

## The Sundanese Family Live Experience about Stigma toward Mental Illness

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**Abstract:** Stigma of mental illness is still a mental health problem that affects the lives of people with mental illness (ODGJ) and their families. Community still considers that mental illness are not a disease but a disgrace to ODGJ families. Stigma of mental illness is influenced by cultural factors. The purpose of this study is to explore the life experiences of ODGJ families about the stigma of mental illness in the work area of PusekmasSukaluyu, Cianjur Regency. This study is a qualitative study with phenomenology approach. The population in the study of the family of people with mental illness, cared for and lived with ODGJ for more than 2 years, and minimum education from senior high school. Eight participants were included in this study. Families experience explored through in-depth interviews and analysis of unstructured data using methods Colaizzi. The results were obtained six themes, namely feeling humiliated, embarrassed, hurt, and sad, labeled "orang gila", mental illness caused by "submissions" and "ngelmu", need empathy and community support, support each other in the family when facing stigma, and be patient and resigned in the face of stigma. It was concluded that stigma of mental illness experienced by ODGJ and his family. The community labeled ODGJ as "orang gila". Sundanese culture, especially Cianjur, is well-known for its good character and religion so that it faces the stigma of giving family support and patience in dealing with it. Puskesmas should make a health promotion program in the form of combat stigma, besides that nurses with mental programs need to improve their knowledge and understanding of the stigma of mental illness.

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### I. Introduction

Stigma is a collection of attitudes, beliefs, thoughts, and negative behaviors that affect individuals or the general public to fear, reject, avoid, prejudice, and distinguish someone (Corrigan, 2009). The stigma that continues to grow in society can harm and worsen those affected by this social label. Girma (2013) said that individuals who are stigmatized in society find it difficult to interact socially even in the worst cases can cause individuals to commit suicide, refuse to seek treatment, decrease quality of life, fewer employment opportunities, decrease opportunities to obtain settlement, decrease in quality in health care, and decreased self-esteem (Covarrubias & Han, 2011). According to the Guidelines for Diagnosing Mental Illness (PPDGJ, 2013) People with mental illness often experience stigma by the community in their living environment, even by their own families. Social factors are one of the causes of mental illness among two other factors namely biological and psychological. These three factors are interrelated in giving rise to mental disturbances to the client, and from these three factors the social environment including "stigma" provides an important role in mental illness. According to Corrigan (2012), individuals with mental illness are often stigmatized by society in their living environment.

Community awareness and perception of mental illness vary in each group of people with different cultural backgrounds. In a group of people voluntarily seeking help from professionals to deal with mental illness. On the other hand, in other groups, mental illness tend to be neglected so that handling will be bad even mental illness are considered shameful or bring disgrace to the family. The existence of these perceptions relates to traditional or cultural factors in societies that are still superstitious and irrational acts of ancestral heritage (Mubin, 2008).

At present the public perception in Indonesia towards ODGJ is said to be still not good, most people consider someone who behaves and looks strange on the streets considered as "orang gila" (Ben-Zeev, 2010). ODGJ also received bad treatment such as being shunned, ridiculed, and ostracized from the public even ODGJ was also taken to a dukun or "kyai" to get treatment by being given drinking water that had been "prayed" (Suryani, 2012). Families with mental illness often get stigmatized from their living environment, the stigma associated with mental illness has been shown to have a detrimental effect on human life with psychiatric illness

and caring families (Ben-Zeev, 2010). As explained in Muralidhalan's (2016) study that families with mental illness have a heavy burden and have a negative effect on work, social functions, psychological health, and physical as well as on the overall function of the family.

The burden on the family affects psychological pressure and decreases in the quality of life for family members with mental illness, psychological stress experienced by families such as anxiety, depression, loss of behavior, and emotional control (Rusch, 2009 & Vander, 2014). In addition, stigma affects the views of family members on mental illness that have a negative impact on interpersonal relationships and family closeness (Crowe, 2014).

The incidence of people with mental illness according to the World Health Organization (2014), there are 450 million people and there are 1 in 4 million in the world experiencing mental problems. Based on the results of the 2018 Basic Health Research, the prevalence of severe mental illness in Indonesia amounted to 7 per thousand of the population while the rate of severe mental illness in West Java alone in 2018 amounted to 55,133 people. The high incidence of severe mental illness causes emotional burdens and enormous financial burdens for individuals, families, and can even change people's views (WHO, 2003). This makes it one of the obstacles to the recovery process for people with mental illness, as explained in the Suryani study (2013) that the experience of recovering mental illness is unique and needs to take a more careful approach personally.

The Sundanese cultural values embraced by the Cianjur people that as Sundanese they have the values of Ngaos, Mamaos, and Maenpo both individually and live in a society to live in harmony, and can also achieve their own goals by carrying out their skills (mastery), also in fulfilling their needs to achieve their own ideas (Intellectual autonomy), and to realize positive experiences in their lives (Affective autonomy).

Their egalitarian values in Sundanese culture also encourage everyone to recognize each other because of the same fate and basic interests as humans. This is not accompanied by the distribution of roles to comply with the obligations and regulations attached to it as Sundanese. A low Hierarchy value indicates a lack of mutual respect for others (Kadiyono, 2017). This is supported by the study of Purnama et al (2016) that the Sundanese community, especially the area of Cileles Village, Sumedang Regency, treated the ODGJ roughly. The same thing as the researchers found in Sukaluyu, Cianjur Regency when conducting a preliminary study, the researchers found that the community still considered mental illness a family disgrace so that as many as 12 ODGJ in the Sukaluyu Health Center Working Area were carried out pasung.

Based on literature searches, in Indonesia Mubin (2008) qualitative research was found regarding the ODGJ family's experience of the stigma of mental illness in Semarang. In the study, it was explained that people's awareness and perception of mental illness differed in each group of people with different cultural backgrounds. From there it can be seen that family experiences of stigma are influenced by several factors, one of which is local culture or the environment. Therefore, researchers feel the need to conduct qualitative research on family experiences about the stigma of mental illness that take place in Cianjur with a characteristic Sundanese culture.

## **II. Material And Methods**

This study uses qualitative. Qualitative research is a study that studies various human experiences with different meanings from each method or approach (Streubert& Carpenter, 2011). The approach used is descriptive phenomenology, phenomenology is the study of how individuals understand their life experiences (Manen, 2017) which aims to explain the essence of the life experience of someone who experiences a phenomenon by identifying meaning and describing accurately his life experience (Rose, Beeby& Parker, 1995 in Streubert& Carpenter, 2011). Qualitative research was conducted on ODGJ families in the work area of the Sukaluyu Community Health Center.

**Study Design :** This study uses qualitative, The approach used is descriptive phenomenology.

**Study Location:** The study was conducted at PuskesmasSukaluyu Community Health Center, Cianjur Regency

**Study Duration:** This research starts from January to June 2018.

**Sample Size:** Respondents in this study were eight ODGJ families

**Sample size calculation :** The number of participants in qualitative research cannot be determined and rigid rules are not determined, but 6-8 participants are sufficient to fit the sample consisting of homogeneous groups and 14-20 participants for heterogeneous samples (Holloway & Galvin, 2017). The interview to stop compiling data has reached data saturation. The saturation data approved in this study discussed interviews that were no longer approved by participants.

### **Inclusion criteria :**

1. Families who care for clients (mother / father / child / siblings)
2. Client's family lives and takes care of clients > 2 years
3. Minimum high school education
4. Able to communicate well and cooperatively

**Exclusion criteria :**

1. Interviews are incomplete because of one other thing
2. The family is not present at the time of the interview

**Procedure methodology :**

Respondents were interviewed twice. In the first interview, information was collected by conducting in depth interviews with respondents who met the research criteria. Interviews were conducted in approximately 40 minutes. Previously the respondents were informed about the purpose and usefulness of the study. The main question posed is an open question. Subsequent questions are submitted with the intention of clarifying or validating the information provided. So that the data collected can be maintained completely, then the interviews conducted are recorded. The researcher also makes notes that aim to write down the situation or situation and the nonverbal response that the respondent showed during the interview. The second interview was conducted approximately one week after the first interview. This second interview aims to validate information that has been transcribed by researchers to participants.

**Data analysis**

Data analysis using the Colaizzi (1978) method. In the first step the researcher transcribed each interview recording. Transcription is then returned to participants to be validated if there is information that the participant wants to add or remove if it does not reflect his experience. All participants agreed with each transcription. Furthermore, the encryption is read repeatedly by the researcher to find the essence of the participant's expressions and determine some important statements, according to the objectives to be achieved in this study. The important statement is then formulated into more general meanings and then formulated into a theme group.

**III. Result**

Based on the results of data analysis using the Colaizzi (1978) method, researchers obtained 6 themes in this study including: experiencing negative emotions in the face of stigma, mental illness labeled as "crazy people", wrong assumptions about the causes of mental illness, requiring community support, support each other in the family when facing stigma, patience and resignation in the face of stigma

**Feelings of humiliation, shame, hurt, and sadness**

In this theme there are no sub themes. Almost all participants in this study revealed feeling humiliated, embarrassed, hurt, and sad. Below this is one of the participants' statements that have been insulted, following his statement:

*"... The front is good, but when you hear it is insulting, if it is in the front, is that so ... because it arrived at the place where the elis was occupied on the lap, ..." (P5.1)*

One participant revealed feeling embarrassed to have family members with mental illness. Here is the statement:

*"... Yes there is a feeling of shame with other people having mental illness like this, ..." (P6.14)*

In addition, participants expressed feelings of hurt when the community stigmatized mental illness, following a statement from one participant:

*"... Yes, what do I do, how do I feel, feeling sick about this life ... It hurts me. I feel that there are many people who agree with that neighbor, ..." (P7.7)*

And finally, participants feel sad when the community thinks negatively on ODGJ and family, here is one of the participant statements:

*"... Well, sad at that time, how come people can think like that even though who wants to get sick like that, ..." (P1.8)*

**Labeled "orang gila"**

The label "mad" causes a very strong stigma about people with mental illness in society, where insane people are considered community trash. Almost all participants revealed that mental illness were labeled "crazy people", following his statement:

*"... Yes, for example, Mamah looks like he is talking to himself, he is crazy who is crazy, so he said ... well, crazy kids, how's that like that, huh ..." (P1.2)*

The same was expressed by participant 3 that the community labeled mental and family disorders as "crazy people" not only in ODGJ but the community considered the ODGJ family to be "crazy people", following his statement:

*"... Neighbors told me this, someone said that the family left, some said their family was crazy, ..." (P3.4)*

In addition, the same thing was expressed by participant 6 that the community labeled ODGJ and their family as "crazy people, following his statement:

"... Especially if there are small children in front of the house who like to say, uh, the house is crazy, the house is crazy, right, the house is crazy, ..." (P6.10)

Participant 7 also revealed that people label mental illness as "crazy people", following his statement:

*"The one I heard the most was" crazy people, crazy people ... "(P7.5)*

And participant 8 revealed that people label mental illness as "crazy people", following his statement:

*"The term is not considered ... what is it ... oh crazy people ... is that what it means" Ah that's crazy, ... "(P8.3)*

#### **Mental illness caused by 'shipments' and "ngelmu"**

The wrong assumption about the causes of mental illness causes people to perceive negatively in people with mental illness. In this theme, some participants expressed this, following below is the expression of participant 1 that the community considers the cause of a mental illness because of a shipment from another person, following his statement:

*"He said that the mental disorder was a slanderous disease or a shipment disease, he said ... well at that time the people said that they got witchcraft, they got black magic, ..." (P1.4)*

The same was revealed by participant 8 that the cause of mental illness due to illness, following his statement:

*"This is the word of love, he said, since the pare business like to have someone who is envious, so the idir has trouble with this, ..." (P8.7)*

Participant 3 revealed that the community considered mental illness because they liked to play science, following his statement:

*"Oh, this is sick because you like you, hahaha, the father also likes you, you know, ..." (P3.6)*

#### **Need community empathy and support**

In this theme, some participants expressed the need for empathy and community support. This was revealed because what the family expected from the community was an attitude of empathy and community support not a stigma. Where if the community is empathetic and gives support, ODGJ will feel comfortable so that it helps the healing process of the patient. The following below is the expression of participant 1 that the ODGJ family wants the community not to differentiate between ODGJ and other diseases, as follows:

*"The community should be the same, so do not differentiate between those who are mentally ill and other illnesses, do not say what disease or descendants say, say it should be, let's go for treatment later it will be cured, give support ..." (P1.17)*

The same thing was expressed by participant 2 that ODGJ families wanted the community not to distinguish ODGJ, following his statement:

*"Do you really want them to be like that to the father, for example, the child is sick or just let it not have to be strange to talk like that ... so the behavior should not be like that, difference ..." (P2.8)*

In addition, participant 3 revealed that family wants the community there is no ugliness at ODGJ and family, following his statement:

*"Well, the people don't have any ugliness with the good family that hurts them too, don't have bad talk ... yeah talk, alright, alright ..." (P3.15)*

And participant 4 revealed that the family wanted the community to be able to respect ODGJ, and the following statement:

*"What you expect from your mother, because you already feel how it feels to have a family that is sick, the community should feel how it feels, ..." (P4.18)*

#### **Mutual support in the family when facing stigma**

Some participants express mutual support in the family when facing stigma. the stigma felt by families makes families stronger and mutually supportive, where families remain strong in the face of stigma. The family feels there is wisdom and becomes compact when there is a problem, this is expressed by participant 1, following his statement:

*"Alhamdulillah, ma'am, the family is tight because we like to call and gather when there is anything, there is a lesson, Alhamdulillah, ..." (P1.19)*

In addition, families feel mutually supportive when facing stigma, participants said 5, following his statement:

*"Yes, children like to support" just let me be patient. "... like to be reminded by children" Don't think about being afraid of pain, just feeling sick already, don't let sickness also hurt ... "(P5.9)*

#### **Patience and submission in the face of stigma**

Almost all participants expressed patience and resignation in the face of stigma. The following below is the expression of participant 2 that the family only asks Allah for help and surrender, following his statement:

*"Ahhh, at least we just, just ask God for help, why is this because it hates their parents too, just surrender to God, ..." (P2.4)*

Participant 3 revealed that the family felt this problem in their family and had surrendered, along with the statement:

*"Sometimes it's heard sometimes or not ... maybe because this has been the family's fate ... the family has resigned, ..."* (P3.7)

The same thing was expressed by participant 4 that the family could only surrender and pray, following his statement:

*"Do you have a long time like mother, like this, now you can only surrender ... resignedly, you want to do that, too, right now mom is just resigning ... Praying and resigning right now, sometimes it reaches this, really ..."* (P4.9)

In addition, the same thing was revealed by participant 7 that the family surrendered to God asking to be strengthened and explained, following his statement:

*"We just like a lot of things, just let go to God asking to be strengthened, the important thing is that we are sincere ... Just fighting and continuing to be patient, just wait, bro ..."* (P7.12)

and participant 8 also revealed that the family surrendered to Allah and asked to be strengthened, along with his statement:

*"But how about that, just surrender to God Almighty" what is that, we are also confused what to do "... ah just go to Allah now, just ask to be strengthened praying now, ..."* (P8.5)

#### **IV. Discussion**

The findings in this study are explained in 6 themes that describe family experiences about the stigma of mental illness. The six themes presented, discussed and linked to the existing literature to see their importance for increasing the knowledge of clinical practitioners and subsequent researchers related to the phenomenon of mental disorder stigma.

The family theme feels humiliated, embarrassed, hurt, and sad in line with previous research which explains that in facing the stigma of families experiencing various experiences that are felt such as family negative reactions, negative perceptions of the family, emotional reactions in the form of feelings of sadness, worry about health and well-being ODGJ's future, feeling stressed, feeling not much support, feeling ashamed to have family members with mental illness, and feeling hopeless. (Koschorke, 2017). The experience felt by the ODGJ family when they get stigmatized is that they experience rejection, blame, and avoidance by others so that heartache, disappointment and shame are felt by the family (Karniele-Miller, 2013).

Community attitudes that blame family members have a negative impact on family life, families experience shame, so that shame causes family members to avoid contact with neighbors and friends. (Larson & Corrigan, 2008). Supporting this statement Muralidhalan, et al. (2014) revealed that ODGJ family members were stigmatized through a number of stereotypes and prejudices, for example families were blamed, insulted, thus impacting emotional responses experienced by families such as feeling worried, losing, feeling responsible for their safety, feeling guilty, and ashamed.

Feelings of humiliation, shame, hurt, and sadness that are experienced by the family are related to the attitude of the community labeling ODGJ found in the next theme which is labeled "crazy people". in line with previous research it was found that people who behaved "strange" like talking and smiling to themselves, laughing improperly, appearing dirty and messy, shouting on the road for no apparent reason, destroying people's property, or suddenly attacking other people labeled "crazy people" (Suryani, 2013).

Judging from the perception of culture, Sundanese culture is famous for the egalitarian values adopted, meaning that Sundanese people are encouraged to recognize and respect one another. But this is not accompanied by a role to encourage this value that is attached to it as a Sundanese. A low Hierarchy value shows a lack of respect and respect for individuals who experience differences (Kadiyono, 2017), in this study it can be seen from the attitude of the people who label ODGJ as "crazy people".

According Pasal 1 UU No. 18, (2014) concerning Mental Health, people with mental illness physically appear to be poorly maintained, behave strangely, some of them go berserk for no reason, are naked and cause people to think negatively of them. The community labeled them as crazy, crazy, sedentary, tilted and considered unworthy of living together in the community. It was supported by Arthur's research (2011) that in Jamaica the community considered people with mental illness people who were not sick but they stigmatized ODGJ as "crazy people" because they did not know and did not understand what mental illness were so they treated ODGJ not well.

Lack of knowledge of mental health is indeed undeniable as the main cause of stigma for people with mental illness (Smith & Casswell, 2010). This is related to the next theme, namely mental illness caused by "shipments" and "ngelmu". Previous research found that the community believed that ODGJ was caused by mystical events such as witchcraft, dangerous, unable to work and would never recover, so that the community's stigma in ODGJ included neglect, prejudice and discrimination (Thorncroft, et al, 2008). This is supported by a statement in Rosyadi's article (2014) that the culture of Cianjur society recognizes the existence of an unseen

realm that is very trusted in its existence, nature can cause fear to humans who are not firm in their faith and forces that exist in creatures that are intended to play games others such as sending power, witchcraft and pellets.

The same was stated by Kapungwe (2010), who stated that the community discriminated against patients because of the wrong stigma about the causes of sick patients and the public perception that people with mental illness were dangerous and had to be shunned. According to Duran and Barlow (2007) explain that the community considers that if one member of his family suffers from a mental disorder is a disgrace to the family.

During the recovery process ODGJ and families need empathy from the community and community support, according to the fourth theme, which requires empathy and community support. Previous research found that ODGJ was unable to overcome his own mental problems. They need the role of others around them, especially families. The role needed by ODGJ and family is the support and empathy from the community (Safliati, 2011). Supported by Suryani's statement (2018) that during the recovery process ODGJ needed support from the environment. They need supportive environments from family, neighbors, the community and the government.

Suryani (2018) states that the support that can be given by the environment in the recovery process is to create a social environment that is comfortable for survivors. The realization of a comfortable social environment can be carried out with positive acceptance or empathy from the surrounding community towards the existence of ODGJ in their environment and not discriminatory behavior (Brichwood, 2011). This was supported by Lubis's research (2014) that the role of the community was needed to help ODGJ in creating so that they could develop their potential by empathizing, how to behave towards ODGJ without looking at ODGJ one eye.

Desired expectations ODGJ and his family are the hallmark of Sundanese culture that has the value of forgiveness and love (mutual love), penance honors (mutual self-improvement), and penance foster (mutual protection) in community (Fitriyani, 2015) so that empathy and community support is needed. In addition, one ethos or character of life that is inherent in Sundanese society or culture in living its life is to be bageur or must do good (Nuraeni, 2013). These cultural values also allow participants who are Sundanese to feel that empathy and giving support to others is an important thing to do.

A comfortable environment for ODGJ is not only in the form of community support, harmonious and mutually reinforcing family relationships also make ODGJ feel comfortable in the home environment. This relates to the fifth theme of mutual support in the family when facing stigma. A strong family bond is one of the efforts to provide support to ODGJ. In research

According to Sirait (2008) said, strong family ties make someone want to help when family members have problems, knowing that members of their family really need help. In this case the family needs strong support when facing problems. This is supported by Suryani's statement (2018) that the family is expected to be able to provide support not only in the form of meteril but also emotional support such as always listening to the complaints of survivors, being able to confide in friends, and most importantly being able to create a warm, intimate and full motivation every day.

With a cultural approach, Cianjur is one area that holds Sundanese culture. In Fitriyani's research (2015), it was explained that Sundanese culture has values that uphold the Sundanese people, which are reflected in the merit of love (mutual love), penance to hone (improve themselves), and choose foster care (protect each other). This is a characteristic of the characteristics of the participants in this study, namely Sundanese people who have a value of mutual protection in the family.

Friedman (2010), states that basic family functions include affective functions, namely the internal function of the family to fulfill psychosocial needs, nurture each other to give affection and accept and support. This function also affects personality. and self-concept of someone. The mutual understanding attitude shown by the family will accelerate the healing process for people with mental illness. According to Chien's research (2018), who conducted research in China in 201 mental illness families proved that families that gave and supported each other had an influence on improving the whole family's functions.

Families in treating ODGJ are a role that is not easy to live by. Many problems that have to be faced while doing care for ODGJ family members such as getting treatment and negative attitudes from the environment, feel the impact of caring for ODGJ. This is related to the last theme, which is patience and resignation in the face of stigma. According to Gitasari's research (2015) that someone in facing any problem in this world generally will surrender to the creator. Relationship with the Creator can be a source of strength for a person to continue to live life when something heavy befalls.

According to Satrianegara (2013) that the involvement of religion and spirituality influences survival and does not reveal anxiety in facing problems. In addition, it is also very spiritual in the healing process. This is supported by Hefti's research (2011) that there is evidence to suggest that there are beneficial effects in integrating spirituality into mental health care. The Hefti (2011) survey shows that 70% -80% of religious or

spiritual beliefs or activities can overcome daily difficulties and frustrations. Religion can help patients to improve emotional adjustment and maintain the hopes, goals, and meaning of life.

In a cultural approach, in the face of the stigma of the family asking God for help patiently and surrender in the face of problems. This is a characteristic that participants have in this study. Participants in this study are people who live in Cianjur Regency with their culture that is Sundanese culture. Sundanese people who are friendly and religious are one of the characteristics possessed by Cianjur people. This is explained in Kadiyono's (2017) study that Cianjur has 3 cultural pillars, namely Ngaos, Mamaos, and Maenpo. Ngaos is a tradition of recitation that colors the atmosphere and nuances of Cianjur with a community that is religiously attached.

## V. Conclusion

Based on the above explanation, this phenomenological research was conducted on 8 family groups that have ODGJ. The experience was analyzed by the Colaizzi approach (1978) to obtain an overview of family experiences of mental stigma, described in 6 themes, namely feelings of humiliation, shame, hurt, and sadness, labeled "crazy people", mental illness caused by "shipment" and "Ngelmu", needs empathy and community support, supports each other in the family when facing stigma, patience and resignation in the face of stigma. The results of this study found new perspectives and strengthened several previous studies. The theme is also associated with the distinctive characteristics of the Cianjur people who are known as religious individuals, and also Sundanese culture who uphold the fairy tale of love (mutual love), penance honors (mutual self-improvement), and penance foster (mutual protection).

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