

# The Experience of Families

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## THE EXPERIENCE OF FAMILIES WHO CARE FOR RELATIVES WITH MENTAL DISORDERS POST ARBITRARY COERCION: A QUALITATIVE STUDY

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### ABSTRACT

People with mental disorders who experience coercion and are referred to a mental hospital are often shackled after returning from the hospital or re-admitted to the mental hospital. However, some families take care of their family members with mental illness who had previously been coerced. The time taken to care for relatives with mental disorders at home is crucial as caregivers of relatives with schizophrenia and early psychosis experience significant stress and psychosocial burden. Meanwhile, the family members are supposed to maintain their relative's condition to avoid relapse. This study explores the experiences of families who cared for their relatives with mental disorders who experienced coercion to give insight and information to patients, families, and communities. This is a phenomenological qualitative study. The sampling technique used was purposive sampling, with the number of participants being 11 family members who treated their relative suffering from mental illness post-coercion. The descriptive analysis resulted in 5 themes: 1) Heavy burden, 2) Family support, 3) Gratitude, 4) Adjustment, and 5) Improved mental health condition. The results of this study can be used as a reference for helping families with the psychological and physical treatment of their post-coercion relatives.

Keywords: *Family experience; mental disorder; shackled; post-coercion*



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### INTRODUCTION

The prevalence of mental disorders has increased in Central Java. In 2018, Central Java rose to the 4th position for the prevalence of mental disorders, which was previously ranked 5th in 2013 (Indonesia Ministry of Health, 2018). The Central Java Provincial Office reported 78,200 patients with severe mental disorders, of which 390 were shackled (Indonesia Ministry of Health, 2018). Repeated coercion was reported to be conducted by family members to create a secure environment for patients with mental health problems (Katuuk et al., 2019).

Shackling leads to limited fulfillment of the basic needs of a decent life, including health, education, and employment (Yusuf et al., 2019). Patients who are shackled for a long time will experience muscle atrophy, issues with walking, and injuries that must be treated when the patient is released from

coercion (Malfasari, E., Keliat, B., & Helena, 2016). Other impacts of shackling include trauma, resentment towards family, feeling discarded, low self-esteem and hopelessness, depression, and symptoms of suicidal intent (Yusuf et al., 2019). To avoid those impacts on the patients, the family should be educated in caring for the patients after being hospitalized because caring for the patients in the home takes a long time and requires full support from the family.

Family support means the family's attitude, action, and acceptance toward the mental illness patient. As supportive family members, they need to always be ready to provide help and assistance if needed (Purba et al., 2020). Thus, the act of shackling is the family's failure in providing support to provide the patients access to health services. The act of shackling only aggravates the condition of the mentally ill person. Saputra's A study mentioned there was a relationship

between family support and adherence to antipsychotic drugs in patients with mental disorders (Karmila, D.R. Lestari, 2016). Family support is needed so that patients can access health services to get regular medical treatment and ensure that they take their medicines. In addition to medicine, it is explained that the higher the family support, the higher the patient's social functioning after treatment at home, and so on (Jessica & Fithriyah, 2021).

Family members experience physical exhaustion, emotional upheaval, and ineffective burden management when caring for post-coercion patients. These factors contribute to their decision to re-shackle their relative. Thus, cases of shackling in mental patients are still high. Post-coercion and free restraint in the community indicate a problem in patients' families and communities (Yusuf et al., 2019).

Families of post-shackled patients experience difficulties in managing burden, manifesting as physical fatigue and emotional upheaval (Reknoningsih et al., 2015). Caregivers who treat their mentally ill relatives using repeated coercion typically experience helplessness and prioritized safety (Katuuk et al., 2019). Thus, the experience of coercion patients for 11 years with no recurrence for that same period is a differentiator in this study.

The findings of previous studies provide the background to this study which aims to explore the experiences of caregivers in caring for post-shackling patients. The role of health workers in handling people with mental disorders includes promotion, prevention, education, and evaluation through counseling, screening, home visitation, and monitoring of the mentally ill patient who is under medication (Ariusta et al., 2018). Meanwhile, health workers are not concerned with caring for the family members responsible for the long-term care of the patients. This study explores the experiences of families who cared for their relatives with mental disorders post-coercion to provide insight and information to patients, families, and communities.

## METHOD

### Study design

The study used a phenomenological approach to explore the family's experience caring for post-coercion patients. This method was chosen to obtain a deep understanding of the caregiver's experiences. The researcher also performed bracketing, a process by which the researcher "suspends" any preconceived beliefs and opinions about the phenomenon being studied. Therefore, the results obtained are from the point of view of the individual studied.

### Informants

The informants in this study are family members who are caregivers of patients with a mental disorder post arbitrary coercion. The participant criteria were adults who live at home together with the patient, are close to the patient, and take care of the patient. The number of participants in this study was based on data saturation. Data collection is performed by sampling until a point of saturation where no new information is obtained, and experience has been gained. Therefore, this study had four participants since data saturation was reached at eleven participants.

### Data collection

The research site was conducted in Ketep Banyuroto Village, Central Java. Interviews were conducted in stages, starting with orientation, collection of data, and evaluation of the families of mental illness patient post-coercion. At the initial implementation stage, the researcher explained the purpose

and objectives of the interview process. The researcher then determined a contract agreement on the interview timing with the informants.

Data were collected using instruments in the form of interview guides and focus group discussions. The interviews were conducted in the family homes of the mental disorder patient post-coercion. Data collection was conducted in September-November 2022, which was comprehended by data analysis and presentation of research results.

The data collection procedure began with obtaining the ethical clearance letter. After obtaining permission from the authorities, the researcher met the facilitator, namely the "health cadres" appointed to orient the families of mental disorder patient post-coercion to explain the purpose and objectives. Researchers visited the family homes of mental disorder patients and collected information until data saturation were reached. The researchers fostered trust with the informants by validating their identities, introducing themselves, and explaining the research objectives. The researchers then asked about the informants' conditions and obtained informed consent forms from the informants. The researchers started by giving questions according to interview guidelines, ranging from general topics to core questions. The language used was easy to understand. The interview process was conducted until saturation was achieved in each participant. The total interview time was approximately 30-35 minutes. The interview results were analyzed by writing down the interview transcript and recording important information.

### Data analysis

This study used Colaizzi's (1978) phenomenological method for the data analysis stage. According to Colaizzi's method, the researchers first had to obtain a clear picture of the phenomenon under study. Thus, the observations and interviews with participants were recorded and transcribed. The transcription process was conducted after every interview. After interviewing all participants, the researchers read the transcripts repeatedly to understand the participants' answers and obtain keywords from each participant's statement. Important statements were underlined so that they could be grouped. Next, the researchers determined the meaning of each important statement from all participants. They then grouped the data into various themes and determined the main themes that arose. After that, the researchers logically integrated the results into a narrative form and returned it to the participants for clarification. This provided an opportunity for the participants to add information or indicate information they did not want to be published in the study. Finally, the researchers concluded the analysis results with the data obtained during the validation process.

### Ethical consideration

The researchers guarantee the confidentiality of participant data by not including the participants' names or other identities in the research results. Numbering and codes are used for each participant in the research interview transcripts. This study did not harm the participants or use any form of exploitation. The researchers also protected against the loss and abuse of participants. In this study, the participants were also given rewards as a sign of appreciation for their willingness to participate in the research. All participants received the same treatment in terms of informed consent. The Institutional Review Board and Ethics Committee of the Faculty of Nursing, Universitas Sultan Agung Semarang, Indonesia, approved this study (Number: 1086/A.1-KEPK/FIK-SA/XII/2022).

**Trustworthiness**

The trustworthiness in this study was tested against four criteria: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). To ensure the validity of the data used in this qualitative research, the researchers performed direct validation by conducting offline interviews. The next step was to triangulate or validate the data with various sources to correct the data obtained since the study used source triangulation. Triangulation was performed by collecting data using other methods: interviews, observations, and surveys of caregivers with post-coercion patients. Next, dependability is ensured by having the researchers examine the research process with lecturers and colleagues who used the same research design. This study involved other researchers who have studied shackling patients to review the study results.

The transferability of this study was ensured by describing the themes identified in the research group and the study's context, namely, the family experience with post-coercion. The researcher explained everything in detail so readers could use and apply the study results elsewhere. Confirmability is the neutrality or objectivity of the data, which was conducted by the researcher by writing a report on the results of the data analysis to show the authenticity of all research results, including interview transcripts, data analysis tables containing categorization and formulation of the themes of the study results, as well as attaching the final research report accompanied by articles presented to facilitate understanding of the researcher's train of thought to readers.

**RESULTS**

**Participants' characteristics**

There were eleven participants in this study, involving 6 males and 5 females. Most participants are farmers with educational background 63% were junior high school and 37% were high school graduates.

**Table 1. Participants characteristics**

| No | Age | Gender | Occupation | Education          |
|----|-----|--------|------------|--------------------|
| 1  | 57  | Male   | Farmer     | High school        |
| 2  | 55  | Female | Farmer     | Junior high school |
| 3  | 35  | Male   | Breeder    | High school        |
| 4  | 24  | Female | Farmer     | High school        |
| 5  | 28  | Male   | Farmer     | High school        |
| 6  | 65  | Male   | Farmer     | High school        |
| 7  | 60  | Female | Farmer     | Junior high school |
| 8  | 57  | Male   | Farmer     | High school        |
| 9  | 57  | Female | Farmer     | Junior high school |
| 10 | 55  | Female | Farmer     | Junior high school |
| 11 | 55  | Male   | Farmer     | High school        |

**Themes**

Based on the results and data analysis, the following five themes that answered the research objectives were found:

**Theme 1. Heavy burden**

Theme 1 consists of a sub-theme of a heavy burden with shackling actions. The family's biggest feeling with shackling is a sense of unwillingness and resignation to the tough decision. The four participants said they could not bear the condition of shackling but could not do anything else because of their insufficient knowledge. The participants confirmed the following statements:

*"As a human being, we can not bear to see people in shackles. At that moment, our father was still alive" (P1, P8)*

*"Well, about the past, there was a condition like that in the Banyuroto community, maybe in the 80s, it has been cured, but from a medical point of view, there may still be residual symptoms like broken glass. But as a family, facing the decision for an elderly family member is very difficult and considered a burden" (P2, P9)*

**Theme 2. Family support**

Theme 2 is about a sense of belonging between family members after shackling. Family members tend to feel both shame and feelings of belonging and desire to care for the patient because they are concerned of their biological family members. Participants stated the following statements:

*"He has some siblings; I am the older brother of seven children in my family. I take care of him because he is my brother" (P2)*

*"Actually because of humanity, because if you are not a family, who else will take care of you. Besides, maybe my knowledge is a little, but I can do as much as I can to take care of him" (P1)*

**Theme 3. Gratitude**

Theme 3 consists of the sub-theme 'gratitude'. The informants expressed their gratitude for the changes in the patient's condition after being shackled. This feeling helped the family accept their relatives and rejoin them in their family home like new individuals. The participants said:

*"There is an instinct for siblings. Something like that creates a very deep emotion (eyes turn red), people look just like that, but how come they are invited to communicate like this, so when they come home from the hospital, they bow down with gratitude, by being treated like someone new, their soul is not like it used to be" (P2)*

*"Yes, I am quite happy (eyes reddened from crying), yes, like a new hope. Can live in the family again, can join again like that" (P1)*

*"Yes, I'm grateful, besides that, the hope from my parents when they were still alive, I still remember, they said that it's better to be taking care of the siblings" (P5)*

**Theme 4. Adjustment**

Theme 4 is the adjustment that creates motivation. Family adaptation is the initial process of accepting family members with post-coercion patients at home. The changing condition needs self-adjustment from the patient and the family to accept each other and continue the treatment process. The informants revealed:

"...but thank God the siblings can accept. Although it needs adjustment for my wife to take care of my brother" (P6)

"There is a feeling of shame when caring for people with mental disorders" (P10)

#### Theme 5. Improved mental health condition

Theme 5 comprises a sub-theme surrounding the post-coercion patient's mental health condition. The changes that become part of the adjustment process include the nature and condition of the post-coercion patients. Being able to perform activities, recitation, and worship is one of the adaptation activities shown by post-coercion patients. Participants confirmed the following statements:

"Actually, I'm proud of him because he always eats the food that we already prepare for him, but he also likes smoking" (P1)

"He goes to the mosque routinely, especially during Friday prayers and Taraweeh prayers. He is always praying in the mosque" (P3)

## DISCUSSION

Based on the data analysis results, five themes were found: 1) Heavy burden, 2) Family support, 3) Gratitude, 4) Adjustment, and 5) Improved mental health conditions. Coercion may force uncomfortable feelings onto patients who experience it. Shackling is a tough decision that families make as the result of insufficient knowledge of how to provide care to patients. Some families were found to not want to shackle their relatives because of various reasons. This study found that some families with shackling actions disapproved of the action, did not have the heart to do so, and believed the act should not be done because of humanitarian reasons. However, some participants who still assumed that being shackled would cure the patient's mental illness.

Shackling is a widespread phenomenon and has become a concern in mental health services. The serious effects of shackling on individual autonomy and freedom make shackling morally disturbing and pose ethical challenges and pressures for everyone involved. Shackling exacerbates the mental health problem, affecting the home situation and providing medical and other alternative treatment opportunities. (Norvoll et al., 2018).

Treatment and maintenance of mental health provide significant benefits for patients. However, coercion is still the most debated aspect of contemporary psychiatry (Sashidharan et al., 2019). Implicitly, shackling is considered a virtue or a moral necessity to prevent acts of violence that patients can commit. This is supported by the literature, which states that coercion is in accordance with the best interests of the family and the patients who experience it, as it protects them from detrimental actions and allows them to recover and live life as before (Lorem et al., 2015).

The use of shackling requires open interaction, trust, and ongoing collaboration between health professionals and families (Lorem et al., 2015). Post-coercion conditions present their own challenges for medical personnel and families in accepting and caring for patients. Communicative skills are needed when exploring and exchanging ideas with post-coercion patients (Lorem et al. 2015). When coercion is decided by a family, the main ethical challenge is to assess the balance between the benefits and harms that will arise. Thus, it is important for health workers to develop a strong

awareness of the ethical challenges in managing families with post-coercion patients (Hem et al. 2018).

Any type of shackling is contrary to the main values in modern society, in particular, the right to freedom. The ability to make one's own choices or rules and responsibility for the individual who considers what to do in a given situation determines the essence of humanity (Hem et al. 2018).

Shackling generally has a negative psychological impact that results in anger, fear, humiliation, degradation, helplessness, pressure, shame, and a feeling that the integrity has been violated to the point of causing retraumatization in the patient. This is supported by research results that state that physical shackling causes psychological injuries that can evoke feelings of not being treated as a human being and not having the same value as healthy people. In addition, studies have found that even mentally challenged patients must feel distressed and neglected (Nyttingnes et al., 2016).

Shackling is evaluated as morally wrong because people with mental illness are stigmatized as more dangerous. However, another opinion from this study states that shackling is morally justified in situations where the patient is in a sick condition and unable to take care of themselves (Norvoll & Pedersen, 2018). External encouragement that comes apart from the family, especially from the wider community, is crucial for patients to adapt to new conditions after shackling and continue living with the assistance of their families and related health workers to reduce moral pressure in daily activities (Norvoll, Hem, and Pedersen 2017).

This study discovered that family became the main support system for post-coercion patients because they still needed minimal care assistance to meet daily needs, such as food, hygiene, dressing, worship, and socialization. The role of the family is essential because positive treatments help the recovery process. Additionally, the results showed that families have a positive perception of shackled people.

The family's response to the admission of patients after shackling at home creates a new problem that will affect each family member. However, this study found that the family's responses to the patient's condition were positive, accepting, and they were willing to help with the treatment process. The participants acknowledged that there were many changes that occurred after post-coercion care that was provided by health workers and supported by regular treatment.

The feeling of comfort, being needed, and being cherished makes post-coercion patients start living life again and reactivate their cognitive functions and aspects. These elements enable them to prevent the recurrence of disturbing mental disorders. This study found that the family bonding develops willingness to take care the post-coercion patients. This condition is related to the level of family understanding in performing post-coercion patient care. Therefore, knowledge is needed in the process of family self-adjustment to the situation.

The basic principle of the psychosocial support system is solidarity and respect for one's own destiny. Solidarity means the support of informal and institutional sections of the community aimed at full participation in the treatment of post-shackling patients. Respect involves the freedom to choose regardless of the type of mental disorder experienced. The effective assistance provided will depend on the system's ability to meet the expectations of families of post-shackling patients (Zinkler and von Peter 2019).

The recovery period is a process that mental disorder patients, after being shackled, will experience. This process involves the community, family, and patients. Nevertheless, recovery starts with the patients themselves. Proper and regular care and treatment are important in providing care to post-coercion patients. The results of this study found that there were changes that led to good actions by the patients, such as routine treatment, maintaining hygiene, regular worship, communication, and socializing in the community.

Shackling impacts not only the patient but also the patient's family in daily life as it adds to the burden on the family by creating a stressful environment in family relationships, dilemmas, pressures, and retrospective regrets due to low-quality care. This creates problems in health care and adds to the challenge of maintaining relationships between family members, where families must strike a balance between the needs of patients and other sick relatives and try to negotiate a good work balance between formal and informal care. In addition, families also face special challenges due to changes in the patient's personality and mental capacity post-shackling. Shackling poses a dilemma for family members, where it is considered an easy and usual thing to do and sometimes creates an ambivalent feeling (Norvoll et al. 2018).

Quality of life is an individual's perception of their position and function in society. It is also affected by their family's views and expectations, which cannot be judged by numbers, but can be seen by actions. Mental disorder patients tend to still need post-coercion observation due to a decrease in psychiatric function and require periodic returns due to cognitive conditions related to thought processes, affective conditions related to perception, and psychomotor conditions related to behavior (Yunita, 2017).

The analysis of this study's result shows a relational aspect which is an important reason why mental health, shackling, and good quality of knowledge and care are needed to positively impact patients with mental disorders. A sense of love and commitment could reduce emotional distress (Norvoll et al. 2018).

## CONCLUSION AND RECOMMENDATION

In this study, the participants mentioned that their experience caring for post-shackling patients was a high burden for the family. Post-coercion patients need continuous family support and adjustment when returning home. Generally, the patients have an improved mental health condition after shackling. Nevertheless, the families still struggle to provide good quality care for their relatives with mental illness. Therefore, support from healthcare providers is important.

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