It also has
Defrilianda, Putri, & Wisanti(https://doi.org/10.58439/jhrt.v1i2.112) different reasons why families choose the desired treatment method. There were participants who initially went to a mental hospital, but there was no progress even though they had taken medication. Participants said that the drug might not work anymore because of the old age of the ODGJ. There are also those who routinely go to the hospital for treatment, but the ODGJ don't want to join them, so only the family controls the hospital to take the medicine and convey the condition of the ODGJ. Finally, there are those who take alternative medicine because the ODGJ condition doesn't bother other people and believes it can still be cured with alternatives.

This is in line with Dewi & Nurchayati's research (2021) which found that out of 7 families, only 3 families still routinely bring ODGJ to get treatment. The treatment provided is medical treatment in the form of outpatient care and caring for ODGJ at home. This is the instrumental support provided by the family to ODGJ by means of medical or non-medical efforts, paying for ODGJ treatment, spending time for ODGJ, and giving rewards.

CONCLUSIONS

There are six themes derived from this research, there are: the response of families in caring for ODGJ, changes in family activities, problems experienced by families while caring for people with mental disorders, how to overcome problems in caring for ODGJ, family expectations in caring for ODGJ, and treatment of ODGJ by the family. The results of this study can be used as basic data for researchers in conducting further research to identify psychological problems experienced by families in caring for ODGJ. In addition, this research can be used as a reference and reading material for future researchers in preparing scientific papers or thesis regarding family experiences in caring for people with mental disorders.

REFERENCES


