

Impact of Family Burden: A Case Study Re-pasung of People with Mental Illness

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ABSTRACT

Re-pasung of people with mental illness is one indicator that pasung liberation program is not implemented properly. The burden faced by families in caring for family members with mental illness is one important indicator in re-pasung actions. The purpose of this study was to describe the burden of the family in caring for people with mental illness post pasung which causes re-pasung. Qualitative design with a multiple instrumental case study approach using two cases chosen to provide an understanding of the re-pasungcase. Six people participated in this study who were selected through a purposive sampling method. The data collection was carried out by in-depth interviews with the case subject's family. Four categories were produced in this study, namely alternative therapy as an initial step in handling mental illness, pasung as a crisis management strategy, release of pasung and treatment in hospital, and re-pasung as a result of burden on the family. Subjective and objective burdens that can not be handled by the family are predictors of re-pasung family members with mental illness. Families need to provide support and burden management in caring for family members with post-pasung mental illness.

Keywords: Case Study, Re-Pasung, Family Burden, Mental Illness

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BACKGROUND

Pasung is a physical and social restriction for People with Mental Illness (PWMI). Pasung as a form of physical restraint or confinement is used for people with mental illness who have aggressive behavior (Minas & Diatri, 2008). Pasung can be in the form of binding or chaining limbs or attaching objects such as wooden blocks to the limbs and being locked up in a room (Jones et al., 2009).

Pasung is one of the treatment methods that are still chosen by families in caring for family members with mental illness. Families usually carry out pasung on the grounds that violence by a sick family member can endanger others and prevent the risk of suicide (Minas & Diatri, 2008; Suryani, Lesmana, & Tiliopoulus, 2011). Another reason is that health care centers are difficult to reach and low family income so families prefer to provide alternative medicine in churches or temples that use medical methods in which patients are chained, beaten, or satisfied because mental illness is believed to be caused by demonic and magic powers (Read, Adiibokah, & Nyame, 2009).

Pasung has a negative impact on PWMI in the form of physical and social changes. Pasung can cause PWMI to experience trauma, feel abandoned, inferior, and hopeless (Lestari, Choiriyyah, & Mathafi, 2014). Twenty-one percent of PWMI experienced injuries and their health conditions worsened when they were shackled (Guan et al., 2015). This condition led to the need for the exemption of pasung in accordance with the Indonesian program for free from pasung by the government.

After the release of pasung, PWMI are faced with problems in adapting social functions due to withdrawal behavior and post-pasung biopsychosocial changes. (Rasmawati, Daulima, & Wardani, 2018) and exacerbated by the stigma that PWMI who were shackled (Adeosun, Adegbohun, Jeje, & Adewumi, 2014). Acceptance and support from families is needed in helping PWMI adapt to the environment.

The family is seen as a support system for each family member and the family can have a positive or negative influence on the individual in the family (Kaakinen et al., 2014). Families often experience a heavy burden in providing care while patients are hospitalized and after returning home. These burdens include financial burdens in care costs, mental burdens in dealing with patient behavior, and social burdens especially in facing the stigma from society regarding family members who have mental disorders. The impact of the burden on the family will affect the family's ability to care for patients (Suryaningrum & Wardani, 2013).

Family burdens on people with mental disorders include objective and subjective burdens (World Health Organization 2013). Objective burdens relate to problems and experiences of family members, limited social relationships and work activities, financial difficulties, and negative impacts on the physical health of family members. Subjective burdens are burdens related to psychological reactions of family members including feelings of loss, sadness, anxiety, and shame in social situations, coping, and stress on behavior disorders of family members. The burden faced by the family is an important indicator of re-pasungaction. Family difficulties in burden management and the re-emergence of a ggressive behavior are reasons for re-pasungactions for family members with mental disorders. This study aimed to describe in depth the burdens experienced by families in the process of pasung and re-pasung actions for family members with mental illness.

METHODS

This study used a qualitative research method with a descriptive multiple instrumental case study approach, which examines several cases to illustrate or provide an understanding

of a problem. Two cases of PWMI were studied to gain a deep understanding of the burdens experienced by the family resulting in shackling, releasing pasung, and re-pasung actions for family members with mental illness.

The research was conducted in East Luwu Regency, which is the farthest district from the capital city of South Sulawesi Province. The study was conducted from May-July 2019. There were 6 participants in this study who were selected by purposive sampling technique. The criteria for participants in this study were the caring family / family members and community leaders. Three participants were the family of the case 2 subject, two of the participants are relatives of the subject of case 1 and one participant is the village priest and also the family of the subject of case 1.

The data collection method used by researchers was semi-structured interviews using interview guides in accordance with the research objectives, through observation and field notes. Interviews were recorded using a voice recorder. The results of the recording were transcribed in verbatim form and then analyzed the data. The data analysis technique used was the data analysis technique according to Miles and Huberman, namely compiling the information that has been obtained completely in a table, creating a category matrix and placing the information obtained according to its category, and presenting data with a flowchart of each case studied. (Yin, 2009).

Researchers made ethical considerations when conducting research by applying ethical principles. In this study, the researcher refers to ethical principles that fulfill the principle of anonymity by not including the participant's name, only using initials; confidentiality by guaranteeing the confidentiality of participant data; beneficence by conveying that the benefits of research are greater than the risks posed by trying to avoid questions that cause inconvenience; respect human dignity by giving freedom to participants to participate or refuse to participate in research, as well as the principle of justice by not differentiating between participants (Polit & Beck, 2012). Another important thing besides ethical issues is the validity of the data. The quality of data from a qualitative study was determined by the validity of the data generated.

The validity of the data used four criteria, namely credibility, dependability, confirmability, and transferability (Creswell, 2013). Credibility is carried out by being directly involved in data collection, observing the condition of the participants, and checking the data again by submitting the results of the interview and explaining the conclusions of the interview results to the participants to confirm whether they were in accordance with the participants' statements during the interview. When conducting a member check, all participants agreed to the conclusion of the interview results. The next step is dependability, which is a criterion that shows that the researcher has found trust. Dependability is done by collecting data and organizing the data as best as possible then thoroughly reviewing the data and submitting it to an external reviewer for input. The confirmability stage is carried out by confirming the results of interviews, observations, and field notes to participants to obtain participant approval whether they match the results of the interview so that objectivity can be guaranteed.

The final stage in determining the validity of the data is transferenceability, which is a form of external validation that shows the degree of accuracy and sees how well the research results can be applied and transferred to other participants who experience the same conditions. (Afiyanti & Rachmawati, 2014). Transferability is done by trying to describe completely and clearly the entire series of research so that it is able to describe the research context.

RESULTS

Case 1

The first case, a male aged 48 years who was PWMI has a history of mental illness for 20 years. The family considered mental illness that were experienced due to supernatural things and the patient's wishes that were not achieved. Alternative medicine was the first step that families take to treat the symptoms of amok they are experiencing. The next action was to lock up the patient using wooden blocks. Apart from being a form of restraint, the family considered this pasungas a way to make patients recover from the symptoms they are experiencing. The first pasung was carried out for 2 years. During the pasung, there was atrophy in both legs which resulted in the family not having the heart and letting go of the patient. When released from pasung, there are no signs of amok but the patient is naked. Then the next step the family did was to take the patient for treatment to the Hospital. The patient was treated in hospital for 2 years (around 2001 to 2003) until finally he was allowed to go home. When he returned home, the patient's condition in the first 2 months was still improving, but over times the patient experienced withdrawal which resulted in a relapse. The long distance from the hospital and the difficulty of family costs to visit the patient when being treated at the hospital caused the family to lock up the patient again.

Case 2

The second case, a 55 year old man is PWMI who had a mental illness of about 12 years. The family considered mental illness experienced as a result of the patient's occult knowledge and the trauma caused by working abroad. The first step the family took was alternative medicine but it did not change. Furthermore, pasung is carried out using wooden beams and chains. The next step taken by the family was to take treatment to the hospital, but the patient ran away back home. Treatment to the hospital was carried out 2 times and the patient always goes home by himself. The amok and murderous behavior committed by the patient caused the family to commit re-pasung to PWMI.

Characteristics of participants

No	Initial	Age(year)	Relationship with the case subject	Role in caring
1	Mrs. MS	52	Sister of case subject 1	Live with the case subject 1
2	Mr. SN	56	Brother of case subject 1	Food Supplier for case subject 1
3	Mr. HR	60	Brother of case subject 1/ village priest	Supply drinks and responsible for the hygiene of the case subject 1
4	Mrs. MR	55	Sister of case subject 2	Live with the case subject 2
5	Mrs. MI	48	Sister-in-law of case subject 2	Food Supplier for case subject 2
6	Mr. BI	53	Brother of case subject 2	Food Supplier for case subject 2

Four categories resulted in this study, namely 1) Alternative medicine as the first step in treating with mental illness; 2) pasung as a family crisis management strategy, 3) releasing shackles and hospital care; 4) Re-pasung as a result of the burden on the family.

Category 1: Alternative medicine as a first step in treating mental illness

Cases 1 and 2 were believed by the family to have mental illness due to occult things. Case subject family 1 assumed that the patient has mental illness due to requests from the ancestors to their parents that are not fulfilled so that the child became a victim, while the family of the case 2 subject believed that the mental illness experienced was because the subject of case 2 has studied the occult. This was stated by the participants as follows:

"In the past, someone had a dream saying to our father that the one who had the tree asked for two buffaloes, if it was not fulfilled, then the children of the father would later replace 2 people, now that's right, these two brothers of mine are now like this (mental illness)." (SN)

"As long as I lost it, my two brothers would have run there to the place where the tree was." (MS)

"Like there is magic, if you can be dammed it is what causes him stress." (MI)

There is a family belief that thinks mental illness occur because of supernatural things, causing families to take alternative medical measures to heal patients.

"He used to be found in a shaman, so sorry for him that he fainted." (MS)

"We tried the first alternative medicine, if I'm not mistaken, twice or three times, we went to some shamans going around here and there." (MR)

The insignificant changes, the uncooperative of the case subject in undergoing treatment and the method of treatment that the family considered had a bad impact on the health of the case subject caused the family to stop the treatment process and carry out shackling action.

Category 2: Pasung as a family crisis management strategy

Amok behavior and the existence of family beliefs that state that pasung is an attempt to treat the family causes the family to act of shackling.

"He started to go amok and was naked. so we did pasung. " (SN)

"We, as brothers, also did not dare to approach, in the end we concluded that pasung should be better because there are also people who say that shackles can be used as medicine. It can be cured if it is in stock. " (HR)

"Worrying, throwing everyone, walking around while carrying machetes everywhere." (MR)

The shape of the pasung that the two patients embrace was to use wooden blocks.

"They were shackled using wood at the feet of the two of them behind the house." (MS)

"When I was at my parents' house, I used morale and tied using chains in a room on the second floor." (BI)

Category 3: Removal of shackles and hospital care

The physical changes experienced by the patient cause the family to take off their shackles

"Because his legs shrank so they were removed, when he opened the shackle he didn't go amok anymore, just naked." (SN)

"Once he released, he ran away, lost to the forest for about a month." (MS)

After the first shackling, the case subject's family put him in a mental hospital. After hospitalization, the two case subjects were hospitalized again. The long distance to the hospital causes the patient to experience withdrawal from medicine.

"For a long time, he was lazy to take the medicine, a little angry, he began to forget, naked again." (MS)

"He did not take the medicine so he relapsed again, we brought him back to the hospital again, but he went home alone." (MR)

Category 4: Re-pasung as a result of family burdens

The recurrence experienced by the two case subjects disturbed the community. Public complaints and the increasing burden on treating recurrences of mental illness caused the family to decide to take re-pasung action for family members. The burdens experienced by the family consist of subjective burdens and objective burdens.

Subjective burden

The subjective burden is felt by the family from reports from the public and state officials regarding the alleged neglect of family members who have mental illness. This was conveyed by the participants as follows:

"Naked again behind the house on the side of the road, the angry police officer was ordered to secure it." (MS)

"The spotlight of the neighbors, neighbors said, because he naked and stood in front of the house, it was not good to see it, especially because he was an old man." (HR)

"Yes, he disturbed the children thus he was shackled." (MS)

"He was locked up because the neighbors were scared." (MR)

"The brothers said it was better to be tied up than making people afraid, We worried that he would kill again." (MI)

"If he lost again, it will be troublesome for us, right?" (HR)

Objective burden

The distance between the residence and the hospital causes the family to choose to take re-pasung action.

"Because we worked in the market, it was difficult for us to visit the mental hospital because we were all busy." (MS)

"That's the problem we didn't want to take it back to the hospital, because it's far." (MS & SN)

"We no longer took him to a mental hospital because he went home alone." (BI)

"Locked up with the consent of the family, no one wanted to take care of it. So, we just made a special house in the back." (MR)

"This is the best way, being locked up, because he had been taken for treatment he remained sick. Even, the land of my mother was sold for medical expenses but he couldn't be recovered." (BI)

DISCUSSION

Alternative medicine is one of the phenomena in dealing with mental disorders in society. The two cases in this study show that alternative treatment is the first choice of families for PWMI before going to the hospital. Both cases show alternative medicine to be an option based on the belief that the disease is due to occult causes. The mental breakdown is thought to have resulted from curses and evil spirits. Fanani and Dewi (2014) in their research shows that supernatural medicine or to a shaman is chosen based on the belief that the pain that a patient experiences is a strange disease that can be cured by going to a shaman. Other findings by Subu (2015) that many family members deny that their family is suffering

from mental disorders and consider the sufferer to be possessed by a demon, so they need to be taken to a Shaman. Shamans are considered capable of healing because they are believed to be able to communicate with evil spirits and benevolent spirits. Alternative medicine is also believed by residents in the country of Kenya by using herbal medicine, an exorcism for sufferers who are considered possessed by demons (Musyimi, Mutiso, Loeffen, Krumeich, & Ndeti, 2018).

Another alternative treatment option chosen by PWMI families is treatment of religious leaders. The results of this study are supported by the findings from Choudhry et al. (2016) that alternative medicine with spiritual treatment to religious leaders is often used as an option to ward off evil spirits, magical objects, or jinn. Treatment methods vary, such as consulting spiritual healers, practicing prayers, reading holy verses, using holy water, and using smoke for the room.

The effects of alternative medicine are manifold and may not always be as expected. During alternative treatment PWMI tends to faint, resist, or be uncooperative. Most of the treatment methods used by traditional healers are not standardized and do not have empirical evidence so that health practitioners have doubts about referring mental patients for treatment to traditional healers (Kpobi, Swartz, & Omenyo, 2019). This insignificant change caused the family to stop the treatment process and choose to do pasung.

Pasung was chosen by the family in both cases after the appearance of angry behavior, nakedness, walking around with sharp objects, and throwing things at people around them. This act of pasung is not only because of family fear of violent behavior from PWMI but it is believed that pasung can be a cure for mental disorders. Laila, Mahkota, Krianto, dan Shivalli (2018) explained that family members, neighbors, and society in general consider that pasung is necessary for the safety or protection of patients and others due to the patient's aggressive behavior such as physical violence against neighbors, breaking furniture, throwing things, stealing food, and running away from the house. In such circumstances, family members feel insecure and helpless.

There are various forms of pasung. The shape of the shackles that the two patients stayed in was using a wooden block, tied with a chain, and placed in a special room. The findings of these findings are consistent with the forms of physical restraint exerted by WHO (2017) that is, holding someone in bed using a belt or chain, locking a person in a cage, tying someone to a tree, bed or fixed object, and confining a person in a room. The same result was stated by several studies which suggested that the usual form of pasung was that both legs were tied with a chain which was planted on the concrete floor for days and restraint using chemical and mechanical methods (Rose, Perry, Rae, & Good, 2017; Patel & Bhui, 2018). Patients with schizoffrenia reveal the effects of confinement experienced in the form of physical injuries, both temporary and permanent. Health workers also highlight the negative psychological impact of retarding and exacerbating disease and increasing the risk of violence against others, making increased access to treatment the most effective way to reduce incidence of restraint.

The physical changes experienced by the patient caused the family to remove pasung. Both cases showed the effects of pasung were atrophy of the extremities. The first case in this study was the first two years of shackling. In addition to physical changes, the effects of pasung had an impact on psychological, traumatizing, crushed morale, and perceptions of unethical practices (Rose et al., 2017). This is because in the process of restraint there is often unnecessary use of physical force.

The pasung process that did not produce the desired results made the family decide to let go of the shackles and take PWMI to the hospital. In the first case, PWMI was taken to the hospital because after leaving his shackling, PWMI was naked and fled to the forest. These findings are supported by Amelia and Anwar (2013) indicates that the family of schizophrenic patients usually gives up the care and treatment of family members to a mental hospital because of the inability to care for the family and believes that appropriate care and treatment in the hospital allows the patient to recover.

PWMI who shows good behavior and decreased symptoms can be recommended by the hospital to undergo outpatient care with family supervision. Both cases show that after hospitalization, both subjects were hospitalized again but both subjects experienced withdrawal. The reason put forward is because of the long distance from the hospital and the subject is getting lazy to take medication. The results showed that of the 400 bipolar patients studied, 140 (35%) had low adherence to their medication (Belete, 2017). The effect of this irregular treatment causes recurrence by showing symptoms such as when not receiving treatment at a mental hospital. This condition is known as a relapse or recurrence. This is because a patient who previously received good enough care and treatment according to the dose given by the doctor, when on an outpatient basis, usually underwent irregular treatment. Factors that cause irregularity in taking medication are family ignorance and PWMI that after being discharged from the mental hospital, they must continue to take medication. The disruptive effect of the treatment made PWMI deliberately not taking medication (Amelia & Anwar, 2013).

The recurrence experienced by the two case subjects caused community unrest and also increased family burdens in caring for recurrences of mental disorders. This recurrence condition caused the family to decide to take re-pasung action. Both cases show that families in treating mental disorders relapse experience subjective burdens and objective burdens. The subjective burden referred to the accusation of neglect by the family. This is because the family allows PWMI to roam outside the house without wearing clothes. Another burden felt by the family is that the family is afraid that PWMI will commit acts of violence such as disturbing other people or killing and running away from home so they have to find it difficult. These findings are supported by Belete (2017) that physical restraint, although deemed inhuman and disrespectful to the inherent dignity of human beings, is still unavoidable until now in controlling and managing the abnormal behavior of psychiatric patients.

The objective burden referred to, in this study, is the treatment of patients who have to go back and forth to the hospital, which is hundreds of kilometers away, starting to interfere with work activities and running out of medical expenses. In the first case, PWMI was not taken to the hospital because the distance from the hospital and busy work activities meant that the family could not always visit. In case 2, PWMI was not taken to the hospital because he often fled home and his family had run out of medical expenses. The results of this research are supported by Amelia and Anwar (2013) that economic difficulties make PWMI unable to always consume drugs. In fact, being unable to pay for the medicine every time they are treated in a mental hospital makes PWMI experience anxiety, restlessness, and sometimes behaves strangely such as talking and laughing to themselves. Family members often do not respond to PWMI requests to be released from pasung because family members have financial constraints to seek mental health care and are also dissatisfied with the services provided. This problem becomes homework for health workers for the importance of providing counseling regarding the importance of proper care and the right time for PWMI (Laila et al., 2018)

CONCLUSION

The burden faced by families in caring for family members with post-pasung mental illness is a complex burden in the form of subjective and objective burdens from within and from outside the family. Financial constraints, long distances and business have forced family members to use alternative or no treatment by taking re-pasung as the last step in an effort to create a sense of security for the community. Increasing access and mental health services, especially in the regions, is very important to prevent cases of pasung and re-pasung by families.

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CONFLICTS OF INTEREST

There is no Conflict of interest

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