



Families' experience caring for mentally ill patients with re-pasung[☆]



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Abstract

Objective: Mentally ill patients tend to endanger themselves and their surroundings. Often times, this fact allows their families to decide whether to apply repeated *pasung* in the patients' treatment. The objective of this research was to determine the experiences of mental health patients' families in treating the patients using repeated *pasung*.

Method: This research used a qualitative design under a phenomenological research approach. The participants were family member caregivers aged 25–82 years old. The data were analyzed using the Colaizzi method.

Results: Caregivers who treated their mentally ill family members using repeated *pasung* experienced helplessness and prioritized safety. The results of this study can be described by 3 themes, namely: (1) the helpless feelings of the families in maintaining an adaptive state for post-*pasung* mentally ill patients; (2) a sense of security as the priority for suppressing the guilt; and (3) the care of mentally ill patients using repeated *pasung*: the reduction in the *pasung*'s intensity and the fulfillment of basic needs.

Conclusions: Repeated *pasung* conducted by family members is defined as an effort to create a secure environment for patients with mental health problems.

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Introduction

Severe mental disorders, such as schizophrenia, are closely related to violent behavior in which hallucination is one of the precipitating factors. Violent behavior is often manifested in environments where verbal abuse, self-harm, injury to others, and danger exist.¹ Violent and

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aggressive behavior committed by individuals with mental illnesses concerns both their families and the environment. The impact of these negative behaviors frequently becomes a trigger for the patient's family to implement *pasung*. A mentally ill patient's immediate family perceives the impact of the patient's disadvantageous behavior.² *Pasung*, which is defined as the act of imposing physical limits or confinement on people with mental disorders who act aggressively, is imposed by family members.³

Several considerations need to be acknowledged concerning decision-making processes, including precipitating factors and the phases of *pasung*. Lack of knowledge, financial problems, maintaining safety and comfort, upholding family honor, dissatisfaction with health services, failed alternative actions before *pasung*, family meetings involving prominent community figures, and community insistence are factors that influence families' decisions on whether to apply *pasung*.² Improper or dropped medical treatments, economic factors, and a lack of family and community knowledge on mental illness symptoms lead to repeated *pasung* for people with mental disorders by their families to prevent them from committing self-harm or endangering others or their neighborhoods.⁴ *Pasung* actions include manually tying ropes or chains on the patient's limbs, thus restraining the patient and making them unable to move. Isolation, the act of locking a person with a mental illness in a room or cage, is also a form of *pasung*.⁵

The prevalence of *pasung* ranges from approximately 6% to 17% around the world, and from 2007 to 2013, the USA saw increased use of restraints by as much as 34%.⁶ In Indonesia, before the launch of the Free *Pasung* Program in 2009, there were recorded 213 *pasung* cases, and 170 of these patients were freed and obtained medical services. The estimated number of *pasung* cases in December 2014 was as many as 57,000 cases, but only 5846 of these patients, around 10%, were freed and treated by health practitioners. From the latest data obtained in October 2015, the amount of found *pasung* cases regarding people with mental health problems was as many as 8543; however, around 7806 of these patients were exempted and obtained medical care.⁷ Baseline of health research data, there were 1655 households with mentally ill family members in the whole of Indonesia, of which around 14.3% had conducted *pasung*.⁷ Data from North Sulawesi alone suggested that around 20.2% of people with mental disorders had experienced *pasung*. The North Sulawesi government already applied the Indonesia Bebas *Pasung* Program (Indonesia Free *Pasung*) but many people with mental health problems ended up on wandering on the streets; the rest were confined by their families because of the families' insufficient funds to obtain medical treatment.⁸ From these data, it is estimated that many *pasung* cases are either undiscovered or left untreated comprehensively; thus, this status quo is far from achieving the goals of the Indonesia Free *Pasung* program and other government policies.

Based on an initial study conducted through short interviews with 2 families who brought mentally ill patients to the hospital, it was determined that the patients' predisposing conditions led to repeated *pasung*. Conditions stated by the family included difficulties reaching out to health facilities, financial problems, and patients' disobedience toward their medical treatment post-hospitalization, lack of knowledge

on their treatment, and fear and shame. The families also expressed disappointment when taking the mentally ill person back home from the hospital. The families wished for the mentally ill patients to be treated humanely and at least show signs of recovery. Unfortunately, however, when the mentally ill patients came back home, their behavior created anxiety for their families; the patients exhibited hostile attitudes toward their families, becoming angry, shouting, and self-harming. They often were unwilling to take medicine and fled from home. The families revealed that they had imposed *pasung* more than two times on the mentally ill patients. They had felt the consequences, including guilt and pity regarding the recurring *pasung* act; however, they stated that *pasung* had been their last option to ensure neighborhood safety and to prevent the patient from hurting him or herself. It can be assumed that a *pasung* act done by a family can be done repeatedly according to the situation, condition, and behavior of the mentally ill patient. However, it is unknown how families as caregivers treat mentally ill patients through repeated *pasung*.

Method

This research used a qualitative method with a phenomenological approach aimed at exploring family experiences in treating mentally ill patients with repeated *pasung*. Phenomenology is a study that describes general definitions from several individuals on every life experience related to the phenomena in question.⁹

This research was conducted in 4 regencies/cities in North Sulawesi from May to July 2018. Ten participants were involved in this research who were obtained using a purposive sampling technique and who fulfilled the following criteria: (1) A mentally ill patient's family member who is also the patient's main caregiver; (2) A family member of a mental health patient who experienced or on *pasung* 2 times minimum; (3) Able to communicate well using bahasa Indonesia or a local language (Manado) that is understood by the researcher.

Data were obtained through in-depth interviews in which the researcher was the main instrument. The data collection began by obtaining information regarding mentally ill patients who had undergone *pasung* from Dinas Kesehatan (the Health Department Office) and Dinas Sosial (the Office of Social Affairs) in North Sulawesi Province. From the data obtained from 22 mentally ill patients who had experienced *pasung*, 14 of them had already been treated in a mental hospital, and 12 of them had experienced *pasung* more than two times. The researcher contacted the participants directly to conduct screening based on the previously determined inclusion criteria. The researcher explained to the participants the purpose, benefits, and processes of the research and the participants' rights. The research process began after the participant signed the informed consent form.

To conduct the data analysis, the researcher used the Colaizzi method, which is an appropriate method for a phenomenological study.¹⁰ The data were saturated, and no new themes appeared when the interview results of the eighth participant were analyzed. To ensure data saturation, the researcher conducted interviews with two participants. The

research was approved by the Ethical Committee Faculty of the Nursing University of Indonesia.

Results

Ten participants, each of whom had implemented repeated *pasung* in mentally ill family members, were included in this research. These participants were the main caregivers of the patients. The ages of the participants ranged from 25 to 82 years, and their education levels varied from elementary school to higher education. The mentally ill family members had experienced *pasung* at least three times through methods that included being tied up, being confined, and using a wooden log. From the data analysis, three themes were determined, namely: (1) the helpless feelings of the family in maintaining an adaptive state in the post-*pasung* mentally ill patient; (2) the sense of security is the main reason used to suppress the guilt, and (3) the care of the mentally ill patient through the reduction of the *pasung* intensity and the fulfillment of the patient's basic needs.

The families' helplessness in maintaining an adaptive condition in post-*pasung* people with mental disorders

The families' helplessness in maintaining an adaptive condition in post-*pasung* people with mental disorders was a theme described by the families in treating these patients.

These feelings often occur because of the family's inability to continue the patient's medication therapy regimen. The first category is unsustainable medical therapy in funding the patient's medical treatment. This can be shown by the following participant statement:

"Dad is unable to fund mom's medical treatment because dad prioritizes our needs, the children... mom was on *pasung* again..." (P1)

Additionally, mentally ill patients who do not take their medicine also become an obstacle to maintaining their adaptive state. This can be seen by the following statement:

"taking medicine just one year... gradually unwilling..." (P3)

The second category is the behavior of mentally ill patients after stopping their medicine. The inability of a family to continue to give a mentally ill patient their medication leads to maladaptive behavior in the patient. Wandering in the streets, damaging property, striking others, and talking to themselves are among the behaviors exhibited by people with mental disorders. This factor can be seen in the following statements:

"when not taking medicine, mom roams the street to the end of the kampong/village..." (P1)

"Rampaging, rebelling, slamming things and hitting people" (P2)

"talk and scream to themselves" (P4)

The said behavior exhibited by mentally ill patients does not necessarily encourage the family to take the patient to the hospital or another health service to obtain treatment.

In this case, this unwillingness is often influenced by the trauma and disappointment caused by the patient's behavior. Additionally, economic factors and lack of support from other family members are a reason that a family may refuse to take a patient to the hospital. This forms the next category, namely inability and unpleasant family experiences as reasons for not hospitalizing a mentally ill patient in a mental health hospital. This is shown in the following statements:

"indeed, the family economy conditions at that time were hard, unable to take mom to the hospital, no money... so we the family decided that mom would stay here in the room... our understanding was that it was safer for her." (P1)

"I feel uncomfortable and unable... moreover, with our last experience in the hospital... (I) was traumatized to see my kid being injected repeatedly if they were home, even if tied, but we could take better care of our kid..." (P2)

"Honestly, I was disappointed in the services of the mental hospital; my kid was treated like an animal.. Anyway, to us, it is safer to be like this, as long as we are not neglecting him... we treat (him) well" (P6)

"I can't work; if I took him to the hospital, there would be no people to watch (him)..." (P7)

Repeated *pasung* was manifested in every family's experience in treating patients with mental health problems. The accumulation of a family's inability to finance the patient's medication, maladaptive behavior in the patient, and the family's disappointment in health care services encouraged these families to impose repeated *pasung* on the patients.

The sense of security is prioritized when the guilt is suppressed

The families stated that they felt guilty when they conducted repeated *pasung*. However, they justified the act of *pasung* by considering safety. This is depicted in the following statements:

"I know it is wrong, but this is the way we feel is the safest for him/her and for all..." (P5)

"So I discussed (it) first with the family... we know it isn't good, but it is safer... better than him/her disturbing people... as long we took good care of him/her." (P2)

"Actually, we want mom not to be chained again, we want to free her; but mom asked for it so that she cannot beat people." (P4)

"Who wants to see their parent treated like that? (It is) sad actually, (I am) angry at myself..." (P4)

Guilt follows repeated *pasung* implemented by families. However, families prioritize safety, both for the patients and for the patients' neighborhoods.

The care of the mentally ill patient: reduction in the *pasung* intensity and the fulfillment of the patient's basic needs

A family's experience in treating a mentally ill patient using *pasung* for the first time provides sufficient knowledge for families who repeatedly treat mentally ill patients using *pasung*. *Pasung* applied by a patient's family started from the method, and the intensity of the *pasung* is decreased to ensure the fulfillment of the patient's basic needs, as stated by the following statements:

"Sometimes we discharge her from the room when there are people at home." (P1)

"Now he/she is paralyzed, so we unleash the log and just lock her/him... there are times when we open the door when he/she asks... but there have to be people watching." (P8)

"Actually, it's not every day that mom is chained; there are times when mom asks to be chained because of her messed up thoughts, and she has to have people watch (her) at home." (P4)

"Even when we did *pasung*, we still looked after the legs' condition, changing leg... and we put socks on to prevent blisters." (P6)

Methods that families use to fulfill the basic needs of mentally ill patients consider the patients' independence. People with mental illnesses are usually untied, which enables them to fulfill some of their basic needs independently, and some helped. However, for a mentally ill person who undergoes *pasung* using a wooden log, their basic needs have to be fulfilled entirely. This is proven by the following statements:

"Most of the mom's needs we help to fulfill; the one's mom can do is eat, drink, and defecate/urinate..." (P1)

"All of the needs we help with because if the log wood is released even once, he/she will run away." (P6)

A family that imposes repeated *pasung* still pays attention to the patient's condition. *Pasung* as a treatment prioritizes the safety of the patient.

Discussion

The purpose of this research was to explore more deeply families' experiences in conducting repeated *pasung* for mentally ill patients. The research results identify a few themes depicting this experience and how the families interpreted it.

The experience of families in deciding to use *pasung* is a dilemma. There are differences when families decide to conduct repeated *pasung* compared to one *pasung*. In this study, the reasons for imposing *pasung* on people with mental health problems were to deal with their aggressive behaviors (79.7%) and to secure the individuals themselves (20.3%).¹¹ Before repeated *pasung* occurs, mentally ill patients experience release from *pasung* and hospitalization. However, when patients are treated at home, families face various challenges and obstacles during post-*pasung* treatment.

Families often express difficulties in continuing the treatment of the patients. This is usually due to family burdens, which include both subjective and objective burdens.

In this research, an objective burden experienced by families was the inability to fund a patient's medication. Unsustainable medication leads to maladaptive behavior in persons with mental disorders, such as violence, wandering, and recurring hallucinations. The reason that persons with mental disorders stop taking their medications after one month is usually due to discontinued medication or health practitioners not following up. Stopping the intake of medication causes recurring mental health problems, such as hallucinations, violence, and withdrawal.¹² On the other hand, a subjective burden expressed by families is exhaustion and the lack of help from other family members. Families' disappointment in hospital services also stops families from having the desire to take mentally ill patients to the hospital.

Family members, especially parents, are the most common caregivers of people with mental disorders. Parents are exposed to a greater burden than other family members, such as children or siblings. This is due to the parents' anxiety regarding the future of their child. They feel anxious about who will take care of their ill child when they are older and unable to do so themselves.¹³

The helplessness of families in maintaining the adaptive state of post-*pasung* mentally ill patients is the main encouraging factor for repeated *pasung* to be implemented. Some participants in this study expressed different processes they are going through compared to the first *pasung*. Repeated *pasung* conducted by family members prioritizes the security of the person with the mental disorder. In this process, the family experiences guilt. However, the family must also consider the potential possibilities that can arise due to mentally ill patients who are not in *pasung*, such as wandering or threatening their neighborhoods with their behavior.

Differences also exist regarding the method of *pasung* chosen by each family, for instance, a decrease in *pasung* intensity. In *pasung* treatment, the patient is not continuously confined or tied; there are times when they are released, or the tie is loosened. For persons with mental disorders who undergo *pasung* using a wooden log, the log is applied back and forth on each leg, and a sock is put on to avoid injury. In implementing repeated *pasung*, the family must also consider its possible impact on the patient, namely fatigue, muscle atrophy, bruises, anxiety, or dehydration.¹⁴

The basic fulfillment of a mentally ill patient's needs is done by considering the safety of the patient. Some participants stated that the basic needs of mentally ill patients, such as meals and personal hygiene, are fulfilled through the help of family. From the observations, there are certainly independent mentally ill patients. However, the patients' families feel anxious when the patients are not under supervision.

Conclusions

This research concludes that repeated *pasung* treatment conducted by family members prioritizes the safety of mentally ill patients and their surrounding environments. Methods of *pasung* are modified to decrease their intensity.

This research implies that families need to pay more attention to the conditions of mentally ill patients in meeting their basic needs, and they also need to make use of existing health services.

There is a limitation of this research, namely that family member caregivers can change. This can cause a lack of validity regarding some data, especially in identifying the first *pasung* process. However, the participants in this study were able to successfully express their experiences in treating their mentally ill family members. Future research is expected to explore the role of health services and related parties in preventing repeated *pasung* within the community.

Conflict of interests

The authors declare no conflict of interest.

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