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Preventing Pasung by mentally ill patients' families

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KEYWORDS

Family; Pasung; Decision making process

Abstract

Pasung is a way of handling the mentally ill in the several Indonesian communities. In many cases, when the patients leave the hospital they are once again turned out by their families and returned to the pasung. This study aims to identify and explore the means of preventing mentally ill patients in the community from being subjected to pasung through a test of Daulima's Pasung Decision Questionnaire that measures a family's intention to use pasung. This study tested the content validity and reliability of Daulima's Pasung Decision Questionnaire by using the Spearman-Brown single test-single trial. The respondents were 300 people drawn from five provinces in Indonesia: West Sumatra, East Kalimantan, West Nusa Tenggara, West Java and the Special Capital Region of Jakarta. The validity and reliability results showed that the content of this instrument is valid once improvements had been made to the statement items numbers 16 and 17. It was also shown to be reliable by the consistency of the responses with an alpha value of 0.729. This means that responses to the instrument are consistent and are reliable measures of the level of intention of the mentally ill patient's family to use pasung.

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Introduction

Mental illness is a maladaptive response to stressors from within or from the environment, which affect mood and behavior in ways that are inconsistent with the culture, habits, and norms of society. Furthermore, it affects the social interactions of individuals, their activities, or the functions of their bodies. Mental illness can also be defined as a syndrome of behavioral and functional changes or a psychological pattern of behavior that is clinically significant and occurs when a person is impacted by stress or disability. It is not easy to define mental illness accurately due to the many factors that can be used as benchmarks to determine whether a person is affected by mental illness. Nevertheless, we can conclude that mental illness involves a set of attitudes and behaviors that are not normal, whether re-

lated to a physical or mental condition, and which are considered incompatible with accepted concepts of the norm¹⁻³. Mental illnesses range from mild to severe.

The World Health Organization/WHO⁴ suggests that approximately one in four people in the world experience mental health problems. The WHO also found that nearly one-third of the population of Southeast Asia has experienced neuropsychiatric disorders. In Indonesia, according to a Household Health Survey conducted in 1995, mental illness is experienced in an estimated 186 out of every 1000 households. The number of people with mental health problems in Indonesia is already high, but it is anticipated that it will continue to increase. According to data from the WHO, in 2006, 26 million people in Indonesia were suffering from mental illness⁵. Data from other studies conducted in the provinces of Indonesia by the Ministry of Health⁶ indicate

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that the prevalence of emotional disorders is 11.6%, and that of severe mental illness is 0.46%. West Java and Jakarta are the provinces with the highest and second highest prevalence of mental and emotional disorders, with 20% and 14.1%, respectively. Jakarta is the province with the highest prevalence of severe mental illness, with 20.3% of the total number of severely ill people living here. In 2007, the total population of Indonesia was estimated at 224 million people⁷, this would mean that in all Indonesia there are 1,030,400 people suffering from severe mental illness.

Based on the data above, it can be assumed that many Indonesian people suffer from mental illnesses, ranging from mild to severe, and including stress, panic, anxiety, depression, and in the most severe cases, psychosis. It is anticipated that this figure will continue to increase in coming years because research conducted by the WHO⁸, shows that after a disaster, trauma, or loss the mental illness rate in the disaster area can increase by up to 20 percent. In addition, the problems of the economic and political climate are such that, allegedly, they are also causing the prevalence of mental illness to rise⁹.

People with mental illness, particularly those with severe mental illness or psychosis, suffer from impaired reality orientation, changes in mood and personality, habit disorders, or they withdraw¹. Disturbances in reality orientation often trigger aggressive and dangerous behaviors, such as harm to self and to others and damage to the environment. The hallucinations and delusions experienced by many psychotic patients can be the cause of this type of aggression.

The aggressive behavior of psychotic patients exacerbates social stigma, and discrimination against mental illness is common in the Indonesian community. The social stigma related to this problem not only has negative consequences for the sufferer but also for the members of their family¹⁰. Stigma becomes a social problem when the environment provides a negative label for the behavior of a person. Social stigma restricts the role the individual can play in society, making it even more difficult for the affected to function effectively in society. Social stigmas are heavily influenced by the myths that have developed in the community, among them that mental illness is a disease caused by the curse of God¹¹. As a result of such stigmas, attitudes of rejection develop, and repudiation by the people excludes and isolates both the person with mental illness and their family. Such stigma eventually makes families feel the need to hide the family member with mental illness, and even prompts them to take the drastic action of pasung.

Based on research conducted in May 2010 with the families of mental illness patients who had committed the patients to *pasung*, the data obtained indicates that the behavior of the patients, who had harassed and threatened their families and neighborhoods, had become a material and moral burden for the family¹². This burden was further intensified by the community's stigma and rejection. The family burden, with the rejection and stigma from the community, makes families stressed to the point where they are unable to meet the needs of the mentally ill through the provision of appropriate nursing care. As a result, they resort to acts that reduce their stress but often violate the patient's human rights, one of these being the separation of the patient from the family's day-to-day life. This exclusion is often accompanied by restraint and confinement, gener-

ally described by the term *pasung*, or the stocks. In this way, the problems imposed on family members by the mentally ill are resolved. *Pasung* is mostly done to patients who have chronic mental illness with aggressive or violent behaviors and hallucinations, which include the risk of harm to self, to others, and to the environment.

Pasung is an act of restraint that limits physical movement. The implementation of pasung violates human rights' law. On June 26th, 1987, the United Nations imposed on Indonesia a 1948 Convention against Torture and Degrading Treatment or Punishment and Other Cruel Inhuman Treatment. Indonesia ratified this convention in 1998¹³. It is clear that the victims of pasung are tortured and treated unlawfully, yet this act is supported by families because, when the mentally ill person is removed from the pasung, their aggressive behavior can once again disturb public peace and order.

In Indonesia, the word *pasung* refers to the physical restraint or confinement of offenders, people with mental illness, and those who commit violent acts and are considered dangerous¹⁴. Physical restraint is a clear violation of human rights, yet this conduct still continues today in psychiatric hospitals and faith-based places of healing. The types of restraint include chain or shackles, ropes, wood, confinement, and being locked in a closed room. These are applied to both men and women, and from children to the elderly¹⁵.

The right to life and freedom are fundamental rights of every human being, even for people with mental illness. *Pasung* is an act that deprives people of their liberty and of the opportunity to get adequate treatment. It is also degrading and an affront to human dignity because, when in the stocks, they are not treated as human beings. The most heartbreaking part is that this undignified and inhumane action is not only still prevalent in society but it is supported by the family, who should be closest to the people suffering from mental illness. According PERSI¹⁶, the estimated number of people currently thus deprived in Indonesia is between 13,000 and 24,000.

Although it looks as though the family has no feelings and no heart that they can take the pasung action, in fact such a decision raises great conflict in the family, especially a conflict between their desire to take the pasung action and a desire to free their family member from pasung. An earlier study found that pasung was undertaken because the family felt powerless against the pressures from the surrounding community, who in turn felt threatened by the behavior of the mentally ill person. Basically, the family did not want to take pasung action because they felt affection for their family member, but the psychological pressure from the neighbors who felt antipathy toward the person's behavior forced the family to make this decision. This situation would cause severe conflict in the family before they finally committed the ill member to pasung. This conflict occurs whichever way the family decides, whether they choose pasung or not, as both decisions will have the same burden of consequences. The decision is not an easy one, and the family often goes through a long process in which they consider all the possible consequences.

In some cases, *pasung* is actually an act by the family that protects their mentally ill member from violence by the community. Patients with chronic mental illness who tend to be aggressive often perform actions that harm both others

and the environment, such as beating people, vandalizing public property, and throwing tantrums. These actions can provoke reprisals from members of the local community who are affected by the ill person's aggressive behaviors. Essentially, it is a lack of understanding about mental health and mental health facilities and services in the community that force families to make decisions in favor of *pasung*.

Pasung is a way in which a community handles its mentally ill. The act of pasung is neither desired nor enacted by the ill person, but by others, and especially by the family. This is done through a complex decision making process. Until now, the government's efforts to resolve pasung have been limited to the curative field as they have freed pasung patients and then referred them for treatment in hospitals. However, in many cases, the pasung patients, once released from the hospital, are turned out and in due course returned to the pasung. For these reasons, the question of preventing pasung needs to be explored further in order both to prevent the initial acts of pasung as well as their recurrence. A measurement tool, Daulima's Pasung Decision Questionnaire, had been developed during earlier research to be used to detect the extent of stressors, the response to stressors, the availability of coping resources and the pressures that eventually trigger families to activate pasung¹⁷. It means that cases where mental patients are exhibiting disruptive and aggressive behavior can be detected early and the family's problem in deciding about pasung can be solved. This instrument has been tested for construct validity and reliability with good results for both validity and reliability (r results > r table value: 0.176-0.761; the Alpha value = 0.935). From this, it can be concluded that this instrument is a valid instrument for measuring the stressors, the response to stress, the coping resources, and the pressures to decide on the pasung action and the pasung decision itself. In addition, this instrument is also reliable, which means that the items in the instrument measure consistently and can be trusted as a measure of the likelihood of the pasung decision being taken by a mental ill patient's family. To further enhance the instrument's measurement ability, the study also tests the content validity and the split-half reliability.

Method

This study tested the content validity and the split-half reliability of Daulima's *Pasung* Decision Questionnaire. A single test-single trial aimed to produce a valid measurement tool for the contents that was reliable in relation to the consistency of responses. According to Cohen and Swerdlik¹⁸, content validity is a measurement of the extent to which the contents of a measurement instrument are relevant and represent the construct to be measured. The split-half reliability is a measure of whether respondents' responses to the measurement instrument are reliable and consistent. The technique used to test the consistency of the responses is the split-half, by which the measurements are performed on two groups of similar items at the same time.

The research population for the instrument test stage was all families in Indonesia who had family members with a mental illness. Respondents had to meet the following inclusion criteria: *a*) they were the family members (caregivers)

who cared for a family member with a medical diagnosis of schizophrenia and who had the following symptoms: hallucinations or violent behavior; b) respondents needed to be at least 20 years old and to give their informed consent; c) respondents needed to be able to communicate in Bahasa Indonesian, and d) respondents needed to be in good physical and mental health.

The sample size for testing the instrument was as determined by Comrey and Lee¹⁹, who state that the test instrument with less than 100 respondents is unfavorable, 200 respondents is quite good, 300 respondents is good, 400 respondents is very good, and 1000 respondents is excellent. This research decided on a sample size with 300 respondents which would be drawn from five psychiatric hospitals in five regions, which therefore became the research sites, with 60 respondents drawn from each hospital.

The sampling technique used in this study was purposive sampling, a sampling technique based on decisions made by researchers on the basis of characteristics or properties known from previous research populations²⁰.

The tests were conducted in the outpatient clinics at RS HB Saanin Padang (West Sumatra), RS Marzoeki Mahdi Bogor (West Java), RS Soeharto Heerdjan Jakarta (Special Capital Region of Jakarta), RS Atma Husada Samarinda (East Kalimantan) and RSJ Mataram Lombok (West Nusa Tenggara).

The reliability test used was the Spearman-Brown prediction formula, while the content validity test was conducted by checking the measurement instrument with experts in the field of psychiatric nursing.

Results and discussion

Split-half reliability test

Based on the results of the split-half reliability test, it was found that the alpha value was 0,729; which is greater than the standard value 0.7²¹. Reliability involves consistency of results in a series of measurements of the same thing. Split-half reliability is a tool for measuring whether a respondent's responses to a measurement instrument are consistent or not. The instrument is reliable in relation to the consistency of responses because the measurements were conducted on two groups of similar items at the same time. The statement with the highest reliability value was numbered 1. This statement is considered very reliable because it is the most consistent item when measured in two groups of similar items at the same time.

Content validity test

The results of the content validity test showed that it was necessary to change the instrument numbers 16 and 17. The number 16 previously read: "I understand that the patient can be cured if treated in a psychiatric hospital". This was changed to: "I understand that a psychiatric hospital is the place to heal a patient". Statement number 17 previously read: "I understand how to take care of the patient at home". This was changed to "I understand taking care of the patient at home". Statement number 16, needed to be changed because not all respondents understood that the

problem of mental illness can be treated in a psychiatric hospital. Statement number 17 on the instrument needed to be changed because the original sentence, using the word "how", could make the respondent confused.

From the test results, it can be concluded that Daulima's *Pasung* Decision Questionnaire is a valid measure of the extent of the stressors, the response to stressors, the coping resources, the intention to decide in favor of *pasung*, and the *pasung* decisions made by the family. The instrument is also reliable, which means that responses to the instrument are a consistent and reliable measure of the level of intention in favor of *pasung* by the mentally ill patient's family.

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