



## The fight against stigma in the recovery process of post-*pasung* mentally ill patients<sup>☆</sup>



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### Abstract

**Objective:** To identify the resistance against stigma as part of the recovery process in post-*pasung* mentally ill patients.

**Method:** A descriptive phenomenology approach was used in this qualitative research. The 12 participants in the sample were selected using the purposive sampling method. The data collected through in-depth interviews with post-*pasung* mentally ill patients. The Colaizzi method was used to analyze the data.

**Results:** Four themes emerged from the data analysis: the reluctance to be confined again; the demand to interact with other people; the sense of discrimination by being stigmatized, and the desire not to be differentiated from others.

**Conclusion:** The freedom from stigma could begin with how mentally ill patients perceive their acceptance by society. Based on the results, optimized community mental health nursing for mentally ill patients in their neighborhoods is urgently required.

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### Introduction

Mental health problems continue to be of concern throughout the world. Every year, the number of mentally ill patients continues to increase. Data published by the World Health Organization (WHO) indicated that as many as 450 million people around the world suffer from mental health problems, including schizophrenia.<sup>1</sup> Global data showed that

around 350 million people suffer from depression, 60 million people suffer from affective bipolar disorder, 21 million people have schizophrenia, and 47.5 million people have dementia. In line with the above data, the results of the Household Mental Health Survey showed that symptoms of mental health problems in the adults in households in Indonesia were diagnosed in 185 cases per 1000 residents.<sup>2</sup>

According to basic health research data, the prevalence of severe mental illness among Indonesian citizens was 1.7 per million.<sup>3</sup> The greatest numbers of cases of severe mental illness were in Yogyakarta, Aceh, South Sulawesi, Bali, and Central Java. Moreover, the data showed that there were many mental health problems in almost every regency in Bali, as follows: Buleleng Regency (25.9%); Bangli Regency (15.3%); Jembrana Regency (9.5%); Denpasar City (3.7%); Gianyar Regency (5.8%); and Klungkung Regency (6.2%).<sup>4</sup>

A common behavior demonstrated by mentally ill patients is mainly talking and laughing to themselves. Some mentally ill patients also exhibit violent behavior, such as screaming, throwing things, and assaulting both themselves and others.<sup>5</sup> These behaviors often make the people around them feel scared and insecure. Mental health problems are also viewed as an embarrassing illness and a disgrace to the family. Furthermore, because of the social stigma attached to mental illness, the family often decides to physically restrain the sick family member at home by tying them up, which is known as *pasung*. The family takes this action because society views mental illness as a consequence of violating prohibitions, witchcraft, and curses, which are based on supernatural beliefs.

The term *pasung* refers to the act of physically restraining or locking up a person. In restraining mentally ill persons, objects are attached to the body to limit their movements, which is an improper therapeutic procedure.<sup>6</sup> The type of *pasung* that is commonly practiced in the home by the family is to lock up the mentally ill person, restrain him or her by chains, ropes, or iron enclosures, and isolate him or her from society.<sup>7</sup>

The Health Ministry has estimated that in Indonesia, *pasung* is experienced by more than 18 thousand mentally ill persons. The proportion of families that practice *pasung* on psychotic and mentally ill family members is as high as 14.3%, that is, around 237 of 1655 families.<sup>8</sup> Data obtained from the Bali Province Department of Health showed that in 2016, there were as many as 23 cases of *pasung*, ranging from caging, chaining, and the use of wooden stocks.

The environment, especially the family, plays an important role in the recovery process of mentally ill patients.<sup>9</sup> However, ironically, the recovery process is hindered by the stigma that is attached to the mentally ill patient's surroundings. The social environment, especially the family, should provide an open atmosphere that is conducive for mentally ill patients to regain their ability to function in society. Instead, mentally ill patients are limited and labeled by the families and by society. The stigma attached to mental illness restricts the activities of these patients, which then limits their social functions. Therefore, the present study is aimed to identify that the resistance of mentally ill patients to stigma is an important part of their recovery process.

## Method

A qualitative method with a descriptive phenomenological approach was used in this study. The objective of the study was to obtain comprehensive descriptions of the experiences of post-*pasung* mentally ill patients who resisted their stigmatization. In-depth interviews were used to collect data on the experiences of post-*pasung* mentally ill patients during their recovery process.

In this study, the participants were selected using the purposive sampling technique. The inclusion criteria were as follows: (a) post-*pasung* mentally ill patients who had experienced treatment in a mental hospital treatment experience, were currently permitted to return home, and were actively involved in outpatient care or social rehabilitation activities; (b) aged 20–60 years; (c) were able to communicate well using Bahasa Indonesia or the Balinese language; (d) had been assessed by a psychiatrist for positive and negative signs and symptoms with a score  $\leq 60$  on the Positive and Negative Syndrome Scale (PANSS). The PANSS assessment was conducted initially by a psychiatrist during the recruitment process.

Before conducting the data collection, permission was obtained from the Ethical Committee of the Faculty of Nursing at Universitas Indonesia. This study followed ethical principles, including beneficence and maleficence, autonomy (self-determination), anonymity, confidentiality, and justice. The researchers used semi-structured in-depth interviews with open questions. The interviews were recorded by a voice recorder and field notes. The Colaizzi method was used for data analysis.

## Results

The participants in this research were mentally ill patients who had experienced *pasung* and who had been treated in a mental health hospital. Twelve male patients participated in the study, ranging in age from 28 to 51 years.

Four themes and eight categories were identified in the data analysis: the reluctance to be confined again; the demand to interact with other people; the sense of being ostracized because of the stigma; and the desire not to be differentiated from others.

**Theme 1: Reluctance to be confined again.** This theme consisted of two categories: the refusal of recurring confinement in response to the act of confinement. The following are examples of the participants' statements describing their refusal of recurring confinement:

"[...] horrible to be confined..." (P1).

"[...] don't want to be locked again" (P2).

"be locked in a special room; I don't like it, don't want anymore..." (P12).

The second category includes responses to confinement, such as the following:

"[...] be confined felt quiet, I don't like stay in the room, horrible..." (P1).

"[...] be confined felt stuffy..." (P8).

**Theme 2: The demand to interact with other people.**

This theme consisted of two categories: the desire to associate and have friends and the intention to interact freely. The following are examples of participants' statements that described the desire to associate and have friends:

"[...] be confined, surely I don't want, I want to go out meet friends" (P2).

"I can't converse with people; I want to have friends" (P4).

The second category was the participants' wish to interact freely, which is exemplified by the following:

"I was handcuffed twice, so I can't go anywhere, please don't handcuff, I am the same as the rest" (P6).

"I was set aside in a room, it's difficult to interact with others" (P11).

**Theme 3: The sense of being ostracized because of the stigma.** This theme consisted of two categories: the cognitive response to being ostracized and the trauma of being exiled.

"I was like a disgraced person, feel estranged in my own home. ... I feel sad to remember it..." (P2).

"When I was locked I feel like an outcast, so now I have to keep healthy, don't want that again" (P10).

In the second category in this theme, trauma was caused by being exiled, which is exemplified in the following statements:

"I don't want to look at the past again, don't want the exiled incident like it was..." (P2).

"I will not come back here (mental health hospital) again..." (P5).

**Theme 4: The desire not to be differentiated from others.** The fourth theme consisted of two categories: the desire to free from the stigma of mental illness and the desire not to be differentiated. The category of free from mental illness stigma is exemplified by the following statements:

"I am not a sick person; I really hate to be called mental illness" (P4).

"People often mock me, I am labeled crazy, I feel most ugly, being stigmatized is the worst feeling" (P9).

"I am told ... crazy, even when I hear it, I don't react even though I am sad actually" (P7).

The second category included participants who did not want to be treated differently, which is exemplified in the following statements:

"[...] don't see me as a mentally ill patient, but I want to be viewed the same" (P3).

"[...] there I felt there was a difference from a normal person" (P10).

## Discussion

The participants in this study expressed that stigma had limited their lives. Being isolated from the environment was a state of ostracization experienced by the participants. The participants described the conditions they had to endure as

the result of the stigma attached to them as persons with mental health problems. The participants also expressed their resistance to the stigma, such as the reluctance to be re-*pasung* (re-confined), the desire to interact with other people, estrangement, and the desire to be positioned the same as others were.

The results of the study indicated that the stigma endured by mentally ill patients could have a negative effect on social and cultural attitudes, such as different understandings of mentally ill patients. Such differences may create negative perceptions of mentally ill patients, which thus leads to the practice of *pasung*.<sup>10</sup> Related studies in the literature also found that families practiced *pasung* to prevent their mentally ill members from harming others and even from attempting suicide. Another reason for *pasung* was described as the family's limited ability to take care their mentally ill member, the cost of health care, and the difficulty of reaching out to mental health facilities.<sup>11</sup>

In fact, when the family practices *pasung* because of the social stigma attached to a mentally ill family member, the recovery process of the patient is hampered. Thus, the stigma must be resisted maintaining the recovery of mentally ill patients, and hope they can be accepted within their social environment.

The stigma experienced by mentally ill patients and their families affects the recovery process, the social relationships of these patients, and the care provided by the family.<sup>12</sup> The participants in this study expressed the desire to interact by reflecting on their experience of seclusion (*pasung*). The results of this study showed that the stigma attached to mentally ill patients and their families caused them to withdraw from the social environment. However, such withdrawal could create distress and inhibit the social function of mentally ill patients and their families.<sup>13</sup>

However, the results also showed that unpleasant emotional experiences, such as exile from the environment, could lead to self-reflection and the determination to overcome the problem.<sup>14</sup> The results also showed that the self-reflection on past experiences strengthened the participants' desire to resist stigma.

The participants also expressed how they wanted to be perceived by other people. The stigma attached to people with schizophrenia, especially female schizophrenia patients, tends to make them lose the chance to develop themselves outside the home.<sup>15</sup> The opportunity for post-*pasung* mentally ill patients to engage in social activities in the community has the effect of raising their spirits, which helps them to function in society. These opportunities are part of the support of social and health services, such as rehabilitation facilities where mentally ill patients can improve their abilities before they reenter society.

The role of the mental health nurse in the community (CMHN) is also required in mental health care. The mental health nurse is the person who is the closest to their clients and their environments. Hence, the mental health nurse conducts comprehensive monitoring and evaluates post-*pasung* mentally ill patients and their families, which helps in achieving their acceptance by society.

Engaging in social rehabilitation activities and performing community services could help the participants in this study to assess their current abilities and strengthen their beliefs that they can function in the social environment. The

positive responses by others in the environment could help foster the adaptation process of mentally ill patients. The results of this study showed that the proper cognitive technique influences the self-adaptation of mentally ill patients. Moreover, it can decrease the feelings of shame caused by experiencing the stigma.<sup>16</sup>

Negative self-perceptions induced by the stigma could hinder the recovery of mentally ill patients. However, the stigma could be decreased by using a different approach to the perceptions of the person and his or her environment.<sup>17</sup> The reason is that the self-beliefs of mentally ill patients are cognitively related to their ability to resist and reduce the stigma. As experienced by the participants in this study, the fight against the stigma was a form of self-defense. They hoped that by showing their ability, they would be accepted by society. Subjective elements, such as self-stigma, must be considered in the recovery of an individual with schizophrenia.<sup>18</sup>

The desire to be free from the stigma attached to people with mental health problems could motivate mentally ill patients to resist it, which could help them to recover. The results of this study supported previous findings that motivation was influenced by the cognitive processes involved in how a person thinks about and solves the problem in the situation he or she faces.<sup>19</sup>

Their acceptance by the social environment helps mentally ill patients to adapt themselves to their surroundings. The absence of physical and non-physical restraints and the freedom to interact with the environment help increase the self-confidence of mentally ill patients in the community, thereby helping them to develop their abilities. Such measures could reduce the stigma attached to mentally ill patients. The roles of the family, society, and health practitioners such as mental health nurses and health caregiver from society member are significant in the achievement of the optimal recovery of post-*pasung* mentally ill patients.

## Conclusions

The stigma attached to an individual with mental health problems leads to *pasung*, which includes limited social interaction, ostracization, and the label of "crazy," which were often experienced by the participants in this study. Social stigma in the community causes the families of mentally ill patients to be ashamed, which often leads to the practice of *pasung* because they decide that it is the best way. Because of their treatment as mentally ill patients, the participants in this study desired to be free from the stigma attached to them. Freedom from this stigma could begin by examining how social acceptance is perceived by mentally ill patients.

The social acceptance of mentally ill patients would help to strengthen the cognitive activity of mentally ill patients in their fight against stigma. Having strong cognitive activity influences the motivation to act. Hence, the optimal function of a nurse in the health caregiver from society member in developing the mentally ill patient's environment is particularly important. Based on the results of this study, it is recommended that the health caregiver from society member perform the comprehensive monitoring and evaluation

of post-*pasung* mentally ill patients to prevent the recurrence of this practice in the family home.

## Conflict of interests

The authors declare no conflict of interest.

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