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The complexity of family stigma living with mental illness patients

Ira Kusumawaty *[1], *Yunike* [2], *Imelda Erman* [3]

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[1]Lecturer, Mental Health Nursing Department, Politeknik Kesehatan Kemenkes Palembang, Indonesia

[2]Lecturer, Pediatric Nursing Department, Politeknik Kesehatan Kemenkes Palembang, Indonesia

[3]Lecturer, Community Department, Politeknik Kesehatan Kemenkes Palembang, Indonesia

*Corresponding Author
Ira Kusumawaty
Lecturer
Mental Health Nursing Department, Politeknik Kesehatan Kemenkes Palembang, Indonesia
kusumawatyira@gmail.com

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ABSTRACT

Introduction

Families with mental disorder are often faced with stigma which results in hampering the patient's recovery process so that it aggravates and prolongs family suffering. Family experience when caring for sufferers is valuable information, however the exploration of Palembang family experiences when treating sufferers is still not much explored.

Objective

This study aims to explore family experiences when facing stigma in providing care for people with mental disorders.

Methods

This research was conducted with a descriptive phenomenological design and data collection through in-depth interviews. Families of people with mental disorders who are in the Ulu 1 Palembang Public Health Center are the study population and 5 participants as research samples were determined using convenience sampling techniques. In-depth information is outlined in the form of transcripts and matrices, then analyzed using the Colaizzi's method.

Results

Six themes have been identified, including: loss response, use of coping mechanisms, change in the response of social relations, the meaning of stigma for the family, expect community support and expect support from health workers.

Conclusion

Recuperation of mental issue can run ideally if stigma can be diminished through great joint effort between families, communities and health care services.

Keywords: Burden, Mental Disorder, Stigma, Family

INTRODUCTION

It is known that the number of people with mental disorders is 450 million, 873,000 people commit suicide each year and more than 90% of suicides are related to mental disorders.[1] Mental illness sufferers in Indonesia recorded an increase based on the results of the Basic Health Research (Riskesdas) 2018. This increase was revealed from the increase in the prevalence of households that have people with mental disorders (ODJG) in Indonesia. There is an increase in the number to 7 per household mile. It means that per 1,000 households there are 7 households with ODGJ, so the total is estimated to be around 450 thousand heavy ODGJ.[2]

Research data shows that family problems rank first cause of mental disorders. The data gives clarity about the problems in the family or surrounding

community that need to be fixed so that the family or community can be the continuation of the patient recovery process. Social, biological and psychological factors can cause mental disorders.[3,4,5] The linkages of these three factors affect a person, causing mental disorders. Stigma as a form of social environment is important in mental disorders. According to individuals with mental disorders often experience stigma by the community.[6-9]

Social factors cause mental disorders, in addition to biological and psychological factors.[10,11] Individuals with mental disorders are often faced with stigma from the environment and surrounding communities.[8, 12-14]

Stigma is a negative label that society gives to a certain person or group.[6,15,16] Cultural influence in the formation of stigma has implications for the role of nurses who must consider the socio-cultural background of individuals with mental disorders.[17, 18] However, the stigma facts to families with mental disorders in Palembang as one of the largest provinces in Indonesia have not yet been explored.

Stigmatization occurs due to presumption/prejudice, discrimination and stereotyping.[19] Stigma can originate from self (self-stigma) [20,21] and from society (public stigma).[12,21] Regarding people with mental disorders as dangerous, angry, afraid, not giving an opportunity to be involved in activities is an example of community stigma. Unable, weak, low self-esteem, different from others who feel people with mental disorders is a stigma on themselves. Stigmatization is strengthened by the community and has a significant impact on families with people with mental disorders.[9,21,22] Loss is one of the responses experienced by families for the occurrence of stigma, including deny, anger, bargain, depression and accept as stated by Kubler Ross.[23] The impact of stigma will be experienced by individuals and families.[12,24] For the families, financial burdens, domestic violence, decreased physical and mental health, disruption of family activities, future worries, stress, feeling unable to cope with problems.[24]

The ability of families to adjust to habits of people with mental disorders such as decreased motivation, difficulty completing tasks, withdrawing from others, inability to care for themselves, unable to manage finances so this condition results in the loss of family emotions.[25,26] For families, the stigma is very frightening, embarrassing, lowering family self-esteem and feeling of helplessness.[6,21] Society as a group around families with mental disorders also feel the existence stigma: When a stigma is believed, people will behave which causes discomfort.[27]

However, there are interesting things that stigma turns out not only to have a positive impact, but also a positive impact. The results of the research reveal that the family accepts the condition of mental disorders experienced by family members and regards it as normal, as is the diagnosis of other diseases. This means that stigma can have a positive impact on families with mentally impaired people.[28,29]

The existence of a wrong family perception due to stigma will not only burden the family and even lead to frustration.[30,31] Understanding family experiences in dealing with stigma will equip nurses to plan and provide appropriate interventions to help families relieve the burden of caring for people with mental disorders.[32]

The inability of families to adapt to conditions of people with mental disorders results in stress as a cognitive imbalance between natural needs and the capacity of caregivers.[31,34] Stress is caused also because of community stigma and self-stigma.[27, 35]

METHODS AND MATERIALS

This qualitative research uses a phenomenological approach that aims to obtain a description of the experience of stigma experienced by families with people with mental disorders, based on psychosocial responses, the impact of stigma, family expectations and the meaning of stigma for families. Efforts to finally form perceptions that are rich in experience in depth[36] explore directly and describe phenomena in detail, seeking to freely examine and describe life experiences by emphasizing experiences without

distance in descriptive Phenomenology. The stages that must be passed in descriptive phenomenology are intuiting, analyzing and describing.[37, 38]
The type of sampling technique used is convenience sampling[38, 39] so that all participants have experienced the phenomenon studied to meet the criteria, namely: family members who live with people with mental disorders, families with chronic mental disorders, able to tell experiences stigma living with people with mental disorders, capable of speaking Indonesian or the language of Palembang. In-depth interviews were conducted with 5 participants who met the criteria according to the researchers' stipulations. Each participant was given a P code and number 1-5 to make it easier for researchers when compiling the transcript of the results of the interview. Data collection was carried out by researchers using voice recording aids and field note. Field notes are sought by researchers to record any conditions or expressions exhibited by participants.

This research was carried out after obtaining information passing the ethical approval from the ethics committee of health research, Faculty of Public Health, Sriwijaya University. The information gathering process is carried out at family homes in the working area of the Ulu 1 Palembang Public Health Center. At present, the Ulu 1 Public Health Center is a reference for community health centers in the development of mental health programs in addition to the development of an integrated service center that involves community members as mental health cadres.

Ethical considerations are carried out by researchers to minimize risk, maintain participant privacy. Signing of informed consent was carried out for all participants after participants received an explanation of their involvement in the research process. The questions raised by researchers were semi-structured and open-ended questions. In order to obtain a complete picture of the participants' experience, the field notes method was used.[40,41] The data collection tools were researchers,[42] using interview guidelines, field notes and voice recorders. The main questions are related to the research objectives and the questions develop according to the responses given by the participants to the questions raised by the researcher.[39]

Data analysis was carried out using the Colaizzi stages because it was based on conformity with Husserl's philosophy that the appearance of the phenomenon would only exist if the participants experienced it so that it was appropriate to comprehend the meaning of the experience of stigma in families with people with mental disorders at home. The analysis passed comprised:

1) Describe phenomena based on participant information as a result of interviews and field notes.
2) The information description is reread repeatedly to get the feeling that is felt by the participants.
3) Formulate keywords through the process of filtering participant information, so there is no repetition of information.
4) Deciphering keywords based on the group by examining the relevance of the sentence and linking it with information from the results of the field notes.
5) Organizing all meanings into themes, then re-validating the themes that have been formed.
6) Integrate all research results into an interesting and deep narrative form.
7) Return all findings to participants to validate their suitability. Participant involvement must be maintained as long as there is additional information.

To obtain the validity of data in qualitative research, researchers apply the criteria of credibility, dependability, transferability and conformability.[39, 40]

RESULTS AND DISCUSSION

Participant Characteristics

The number of participants was 5 people, residing around the working area of the Ulu 1 Palembang public health center. Age of participants at the age of 30-70 years, 2 people are male and 3 people are female. The relationship between family and sufferers is as a parent. The level of education of participants varies, from elementary school not

graduating to junior high school. Monthly family income ranges from 750,000 to 1 million rupiahs and there is an uncertain amount. The work of the participants is a pedicab driver, pensioner, laborer, boat driver.

Theme Analysis

Theme 1: Loss Response

The sadness was expressed by all participants, as was the anger over the fate that they faced must have children who suffer from mental disorders. Anger, confusion, depression, conveyed by participants and consider it a disaster.

It feels sad, having children who are different from other normal children, sometimes talking to themselves ... (P1).

I don't know ... it feels mixed, sad, angry, annoyed uhh ... why should I have the trials of God .... what is my sin ... (P3).

No one wants to talk to my child, they are afraid of everything ... even though what are we ..... (P2)

I am very sad, he said, my child cannot recover, will this continue forever ... (P5)

I am worried about my child's future, even now I cannot go to school anymore (P4).

Let them say as they wish, I just pray to God that my child will recover quickly ... (P3)

Just surrender ... everything has been arranged by God Almighty ... (P5).

Theme 2: Use of Coping Mechanisms

In general, participants use confrontational and defensive mechanisms, as participants say the following:

Sometimes they get annoyed, they say my child is scary, when in fact it is not like that ... (P2).

I often tell my neighbors, don't talk like that, because it hurts our feelings ... (P1).

I leave it alone ... I'm afraid there will be a misunderstanding if I talk and explain to him ... (P5).

Let them mock us, just let it alone, it will also stop itself ... (P4).

Theme 3: Change in the Response of Social Relations

Participants felt a change in the attitude of their neighbors towards their families, as the following participant said:

I feel my friends are different now, a little away, but let it be their right ... (P4).

It's a bit stiff in the way they talk, no longer like they used to ... (P3).

Theme 4: Positive and Negative Meaning of Stigma for the Family

There are positive and negative meanings found based on family expressions, as follows:

Maybe this is a trial for my family, so that my family becomes more patient and devout worship ... (P3).

Because someone is sick, we think of one another, being compact about how to think of X's future, don't let X not have a good future ... (P2).

It feels scary, worrying, cannot be strength if you think about him ... (P1)

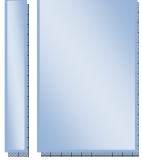
Life like there is no hope anymore, shame, not eager to guard this life, I don't know what to do anymore ... (P4)

It was frustrating to care for him, not healed, and often hospitalized again ... (P5)

Theme 5: Expect Community Support

The family hopes for the support and understanding of the surrounding community regarding the condition of their family members suffering from mental disorders, as the following expression:

The important thing is not to stay away from us, keep communicating, don't be suspicious ... (P3).



At least don't mock the Z, poor him, he also doesn't want to be sick like that ... (P2).

Please do not avoid my child, my child is not dangerous, he can be invited to speak well, and respect the elders ... (P1).

Theme 6: Expect Support from Health Workers
Participants expect repeated counseling by the public health center to residents so as not to behave which makes families and people with mental disorders uncomfortable, as the following expression:

So they understand and don't avoid us anymore ... (P5).

It is really necessary counseling for residents, so that they understand about this disease and feel our suffering ... (P4).

So that my child would not be ridiculed anymore and they would not laugh at my child ... (P2).

DISCUSSION

Theme 1: Loss Response

In the participants there were five stages of loss according to Kubler Ross including denying, angry, bargaining, depression and acceptance.[23,43] Feelings of guilt, worry can be categorized in response to loss. Participants expressed were very dependent on the phase of loss, which can occur in the acute and chronic phases. The process of loss is very individual and subjective, so the responses that arise as a result of stressors for family members who suffer from mental disorders are also different. The results showed that not all participants showed five stages of loss response. There are several stages of bargaining that are not skipped by some participants. Differences in responses can arise because during the interview process, participants try to recognize some experiences that have long passed, not experience during the interview. The participant's experience in dealing with the loss process also influences the form of response shown by the participant. The loss response to the mental condition can also be caused by the characteristics of the participants who differ in spiritual aspects. Participants whose spiritual understanding is better are more likely to accept the conditions of loss they face than participants whose spiritual understanding is inadequate.

Theme 2: Use of Coping Mechanisms

It was found that there was a denial or defensive participant in the presence of family members suffering from mental disorders, which is stated in the sentence annoyance. Besides that, there were also participants who explained to residents about their feelings about the stigma given by the citizens towards him. Participants have tried to adapt their burdens and problems in caring for people with mental disorders, in a constructive and destructive form. There are two forms of mechanism that can be shown when facing stressors, constructive and destructive.[44] Participants who accumulate and suppress the burden of their feelings, will further aggravate the burden of suffering due to stigma. This fact has a negative impact on the psychological condition of the participants. Someone who is able to open up and tell the problem to others will be easier to restore the psychological condition, compared to a personal figure who tends to accumulate his own problems. In general, participants did not share the burden of stigma they experienced, because they were ashamed and considered all the suffering they experienced was a fate of God.

Theme 3: Negative Effects of Stigma on the Family

Changes in community interaction are felt by the participants, by avoiding local residents to interact with them or with family members who suffer from mental disorders. This fact is painful for participants, because actually interacting with participants or with sufferers is not dangerous. Stigma causes the motivation of participants to decrease and even frustrates and can lead to depression,[45,46] as expressed by several participants. This can occur due to lack of understanding of the community about the condition of patients who are not dangerous. In addition, negative impacts can be caused by socioeconomic conditions[47,48] and the level of education of participants.[19,27] In this study, participants' socioeconomic conditions were very depressing, with family incomes below the minimum standard. The majority of participants work as

unskilled laborers, so frequently the fundamental requirements of the family are not encountered.

Theme 4: Positive Effects of Stigma on the Family

The existence of stigma against people with mental disorders on the one hand can have a negative impact, but conversely a positive impact. The emergence of a strength in the participant's family to help one another and think of treatment and the future of sufferers is a form of positive impact of stigma. The growth of strong motivation arises when there is the same perception of the burden suffered. This study is consistent with the previous study that the family will try to provide support by together other family members caring for people with mental disorders.[49] The spiritual aspect also strengthens positive acceptance of the patient's condition. Confidence in God's gift gives positive hope and strengthens motivation between the partners and other family members to restore the sufferer's condition.

Theme 5: Expect Community Support

Participants really expect the growth of community awareness to understand the condition of sufferers, understand the burden of suffering. This is in accordance with research which concluded that citizens provide comfortable conditions for sufferers and their families, do not discriminate, provide equal opportunities to sufferers in various ways.[50,51]

Theme 6: Expect Support from Health Workers

Participants really hope that health workers can provide counseling on an ongoing basis, with the hope that the understanding of the surrounding community will be better. Improving the understanding of citizens will be able to minimize the stigma of citizens against people with mental disorders and their families. It was known that health education has a significant effect on community understanding in treating people with disorders.[52,53] The reduced stigma felt by the participants will certainly increase self-esteem and motivation to provide full support for the recovery of sufferers' conditions that require a long time.

Various roles and functions are carried out by the family in carrying out caring for people with mental disorders.[54] The central role of the family that can be carried out optimally determines the success of the family in carrying out its functions.[55] The family has an affective function, socialization, social placement, reproduction, economy, health care. The existence of mental disorders among families gives an additional burden so that adaptation is needed in dealing with it,[56] because it is faced with external stigma (public stigma) and internal stressors (self-stigma).

Family stress occurs when the family is unable toadapt to the stigma faced, thus creating a caregiver crisis.[30,57]

CONCLUSION

The burden on families who have to care for people with mental disorders is very heavy, especially if caused by the stigma. Many factors can contribute to addressing the stigma experienced by families with mental disorders, which can come from oneself and stigma from the community. Recovery of mental disorders can run optimally if stigma can be reduced through good collaboration between families, communities and health workers.

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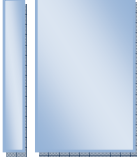

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