

Family stigma who have family member with mental illness: schizophrenia

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Abstract

Stigma negatively affects individuals as well as entire families. Stigma is not limited to the individuals experiencing it directly, family members as associated with those individuals could be affected. Family Stigma is negative perceptions, attitudes, emotions, and avoidant behavior towards family by others or societies, families will feel inflicted consequences includes emotionally, socially, interpersonal and financial consequences. The purpose of this study is to describe of family stigma who have family members with mental illness. Methods: This study used a qualitative research design phenomenological approach, participants of this study were 8 people, data were collected with in-depth interviews. Results: Results of this study obtained 23 themes, namely the attitude of the family, family perception, knowledge, type of treatment, support resources, adherence to the rules of treatment, family effort, the lost response, the burden of the family, the community response, conformity, public stigma, family stigma, public attitudes to the family, the burden of the family, the family rift, interruption of activity, decrease health status, social relationships, healing, role, caring, confidence, and realize the desire. Analysis: Negative perceptions by others, societies or family to members family are still being felt by families, those were avoidance, shamed to others or societies and limit the social relationship with the environment. So, negative perception is one of caused being family stigma. Discussion: Families who have family members with mental illness feel stigma from the society. The consequences of family stigma were emotional consequences, social consequences, interpersonal consequences and gained from this study financial consequences, which is a financial burden for the family in providing care. Future studies are expected to quarry deeper into the family stigma who have family members with mental illness by expanding the data retrieval support.

Keywords: *Family stigma, mental illness, qualitative research*

INTRODUCTION

Stigma is a barrier that can prevent patients with mental illness from getting appropriate treatment of care (Cooper, et al, 2003). In fact, 50-60% of people with mental illness avoid treatment or care because the fear of being stigmatized (Substance Abuse and Mental Health Services Administration, 2003, in Park, et al, 2014). Stigma is not limited to the individuals experiencing it directly, family members as associated with those could be affected (Leafley, 1989). The structure of culture in society also contributed to affect the formation of values and norms in the family. Families feel the negative perception labeling and discrimination that affect their lives, it fosters the desire to withdraw physically and socially and limit themselves to use the opportunity to mingle with society (Napoleon, 2010). The family also conceal sick's

family member, so that they delay in treatment, and get discrimination in services. It could cause a weak quality of life, depression and increase the emotional burden of the family.

Mental illness is a behavioral syndrome when a person has characteristics, those are psychological, behavioral, biological function, and the disorder is not related to the individual but to the society. Generally, the classification of mental illness according to the Basic Health Research in 2013 is divided into two parts, namely a severe mental illness or psychosis groups and mild mental illness contains all the emotional mental illness are anxiety, panic, mood disorders, and so on. Schizophrenia is included in the group of severe mental illness (Maslim, 2002; Maramis, 2010; Yusuf, 2015).

Schizophrenia is the most common of mental illness, which is one of mental illness type

that can decrease the quality of human life. Schizophrenia is caused by the disproportion of dopamine (a chemical that regulates pleasure and satisfaction) on brain cells that make interpretation of the matter. Patients with schizophrenia have hallucinations, illogical thinking, delusions cause aggressive behavior, and often scream hysterically. Although the symptoms of a schizophrenic can be different from one patient to another, a schizophrenic behavior is different from normal people (Maramis, 2005; Ariananda, 2015).

According to the World Health Organization (WHO), the problem of mental illness around the world has become a serious problem. WHO estimated that 25 million people suffer from schizophrenia, while the number of schizophrenics in Indonesia was about 2.6 million people (Siswadi, 2014). Basic medical research in 2013 showed the prevalence population of Indonesia (schizophrenia) severe mental illness such as psychotic disorders, prevalence was 1.7 / 1000. This incidence means that more than 400,000 people suffer from severe mental illness (psychotic). The incidence of severe mental illness in East Java indicated approximately 2.2 / 1000. If the population of East Java about 38 million more, and severe mental illness is experienced by the adult population (about 70%), then the severe mental illness in East Java was $2.2 / 1000 \times (70\% \times 38 \text{ million}) = \text{approximately } 58.520$ people (Yusuf, 2015). We had done a preliminary study at Menur Psychiatric Hospital Surabaya in March 2016, that the total number of patients with schizophrenia in the Menur Psychiatric Hospital Surabaya is 18.774 people, while schizophrenic patients Menur Psychiatric Hospital who had families total 17.835 families (Menur Psychiatric Hospital, 2016).

Family stigma is people or society have negative perceptions, attitudes, emotions and avoidance of people toward family (and every family member) due to unusualness family (having a sick family member) so that inflict the emotional, social, and interpersonal consequences which could decrease the quality of family life (Park & Park, 2014). Meanwhile, according to Larson & Corrigan (2008) family stigma is a special case stigma experienced by individuals as a consequence of its connection to the family members who experience stigma. Stigma felt by every member of the family (Corrigan & Watson, 2003) and affected family's life, it causes limit opportunities for the family members, physical and social isolation and could integrate into life in society (Goffman, 1963 Malshc, 2008). Based on the literature above, it could be concluded that

family stigma is the negative perception by the public or others who influence the views and the treatment society to the families about attitudes, emotions, and social relationships, so it could be caused by consequences on the family, those are emotional, social, and interpersonal which can low quality of family's life.

Other studies conducted by Yin, et al (2014) describes the experienced caregiver treat patients with schizophrenia and received the stigma and discrimination explains that the caregiver gets a stigma, it is associated with social support, family ties, education level of patients, and factors in the family circle.

Based on that explanation, the family stigma is essential for nurses, it has been implicated for nursing practice that stigma families have a negative influence on the health status of the family, family health service including nurses, only focus on the patient's medical condition, not to much in discussion about the description of a family stigma of mental illness. Therefore, researchers wanted to explore the stigma of families who have family members with mental illness: schizophrenia by qualitative research methods, the phenomenological approach.

METHODS

The design of this study was a qualitative research with a phenomenological approach. The population in this study were family people with mental illness in Menur Psychiatric Hospital, Surabaya. This study used purposive sampling which means sample was selected by the population according to the desire of researchers so that the sample could represent the characteristics of the population that had been known previously. The sample was taken in accordance with the predetermined inclusion criteria, with the number of respondents as many as 8 people. The inclusion criteria in this study were:

1. Participants were family caregiver (parent/child, husband/wife or other family members) who care family members with mental illness: schizophrenia
2. The family caregiver had at least 1 year of experience in caring family members with mental illness: schizophrenia.
3. Participants must be at least 20 years
4. Be able to communicate well with the Indonesian language or regional language (Java language) understood among participants and researchers

5. Participants lived with family members with mental illness: schizophrenia since being diagnosed
6. Participants were health conditions in the physic or mental

The study was conducted at room Wijaya Kusuma, Menur Psychiatric Hospital, Surabaya. It was started in the late June to early July 2016. The instrument used for data collection in this the interview were tape recorder (MP3) and field notes to declare the expression of participants. Guidelines semi-structured interviews were made by researchers. The methods to collect data was done by depth interview for \pm 60 minutes. Furthermore, data collection procedures in this study were divided into three phases, starting from the preparation phase, the implementation phase, and termination phase. Data collected were then processed and analyzed using the methods of data interpretation Collaizi in nine steps.

RESULT AND DISCUSSION

The theme that emerged was formulated based on the participants' answer to the question of interviews and field notes during the interview process. This research resulted in twenty-three themes that were pursued into five major themes appropriate for particular goals: perception of family, the feeling of family, family stigma, the impact of family and family expectation to family members with mental illness: schizophrenia Menur Psychiatric Hospital in Surabaya.

Scene 1: Perception of Family

Family perception in view of family members with mental illness will build knowledge and attitudes. Based on the interviews conducted by the researchers, the participants had a negative behavior and positive behavior in caring for family members with mental illness.

Sub-themes: Behaviour

According to Wawan & Dewi (2010), negative's behavior will be tendencies from avoiding, hate, dislike a particular object.

"... He does not want, unhappy, against the rules of parents ..." (P5)

"... I ran away to the neighbor for getting help, my neck was hand placed by him, beaten (clenched hand) So I am ..." (L6).

Positive behavior will be tendencies in actions such as approaching, happiness, expecting in the certain object (Henry & Dewi, 2010).

"... Anyway, he was, after hitting me, broken many plates, and then he apologized (smiling).

"Mom, I'm sorry" ..."(P4).

Sub-theme 2: How to Take Care

Perception of the family in caring for family members with mental illness, according to this study found that the type of family care, adherence to treatment rules, resources, and efforts of the family.

".... doing what they do, up to him... .. how to care, just allowed" (P3)

"... I Drink to him (medicine), three days. My mother was clever if She drinks medication, I give it to her, then I see, Just clever, directly she is disposal. Sometimes, she wants to drink, but after that, She throws out the medicine from her mouth,, ,, My mother was clever in hold principle.. if taking medication ... "(P8)

"..... I call my sister, call my brothers, then he said,"yeah, its better you go to Psychiatric hospital (Menur)... "(P4)

Scene 2: Feelings Family

The theme that emerged in this study is loss response and the burden of the family. Loss response consists of five stages, those are denial, anger, bargaining, depression and accept. Meanwhile, the burden of the family consists of objective and subjective burden.

"... Why I have a sick son like this (crying) so what happened in my family?" (P7)

".... Yes, all over comes from Allah anyway, but why until I get my son has the mental illness? (crying)..." (L5)

"..... This like overburdened, right? such as I come here (Psychiatric Hospital), I come here also left my children in my house, so it is a burden from me, my mine has part divided into two things ..." (P3)

"..... if my son is sick for the rest of his life, why should I live? I'm so (sadness) ... "(L6)

Theme 3: Family Stigma

Family Stigma is a negative perception, the negative attitudes of others or society, so families are also looked after sick's family members as a consequence attitudes toward patients caused by handling from society (Park & Park, 2014). Therefore stigma appears based on negative perceptions conducted by the subject.

Researchers divided two sub-themes, namely public attitudes to the family and response family toward the public.

Sub-theme 1: Public Attitudes

The description of public attitudes is reflected in the attitude of public not only impacts the client but also on the family. The public perception will affect people's attitudes and treatment of a family member who has a mental illness (Romadhon, 2011). The negative attitudes of the public toward family based on the researches conducted, public

blame, insult, unappreciated, shunned, dislikes, talking in the back, apathetic in the family, people create a deterrent to families, sometimes angry, tired and apathy due to the behavior of people with mental illness.

".... Yes yes, it has mistake from me, I got blamed from my family, my friends," this is your fault, your son hasn't got work, hasn't passed from their school, you directly get marrying him. It is not strong (shaking his head) His thinking hasn't toward there yet, bear load" (P1)

".... Sometimes he throughs ... sit down, and I (family) has given meal from a neighbour that stale food ... the parents was so hurt cause neighbor's action ..." (L5)

"..... So, my brothers don't want to be near with me..." (P1) "..... if we meet each other, he is apathy, unhappy with me, I haven't negative thinking, but I feel like that..." (P8)

The study also found positive attitudes from public to the family, which many people are a pity with family members have the mental illness for this family condition perceived by some participants. The Public also understands the condition of the family, one of the participants stated that people don't hate his family and even give a lot of good to them. Public also give attention to the family as providing materials, food and so on. Therefore, family stigma comes from the knowledge and the negative perception of other people or society, so that consequences received by the family that can decrease the quality of family life.

Sub-theme 2: Response Family

Families also feel the consequences having a family member with mental illness, they feel embarrassed and limit their social interaction and relationship.

"... Every morning, My mother bother people, so I feel so embarrassed much the same as my neighbor ..." (P8)

".... Morally ashamed yes there is (looking down) but It depending on what a strong person or not, if my wife, she is strong, My mother in law is strong also, but my father in law isn't strong (laughs) ..." (L5)

".... So if I want to say, but why, I am lazy to say with public..." (P8)

Theme 4: Family Impact

The impact is felt by families who have family members with mental illness obtained five themes, namely the burden of family, the family rift, interruption family activities, family health status, and social relationships.

Sub-theme 1: Burden Family

Family burden obtained objective and subjective burden. The burden consists of objective physical burden, financial burden, and time burden. Five participants stated that felt the brunt of the physical. Four participants stated family members experiencing financial burden, and two participants stated time burden of caring for family members of mental illness.

"... I Came home from work to Dudusampeyan (local name's district), then to be a half day here, to Sidayu (local name's district) .. so, my body is so tired, then my money also. tired body, thinking, money also..." (P8)

".... I've beaten (both hands clenched) twice ... Keep me till anesthetized, if I ask the same out of people, exhausted I have beaten again. Be pursued by him" (P4)

".... Mom, mom cigarette" (hand exemplifies like smoke) O God (his chest) I run away. It was debts .. "... No cigarettes, don't be like that, six cigarettes pack of tablets in one day. I wanna cry. There is no everybody in family that working (low tone) (sadness)...." (P2)

Sub-theme is the burden subjective, consisting of categories of the psychological burden, the burden of thinking and moral burden. Six participants revealed that feel the psychological burden, the five participants who have family members with mental illness expressed the burden of thinking, and the moral burden is expressed by one participant.

"... All feel sadness (hands placed on the knee), till occurred happen, my son is disappointed (nod) ..." (L6)

".... Here it's branched thinking (rising tone) anyway my mind, after this problem has overcome, continues new problems again (illness mental illness) ..." (P3)

Sub-theme 2: Broken Family Relations

The impact of a family who has family members with mental illness are a family rift. Their family members who are mentally handicapped will indirectly lead to internal conflict in the family.

".... then, in this final my mother and the father have ended, divorced. I am afraid my mother was killed by my father anyway. crazies people like that right do not realize what they conscious ..." (P3)

"..... Death (father) is not because of something or other, but the dizziness, right not strong mentally right" (L5)

Sub-theme 3: Disorders Family Activity

In the sub-themes of this theme was found that the impact of families who have family members with mental illness are disturbances family activities. In another study, Prawtaku (2006) report that tensions role/role conflict more experienced for

the caregiver due to leave work to care that affect the family economy.

"... The impact of family, hehe (laughs) impact family is shambles. No work one of us (family), this committee also children in this house housewife ... "(P3)

Sub-theme 4: Family Health Status

If one or more family members have health problems, it will affect family members and other members, and families in the surrounding areas (Effendi, 1998). The impact is felt by families who have family members with mental illness in this study get a theme of family health status.

"... Well, I get heart attack.... there is in 1 year. My heart is weak.."(P4)

Sub-theme 5: Social Relationships

One of their family members who has experience mental illness in the family will automatically affect the pattern of family relationships and how to behave towards the environment. This tends to happen because of the assumption of the family that the environment is looked at with family members with mental illness as an individual who is considered to deviate from the values and norms adopted by society, so it needs to be shunned and considered dangerous (Keliat, 1996). The impact is felt by families who have family members with mental illness limited social relationships.

"..... If I greet them.. "There is not a response from the public, only smile but not from sincerely .."

.... Yeah different view, rarely said hello .. "(P8)

Scene 5: Expectation Family

The family as a provider of mental health services and the public need to treat people with mental illness by encourage and support for growing expectation and optimism. Expectation and optimism will be a motor force of recovery from mental illness. Their expectations are the motor to recovery process (Setiadi, 2014).

In this study, was found that one of the family's expectations are given a cure, can still care for, work, and increased spirituality.

".... My hope yeah (glazed), I want mother was healed ..." (P8)

".... then, thanks to God Allah for giving longevity, I don't know for caring him, I will be strong for care him.. "(P2)

".... I'm the same Almighty to give truly he was given tranquility, opened his heart.." "Oh my family, my grandchildren, others will be like him (crazy) ..." (P7)

CONCLUSION

Family Stigma is a negative perception of another person or society that arises so that the

family also looked after sick family members as a consequence of the treatment of patients due to the attitude of the community. Therefore stigma appears based on negative perceptions conducted by the subject. The process stigma begins on stereotypical or knowledge and beliefs about a particular group, then will separate us from them or separation, this separation will be made between the group that did not get a stigma, then the victim who bears the stigma is a family would have the status of losses and would get experience discrimination by a particular group so it can be said labeling, the distinction, and labeling based on the differences of community members.

SUGGESTION

1. For health care

- There should be health promotion related to public ignorance about health care, especially mental health.
- The promotion health of the role of nurses in providing care to people with mental illness
- Needs for promotion health of families with mental illness, how to treatment if the patient relapses.

2. For the development of nursing science

The development of mental nursing is expected to utilize the results of this research as a topic in the classroom and practice in the communities directly.

3. For further research

Researchers are advised to continue and to dig deeper about the stigma of families who have family members with mental illness through other qualitative research more comprehensive. Especially in the case of the determination more specific inclusion criteria for patients with mental disorders deprived by the family and samples such as expansion of data retrieval support such as the patient's family, family members of patients, the environment around the patient and health providers.

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Families who have family members with mental disorders feel the stigma of society. The consequences of family stigma are emotional, social, interpersonal and gained from this study financial consequences, which is a financial burden for the family in providing care. Future studies are expected to quarry deeper into the family stigma who have family members with mental illness by expanding the data retrieval support.

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