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## A Journey of Hidden Outburst of Anger Shackling a Person with Schizophrenia: The Indonesian Context

Heni Dwi Windarwati

*Universitas Brawijaya*, henipsik.fk@ub.ac.id

Budi Anna Keliat

*Universitas Indonesia*, budianna\_keliat@yahoo.com

Raden Irawati Ismail

*Universitas Indonesia*, ira\_ismail@yahoo.com

Adang Bachtiar

*Universitas Indonesia*, adang@post.harvard.edu

Erna Erawati

*Poltekkes Kemenkes Semarang*, ernaerawati57@yahoo.com

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### Abstract

Shackling a person with schizophrenia violates human rights. This process is often carried out when the person has committed acts of violence and hostility. In this study, we focus on considering the shackling of a person with schizophrenia in Indonesia's context. We used grounded theory (GT; Charmaz, 2011) with 23 participants located in the East Java Province, Indonesia. The participants consisted of people with schizophrenia who were shackled by their ankles, families treating people with schizophrenia, the cadre volunteers, prominent figures, and nurses. We used in-depth interviews using semi-structured questions. We identified five phases associated with the process of shackling a person with schizophrenia: (a) distress signal, (b) high demand for treatment, (c) a change of positive convictions, (d) loss of confidence and capability, and (e) restrictions. Understanding the process of shackling people with schizophrenia will help the Indonesian government prevent people with schizophrenia from being shackled by their ankles.

### Keywords

schizophrenia, the process of shackling people with schizophrenia, grounded theory

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### Acknowledgements

Thankful for all participants in this study

# A Journey of Hidden Outburst of Anger Shackling a Person with Schizophrenia: The Indonesian Context

Heni Dwi Windarwati  
Universitas Brawijaya, Malang, Indonesia

Budi Anna Keliat, Raden Irawati Ismail, and Adang Bachtiar  
Univeritas Indonesia, Depok, Indonesia

Erna Erawati  
Poltekkes Kemenkes Semarang, Indonesia

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Shackling a person with schizophrenia violates human rights. This process is often carried out when the person has committed acts of violence and hostility. In this study, we focus on considering the shackling of a person with schizophrenia in Indonesia's context. We used grounded theory (GT; Charmaz, 2011) with 23 participants located in the East Java Province, Indonesia. The participants consisted of people with schizophrenia who were shackled by their ankles, families treating people with schizophrenia, the cadre volunteers, prominent figures, and nurses. We used in-depth interviews using semi-structured questions. We identified five phases associated with the process of shackling a person with schizophrenia: (a) distress signal, (b) high demand for treatment, (c) a change of positive convictions, (d) loss of confidence and capability, and (e) restrictions. Understanding the process of shackling people with schizophrenia will help the Indonesian government prevent people with schizophrenia from being shackled by their ankles.

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## Introduction

Indonesia's basic health research report in 2007 stated the estimation of around 13,000–24,000 people with schizophrenia in Indonesia were shackled by their family members (PPSDM Kemenkes RI, 2007). In 2013, the estimated number increased by 14.3% (PPSDM Kemenkes RI, 2013). Shackling, or in Indonesian terms known as *pasung*, is a condition for isolation or restraint of people with a mental disorder in the community even though shackling has been banned by the Indonesian Law, but the practice continues in the community (Hidayat et al., 2020). Shackling is done by chaining both legs, chaining or tying up the person in a vacant house on the dirty floor, and logging both legs with rope in the specific room (Buanasari et al., 2018; Laila et al., 2019). Shackling occurs in situations where a family caregiver confines or restrains an individual to prevent them from harming oneself and other people. If the number of people with schizophrenia is 1.7 per million, and Indonesia has a population of about 250 million, then there are about 60,000 people with mental health problems in Indonesia who have been shackled by their ankles. Of these, 18.2% of people are shackled in rural areas and 10.7% in urban areas. Moreover, the 2018 Basic Health Research revealed that 31.5% of people with

schizophrenia, or 15,664 people, were shackled by their family caregivers. Of them, 31.1% lived in rural areas, and 31.1% lived in cities (PPSDM Kemenkes RI, 2018).

Shackling negatively impacts a person with schizophrenia. The most frequent consequences are psychological and psychological trauma (Fereidooni Moghadam et al., 2014). Physical trauma means there is some damage to a specific organ. In a certain position, the shackling can have a restrictive effect on respiratory functions (Barnett et al., 2012). Shackling or restraint can cause secondary physical injuries such as malnutrition, infection, nerve damage, muscular atrophy, and cardiovascular problems (Human Right Watch, 2020). Furthermore, psychological trauma includes agitation, low quality of life and life expectation, suicide attempts, and self-harm (Ye et al., 2019). Subsequently, those shackled may develop post-traumatic stress disorder (Chieze et al., 2019). Shackling also relates to stigma in patients, which forces the patients to alternative “treatment” rather than proper medication (Human Right Watch, 2020). Shackling a person with schizophrenia is a violation of human rights and is against a WHO program on quality rights (WHO, 2017), since it makes the victims lose their status and feel discriminated against to the point of needing mental health treatment.

To prevent caregivers from taking this adverse action, we must understand the process of shackling a person with schizophrenia. It will become our basis to avoid any people with schizophrenia from being bound by their ankles. So far, no research has described the shackling process for a person with schizophrenia in the Indonesian context. Therefore, the purpose of this study to investigate the process of shackling people with schizophrenia in the Indonesian context.

### **Significance of the Study**

The health minister created regulations which stated minimum service standards for mental disorders in community-based mental health services. Providing integrated care and proper support for people with schizophrenia will reduce disability, improve social functioning, and improve quality of life. Community is an essential component in overcoming mental health problems, the gap between mental disorder’s burden, and mental health service’s access. Community-based mental health services offer an essential contribution to improve intervention for schizophrenia (Asher, Patel et al., 2017; Kohrt et al., 2018). The high level of shackling in the East Java Province is currently unknown. The leading cause of shackling in people with schizophrenia is often associated with the encouragement of a sense of security from family and society (Daulima et al., 2016; Sari, 2017). Identifying the causes of this shackling is the first step in understanding the process of shackling in people with schizophrenia. There is limited exploration of the process of shackling in people with schizophrenia. Limited research has been done on the causes of shackling in people with schizophrenia, but we did not find any descriptions of the stages of shackling. By knowing the shackling process for those with schizophrenia, we hope the result could raise awareness and encourage family caregivers and community in prevention of shackling, so people with schizophrenia get proper medication.

### **The Shackling a Person with Schizophrenia**

The global effort to end shackling is known worldwide. Many countries including Indonesia have a law and policy to support this effort, but shackling prevention has not been easy to implement in the community. Therefore, we try to understand the process of shackling to end the shackling itself. Shackling can occur for a variety of reasons. The first reason for shackling is associated with violent behavior wherein the public perception, schizophrenia is manifested with aggressive behavior. The second reason for shackling is related to pervasive

stigma towards people with schizophrenia (Asher, Fekadu et al., 2017). The third reason for shackling is the failure of families to recognize and obtain information about schizophrenia treatments. This condition impacts families' ability to make decisions to care for people with schizophrenia (Stuart, 2016). Limited information about schizophrenia creates negative perceptions of people with schizophrenia. Schizophrenia is a permanent disorder, so it is difficult to cure, and people with schizophrenia are unable to control their behavior. Another perception that develops in society is people with schizophrenia may be associated with "witchcraft," so that in the first stage, families tend to bring people with schizophrenia to traditional health services such as religious leaders or psychics (Windarwati, 2008). Families new to schizophrenia bring their family members to professional health services when traditional health services do not produce positive results, so people with schizophrenia are in crisis and chronic conditions. The fourth reason for shackling is non-compliance and limited access to mental health services. Health services for people with schizophrenia who are in chronic conditions require compliance from both the sufferer and their family so treatment and care efforts can be successful. The fourth and greatest challenge in caring for people with schizophrenia is noncompliance. The noncompliance of people with schizophrenia was at high risk when there are a high duration and severity of the disease, family relation's conflict, lower class, and the age is more than 40 years (Ponomareva & Nomokonova, 2020). Research by Chaudhari et al. (2017) showed as many as 52% of patients with schizophrenia have a low level of treatment adherence.

Shackling fulfilled a sense of security from the surrounding environment and the powerlessness of the family. The unsuccessful recovery process for people with schizophrenia causes familial confusion. The demand for comfort from the environment increases along with the threat of maladaptive behavior in people with schizophrenia (Daulima et al., 2016). A study conducted by Daulima et al. (2016) found financial constraints, failure to use alternative measures, limited knowledge, and dissatisfaction with the results of mental health services are often experienced by these families. The absence of this source of coping causes the family to finally decide to shackle people with schizophrenia.

### Research Question

We aimed to investigate the process of shackling a person with schizophrenia in Indonesia's context. We used the following research question to guide this study: What is the process of the shackling of a person with schizophrenia in Indonesia's context?

As the first researcher, I had both professional and personal interests in this study as a community psychiatric nurse and psychiatric nursing doctoral in the community of East Java and significant aspects of my position in schizophrenia research that focused on shackling free program for people with schizophrenia. I was an active interviewer in the process of collective data.

As the second researcher, I have an interest in people with schizophrenia treatment in the community. Based on my professional in the community and my position as a psychiatric nursing professor in Universitas Indonesia, we have tried to free people with schizophrenia from being shackled for many years with the program called *Indonesia Bebas Pasung*. Nevertheless, all aspects within government, education, and community should work together to make this program succeed.

As the third researcher, I believe the result of this study could impact local government policy and increase community awareness, to humanize those with schizophrenia, and to make proper treatment for people with schizophrenia available. I had competency as a psychiatrist from the medical faculty in Universitas Indonesia and started to teach in the psychiatric

department. This phenomena of shackling people with schizophrenia was our main concern in community nursing.

As the fourth researcher, I had a capacity as a professor in the community health department in Universitas Indonesia and analyzed the process of shackling a person with schizophrenia.

As the fifth researcher, I had the capacity as a psychiatric nursing magister and was actively involved in implementing community health nursing. I realized this issue needs to be solved with a specific approach and humanize the people with schizophrenia in the community.

We had multiple authors to improve the outcome and the discussion of this study. We were a team of health professionals in mental health with different backgrounds, namely mental health nurses, psychiatrists, public health professionals, and lecturers/academics. The partnership in this study addressed to gain knowledge about shackling in patients with schizophrenia according to the background of each researcher to provide a more comprehensive understanding of the shackling process in patients with schizophrenia. Research collaboration increases the coverage and support of the local government and community We transform the research by analyzing the process of shackling a person with schizophrenia as a challenge and opportunity in shackling prevention that exists in the development of effective partnerships between indigenous and non-indigenous researchers.

### **Methodology**

We explored the process of shackling a person with schizophrenia using a qualitative study with a grounded theory approach. We carried out the study in East Java, which is the second-most populous province in Indonesia. People with schizophrenia who are shackled by their ankles account for 16.3% of the total population of East Java. About 14,000 people with schizophrenia have been or are being shackled.

We choose to use a grounded theory approach in this research because grounded theory (GT) is a structured yet flexible methodology. The grounded theory approach is suitable when little is known about a phenomenon to be studied. Also, the aim is to produce or build explanatory theories that reveal the processes inherent in the problem to be studied. Grounded theory is suitable for use in this study because what is known about the phenomenon of shackling is still minimal, and the explanatory theory of the shackling process in schizophrenic patients does not exist.

### **Research Participants**

This study involved 23 participants. This is the number where we reach data saturation. The participants were five people with schizophrenia who were physically shackled on their ankles, four families treating those people with schizophrenia, five prominent figures in the neighborhood where the people with schizophrenia lived, four cadre volunteers, and five nurses who were involved in the shackling case finding. We interviewed the process of shackling of a person with schizophrenia from multiple types of participants. All of the participants were over 20 years old and were able to speak Indonesian or Javanese. The people with schizophrenia (P1) had to meet specific criteria; they had been shackled several times for at least one month and had to be free from mental retardation or any organic mental disorders.

The shackling decision making is from their families which is four families treating those people with schizophrenia (P2). The families had to meet specific criteria; they had to be the primary caregivers taking care of the daily needs of the people with schizophrenia. Five prominent figures in the neighborhood where the people with schizophrenia lived (P3). Five prominent figures had to meet specific criteria; they live in the neighborhood where the people

with schizophrenia lived and were the witnesses of the shackling process. The prominent figures were the religious leaders, village leaders, and respected local members of the community. There were also four cadre volunteers (P4) who participated in this study. The cadres were the volunteers involved in taking care of the people with schizophrenia.

Five nurses tried to help families to find the case of shackling and release the shackling (P5). The nurses had to meet special criteria; they had to be mental health nurses in health services or mental health resident nurses who had cared for people with schizophrenia who were shackled.

Grounded theory (GT) is a qualitative data analysis methodology to develop a theoretical framework that describes and explains interesting social process phenomena. The process of shackling is a symbol of human interaction that results in an activity. The symbol of interaction believes that humans have natural behavior and interactions expressed verbally (subjective) and nonverbally. We emphasized the personal values conveyed by the participants from the existing reality and presented in a narrative form. The researcher in this study acts as a research instrument in interpreting the data with validation from the participants. We aimed to develop a theoretical framework to describe the shackling process in people with schizophrenia.

We identified and recruited participants based on the following stages. First, we coordinated with the regional health office to obtain data on shackled patients. Second, we selected participants using purposive sampling, the shackled patients were predetermined into inclusion and exclusion criteria, namely being over 20 years old and speaking Indonesian or Javanese. The specific criteria for people with schizophrenia (P1) were shackled several times for at least one month and had to be free from mental retardation or any organic mental disorders.

For families, namely, the families had to be the primary caregivers taking care of the daily needs of the people with schizophrenia (P2). The third step was to determine the data for prominent figures (P3), cadre volunteers (P4), and nurses (P5) based on the area where the data for shackled patients has been previously obtained.

Prominent figures, cadre volunteers, and nurses were selected using purposive sampling based on the following inclusion and exclusion criteria, such as prominent figures were the religious leaders, village leaders, and respected local members in the neighborhood where the people with schizophrenia lived.

We have made sure that in the results and discussions, we discuss collectively and adjust to the group. We ensure the confidentiality of participants in this study by writing a code for each participant instead of their identity, and by informing them that all participants would remain anonymous. Data generation and collection begin with providing explanations to participants regarding the research objectives being carried out, and then participants are given informed consent. Researchers conducted semi-structured in-depth interviews with participants who agreed to take part in the study. The researcher records with an audio recorder and writes field notes immediately after the interview. We complete the data collection and analysis concurrently so analytical interpretations can be further explored through the views and experiences of subsequent participants. We conducted interviews with a duration of 60-90 minutes according to the agreement with the participants, and we conducted interviews in a closed room to maintain privacy. Environmental settings arranged in such a way do not give the impression of participants being interrogated. Using this closed room is so that the participants' concentration is not disturbed during the interview.

We have ensured that the data analysis process is fully described in the data analysis section. We make a change with the data analysis process consisted of 2 stages: the concept formulation stage and the concept development stage. The first step was formulating the concept, which consisted of three stages: coding the substances, categorizing, and identifying

basic socio-psychological processes. The second step of the data analysis process was to develop the concepts by reduction sampling, selective sampling of the literature, and the selective sampling of the data. We explain each step in the analysis process in detail in the data analysis section. The formulating concept consisted of three stages: coding the substances, categorizing, and identifying basic socio-psychological processes. The coding of the substances involved data collection from both the interviews and the field notes. The data obtained was examined word-by-word and repeatedly read to determine the right code. The participants' expression represented their experience through symbols in the forms of speech and meaning (Armitage et al., 2017). The identification of results has been written as a code or a keyword. The second stage was categorizing the codes, where we gave a code out of the data that they obtained by comparing them with other data and placing the data into categories corresponding to the reality. During this stage, the researchers compared the categories to generate interrelated categories. The third stage was identifying the codes of socio-psychological processes by formulating the main theme generated from the data. The second step of the data analysis process was to develop the concepts by reduction sampling, selective sampling of the literature, and the selective sampling of the data. Reduction sampling was carried out because the number of categories generated was high. The categories are compared to one another to see their relevance to the social process learned and to check for overlap. Next, the categories were reduced to determine the social behaviors studied. The next stage is the selective sampling of the literature. We compared it with existing literature to strengthen the findings and refine the results. We carried out a literature review to help the researchers connect the new concepts.

### **Sampling and Recruitment**

This study on shackling was located in the working area of the East Java Provincial Health Office, Indonesia. We selected East Java as the location of the study since 25% of people with schizophrenia are shackled by their ankles. We used an in-depth exploration to know how those people with schizophrenia were shackled. The participants' sample triangulations were selected from heterogeneous samples using a purposive sampling technique. The study on the process of shackling people with schizophrenia reached data saturation for the twenty-third participant.

There were five groups of participants in this study. They were five people with schizophrenia shackled by their ankles (P1). People with schizophrenia are mostly over 40 years old, and all are men. Most of them have primary school education levels and work as craftsmen. Two of them are married, and two of them are widowers, while one other person is not married. All people with schizophrenia are Muslims.

Four families take care of those with schizophrenia shackled by their ankles, mostly over 40 years old and women (P2). Most of them have primary school education level and work as rice field laborers. Three out of four families who care for people with schizophrenia are married, and one other person is not married. All families who care for people with schizophrenia are Muslims.

Five figures prominent in the neighborhood where those with schizophrenia lived are mostly men over 40 years old (P3). Most of them have a junior and senior high school education and work as craftsmen. All prominent figures are married and are Muslim.

Most of the four cadres (volunteers) who cared for and took care of those people were women over 40 (P4). Most of them have a junior high school education and work as housewives. All cadres (volunteers) are married and are Muslims. The five nurses who help families release shackling are mostly women who are over 40 years old (P5). All nurses have

graduated from college and work as government employees. Most nurses are married, and all the nurses who care for people with schizophrenia are Muslim.

We used a qualitative research design based on a grounded theory (Charmaz, 2011). We explore the participants' insights and experiences concerning the process of shackling people with schizophrenia by their ankles in Indonesia's context. We collected data from July 2018 to February 2019. When collecting the data, we employed semi-structured, in-depth interviews with a field note for us to document the process of shackling people with schizophrenia. Table 1 elaborates on the interview guide.

**Table 1**  
*The Interview Guide for In-Depth Interviews*

No	Interview guide	PWS restricted	Families who taking care of restricted PWS	Psychiatric nurses who took care of restricted PWS	Cadres who taking care of restricted PWS	Community Leader
1	Tell me what happened before the process of Shackling occurred?	√	√	√	√	√
2	What happens just before the process of Shackling happens?	√	√	√	√	√
3	What are your expectations when you are in a situation before the process of shackling?	√	√	√	√	√
4	What is the attitude of the family to a Person with a Schizophrenia condition before the process of Shackling?	√	√	√	√	√
5	What is the attitude of the community with a Person with Schizophrenia condition before the process of Shackling happens?	√	√	√	√	√
6	What is the attitude of the health workers with a Person with Schizophrenia before the process of Shackling?	√	√	√	√	√
7	Tell us about your efforts to overcome a Person with Schizophrenia problem before the process of Shackling	√	√	√	√	√
8	Tell me how before the process of Shackling was carried out?	√	√	√	√	√

We secured informed consent from the participants before we conducted the study. The researchers carried out the interviews and recorded them with a voice recorder. Then, they wrote their field notes immediately after the interviews were conducted. We conducted data collection and data analysis simultaneously, so we would be able to further explore the analytical interpretation through the next participant's point of view and experience. Each interview took 60–90 minutes. The interviews were conducted by appointment, at times when the participants were not busy with their daily tasks and routines. Moreover, they were conducted indoors (such as in the living room) to keep the participants focused and undistracted. Furthermore, only the researcher (the interviewer) and the participant (the interviewee) were in the room when the interview took place. We decorated the room in such a way that it did not look like an interrogation room to the participant.

We prefer using grounded theory because we try to find out the phases associated with the process of shackling a person with schizophrenia. The grounded theory is widely used in areas that were considered more discovery-oriented because, so far, we did not find any theory about the process of shackling a person with schizophrenia. We start with an open-ended sampling strategy with in-depth exploration. The participants' sample triangulations were selected from heterogeneous samples using a purposive sampling technique. Then, through an iterative process of data collection and analysis, we refine our sampling strategy to be increasingly focused.

## **Data Analysis**

We use Charmaz (2011) grounded theory model in our data analysis procedure. We carried out selective data samples with collected additional data to develop and identify the main categories. We applied comparative analysis of the data and the analysis simultaneously, so the codes, categories, mapping, and theory development could be determined and examined by applying and modifying the entire body of data (Charmaz, 2011). We read out the field notes with the transcripts to reflect on the context of data and to examine whether those matters supported the analytical findings. We used analytical comments and memo writing to assist in the analytical process (Charmaz, 2011).

There were two steps taken in analyzing the data. The first step was formulating the concept, which consisted of three stages: coding the substances, categorizing, and identifying basic socio-psychological processes. The first stage, coding the substances, involved data collection from both the interviews and the field notes. We obtained the data by examining word-by-word and repeatedly read to determine the right code. The participants' expression represented their experience through symbols in the forms of speech and meaning (Armitage et al., 2017). The identification of results has been written as code or a keyword. In the second stage was categorizing the codes. We gave a code out of the data they obtained by comparing them with other data and placing the data into categories corresponding to the reality. During this stage, the researchers compared the categories to generate interrelated categories to determine the similarities and differences (Charmaz, 2011). The third stage was identifying the codes of socio-psychological processes by formulating the main theme generated from the data.

In the second step of the data analysis process, we developed the concepts by reduction, selecting the sampling literature, and the samples out of the data obtained. During the analysis process, the number of categories generated was high. The categories are compared to one another to see their relevance to the social process learned and to check for overlap. Next, the categories are reduced to determine the social behaviors studied. After reducing the categories, the researchers conducted a literature study to support data analysis. We carried out literature reviews to help the researchers connect the new concepts. In the last stage in this second step,

we selected the data samples. We collected additional data to develop and identify the main categories.

Our finding shows the drifting that happens throughout this study between presenting a series of people with schizophrenias' life stories and sharing a grounded theory-informed qualitative data analysis of these stories.

### **Ethical Issues**

This study has ethical approval from the Ethical Committee of the Faculty of Nursing of Indonesia University (number 26/VN2.F12.D/HKP.02.04/2018). All participants received written information elaborating the aims of the study, the interview process, and the voluntary nature of participation. Moreover, all participants' answers are anonymous, and all participants gave informed consent to the researchers to be involved in this study. Researchers achieve anonymity by giving participants a code number meant to protect their privacy.

### **Results**

All participants underwent each phase of the shackling process. Although each participant's living conditions were unique, we identified a general pattern of the process of shackling people with schizophrenia. There were five phases to the process: distress signal, high demand for treatment, a change of positive convictions, loss of confidence and capability, and restrictions. A journey of one's hidden outburst of anger showed the process of shackling people with schizophrenia in Indonesia's context. We would like to describe how these phases or themes emerged from the analyzed data through Figure 1.

#### **Phase 1: Distress Signal**

The first phase was distress signal. The distress signal was an early alarm taking place due to various factors, both from people with schizophrenia and from their families and society. Distress signal meant a symbol showing a dangerous situation. Distress signal depicted something harmful, painful, or destructive both to oneself and to others. The central idea of this phase was a series of experiences indicating a threat in the form of a change of behaviors, both from people with schizophrenia and from their families or society. At first, they felt things had been mixed up, but later on, they identified a feeling of being threatened, scared, confused, guilty, embarrassed, lonely, and easily aroused. This participant's statement is representative of the distress signal stage: "When he started to be furious, we were all scared; no one dared to approach him. We were worried that we would be the victims" (P4).

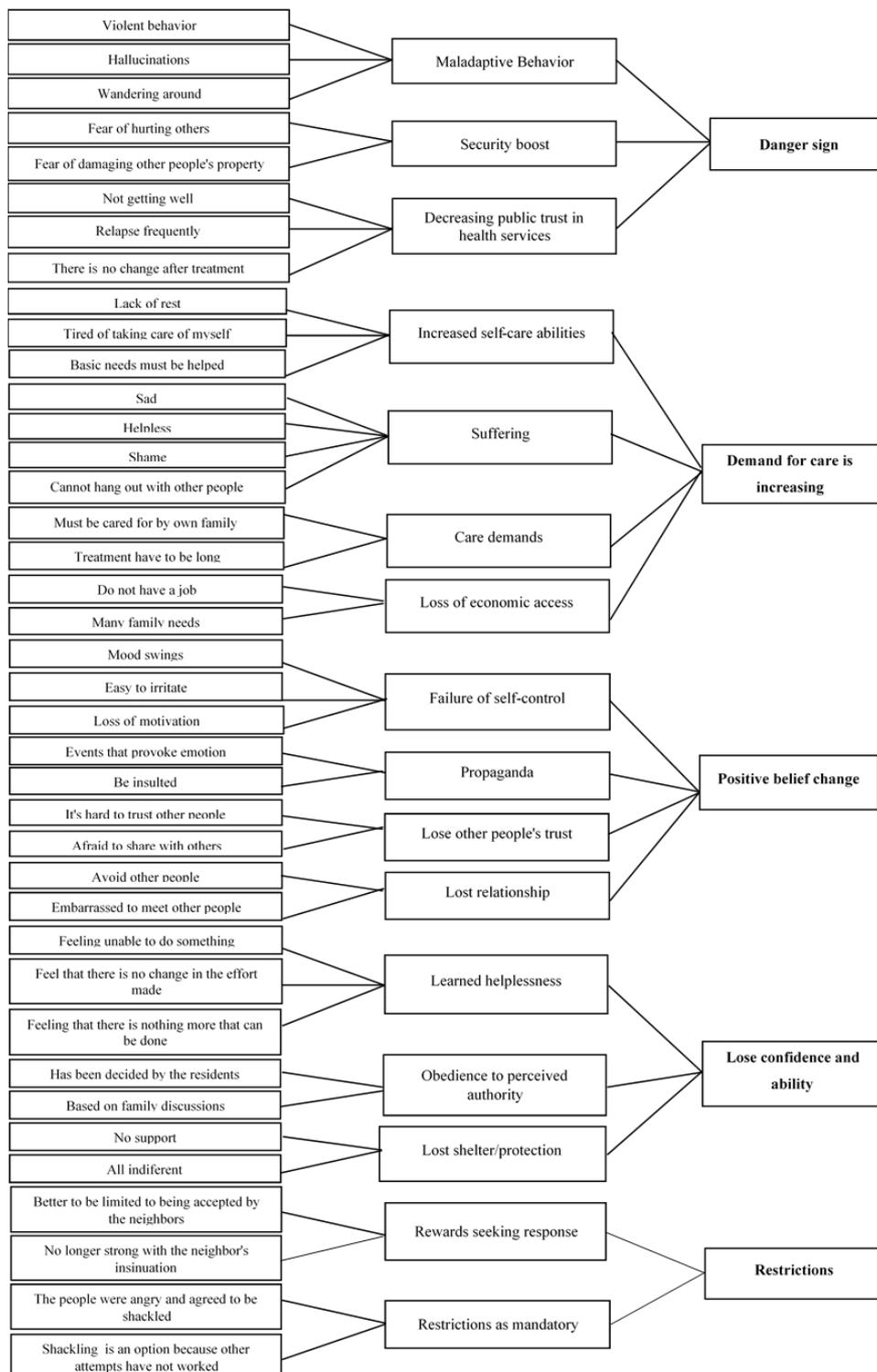
#### **Phase 2: A High Demand for Treatment**

The second phase was a high demand for treatment. High demand for treatment occurred as a result of a higher need for any system, whether it was the patient's, the family's, the society's, or the health worker's system. High demand for treatment was a symbol showing a shift of needs toward the peak fulfillment of comfort. High demand for the treatment described a dilemma of limited capabilities and a higher demand for a need. The central idea of this stage was an agreement and a loss of compromise. During this phase, the people with schizophrenia felt moody, easily upset, and emotionally volatile; they avoided other people, felt worthless and unmotivated, and found it difficult to make up their minds. This family member's statement is representative of this stage:

How can we not be worried about him? If he gets angry, he can destroy someone else's house. If so, they could not afford any compensation for us. (P3)

We already took him to a hospital to get proper mental health treatment, but there was no progress made. Hence, why do we have to take him to a hospital again? We will simply waste our money. (P2)

**Figure 1**  
*Formulating the Concept*



### **Phase 3: A Change of Positive Convictions**

The third phase was a change of positive convictions. Positive convictions were a symbol of one's capability of solving problems and challenges. The end of the results were positive convictions which included positive expectations and successful treatment. A change of positive convictions occurred as an impact of high pressures and declined self-potential due to the suffering they continuously underwent. A change of positive convictions was a consequence of problems deemed worsened and failed control due to the behaviors of people with schizophrenia and the attitude of the surrounding society. The central idea of this phase was one's faulty capacity as an impact of his or her social capacity in assessing his or her response to pressure. During this stage, they felt moody, easily upset and emotionally volatile, worthless, and unmotivated. They avoided other people and found it difficult to make up their minds. This participant's statement is representative of this stage:

We have taken him to several psychics to get him an alternative treatment. His treatments have cost us a fortune. We have sold our house and our land. (P2)

We have taken him to the hospital to get him medical treatment many times. We have consulted with the psychiatrist. However, he made very little progress. (P5)

We can only keep him at home, since what else can we do? It is better than getting blamed by other people all the time. (P2)

### **Phase 4: Loss of Confidence and Capability**

The fourth phase was the loss of confidence and capability. Loss of confidence symbolized a change of convictions. Confidence would eventually result in involvement, introduction to one's personal needs, and hope and optimism. The central themes of loss of confidence were the disappearance of self-involvement, introduction to one's personal needs, and hope and optimism in caring for people with schizophrenia. The results of capability were fulfillment, task completion, and enhanced self-confidence. The central theme of loss of capability was the disappearance of the ability to fulfill one's needs, to complete one's tasks, and to have self-confidence. Eventually, this loss of confidence and capability would result in a degradation in the quality of life and depression.

Loss of confidence and capability occurred as an impact of strong pressures that took place all the time and were predicted to be able to stop the positive attitudes in taking care of people with schizophrenia and to decide to restrict their movement. Loss of confidence and capability was a consequence of a higher intensity of the problems originating both from people with schizophrenia and the surrounding society. During this phase, they felt infuriated and intended to punish people with schizophrenia. This participant's statement is representative of this stage:

At first, I was convinced that he could get better. However, I found him getting worse. It seemed impossible for him cured. Therefore, why don't we let him do what he wants? We cannot do anything else about it. We have tried our best. Everything has its limit. We are already exhausted since nobody cares and is willing to help. They are lucky they do not feel what we feel. It is time for us to move on now and to take care of the others. We have even abandoned the other

younger brothers and sisters due to being so preoccupied with his problem. Hence, I think shackling him is a better way. (P2)

### Phase 5: Restrictions

The fifth stage was restrictions. Restrictions occurred at the peak of uncontrolled anger. Restrictions indicated helplessness, fatigue, aggressiveness, and apathy. The central idea of this phase was an outburst of anger at the end of a long journey of incessant stressors. At that moment, they felt an outburst of uncontrolled anger. It is characterized as violence against other people. This participant's statement is representative of this phase:

Shackling him is the best method. I am calm, and so is he. Since I was confused and did not know what to do if he was left outside the house, I had better have him shackled by his ankle. After we shackled him, everybody was pleased and calm. It is okay for me to see him treated that way, since I cannot stand being blamed by the neighbors all the time. (P2)

## Discussion

Our current findings show that there are five phases of the shackling process of people with schizophrenia. The phases are distress signal, high demand for treatment, a change of positive convictions, loss of confidence and capability, and restriction (see Figure 2).

**Figure 2**

*Conceptual Model of the Process of Shackling People with Schizophrenia in Indonesia's Context*



The first phase of shackling process of people with schizophrenia is distress signal. Distress signal started with a sense of being bothered and with a sense of mild irritation due to various factors. Symbols deemed to represent the driving forces of a distress signal phase were the behaviors of people with schizophrenia, such as destructive behaviors, violence, hallucination, and wandering around. Other people might have paid attention to its symptoms and realized that changes in the behaviors of people with schizophrenia would make other people uncomfortable. The family and the society would, therefore, desire to increase their sense of security.

The participants understood the change in behavior based on recognition and knowledge. Recognition was defined as the act of admitting the existence of changing behavior and the family or society changing perspectives as an impact of the unexpected assault of the person with schizophrenia. This condition was dependent on their social context and how far their changing feelings and behaviors were acknowledged and handled by the family and by society. Knowledge was information known and realized because of the changing behaviors of people with schizophrenia. Good knowledge would slow down or prevent the distress signal phase from moving on to the next phase.

The non-compliance to the treatment can affect the functions and general conditions of people with schizophrenia manifested in the form of severe symptoms so that this condition

could increase the risk of relapse and economic burden (Wander, 2020). Severe recurrence could be a distress signal to people with schizophrenia, their families, and their society. A study found there was a relationship between family social support with the risk of recurrence (Kristina, 2020). Knowledge of the disease, the need to continue the treatment and follow-up, and the uncertainty of prognosis or recovery were the main problems that occurred during the distress signal stage. Family support such as monitoring people with schizophrenia to comply with the antipsychotic administration, the understanding of family in caring for schizophrenia, and the increasing quality of life of schizophrenia patients could reduce stigma in the community (Erawati & Keliat, 2015). The perception of danger often had psychological discomfort consequences. One of the efforts to anticipate the distress signal was knowledge. A previous study showed us that psychoeducation could enhance the family's knowledge of mental health problems (Afriyeni & Sartana, 2020) and could reduce the family burden (Afriyeni & Sartana, 2020; Mubin et al, 2019). The patients often asked for information on their diseases, especially regarding the treatment plan and various alternative treatments based on the information given during the patients' educational program (Wolters Kluwer, 2017). A study reported that educating the patients and their families could reduce emotional expression felt by the families (Mubin et al, 2020).

High demand for treatment is the phase that occurs after the danger signal. Feelings of annoyance and frustration as a result of various driving forces. This is described as high demand for treatment for people with schizophrenia. Other people might have perceived the condition as an unpleasant situation. This condition is made worse by the suffering attitude, the demand for treatment, the financial costs, and the loss of access to the family and society.

The participants required understanding to recognize this phase. Understanding here was defined as the ability to see things meticulously and thoroughly from both the standpoint of the existing needs and demands. This condition depended on family member's educational background and how capable they were of assessing their needs and demands proportionally. They had to understand the consequences of the tendency toward these increasing needs or the tendency for the enhanced capability provided by people with schizophrenia, their families, society, and health workers.

Health care for people with schizophrenia requires funding (Jamison et al., 2013) and an integrated health care system at the primary level supported by sufficient resources (Patel, 2016). All mental health problems are more often associated with high costs. A study revealed the expenses and the cost-effective interventions must not exceed the health, economic, and social costs (Walker et al., 2015) since they could affect the demand for treatment. People with schizophrenia served as a significant predictor for the caregiver's burden (Yu et al., 2017). A study showed the patient's social function directly correlated with the family function. This condition could end up with a higher demand for treatment (Trang, 2018; Yazıcı et al., 2016).

A study revealed that when a patient's income decreased, the caregiver's burden increased. Many countries did not give the necessary economic support needed by people with schizophrenia and their families (Chan, 2011). Poverty affected the problem areas such as access to health care services to monitor and treat the disease, access to social and recreational facilities, fulfillment of basic needs, and integration with society (Awad & Voruganti, 2008).

Several studies conducted in Asian countries showed the caregivers' burden increased as they got older. On the contrary, in Mexico and the United States, the burden decreased as they got older (Chan, 2011). Another factor that increased the demand for treatment was the time spent by the family with the patient in the same house, namely about 14–15 hours with the patient everyday (Arslantaş & Adana, 2011). We could conclude that enhancing the patient's health was a proper method to reduce a high demand for treatment.

We could enhance the patient's health by promoting recovery and connecting them with a profession. Accessibility, personal approach, and flexibility were very helpful in the recovery

process. It was important for the professional to be able to treat his or her patient as a unique individual and to listen to and see them promote the patient's psychiatric health (Gopal, 2020). Sustainable health care implies developing trust and promoting interactions with health professionals. Law Number 18 of 2018 on mental health and Regulation of the Minister of Health of the Republic of Indonesia Number 43 of 2016 on the administration of a minimum service standard of mental health problems at the primary health center played an important role in enhancing society's knowledge of mental health problems.

Continued health care and an increase in mental health knowledge can develop trust and a change of positive convictions. As a result of various driving forces triggering that phase, a change of positive convictions was characterized by angry and hostile feelings. This condition is worsened by society's propaganda, the loss of other people's trust, and the loss of social relationships.

How the participants understood this change of positive convictions required commitment. Commitment is defined as a profound individual's feeling, and it had to promote for them to maintain and develop a quality treatment of these people with schizophrenia. This condition was dependent on the quality of the relations nurtured among people with schizophrenia and the level of prosperity that they had. The quality of the relations would directly impact their love and emotional coping when they faced any problem with people with schizophrenia. The better the quality of the relations, the stronger the love and the weaker the emotional coping would be. On the contrary, the worse the quality of the relations, the weaker the love and the stronger the emotional coping would be. The level of prosperity is defined as good social support and health services as a part of social capital.

Positive convictions played a central role in the treatment of people with schizophrenia. The success of the treatment of people with schizophrenia positively correlated with positive convictions. The positive convictions emerged as a result of the acceptance of schizophrenia patient's condition (Suryani et al., 2019). However, the need for a large magnitude in psychiatric caregiving and demanded to adequately meet the needs could result in increased psychological distress (Riley-McHugh et al., 2016). Positive convictions were developed through the encouragement of the caregiver's optimism on the positive results of the treatment of people with schizophrenia. However, continuous stressors sometimes triggered a change of positive convictions.

Stressful and difficult treatment experiences would correlate with negative convictions. Their assessment of negative experience was reported when they thought the disease people with schizophrenia suffered from harmed themselves, people with schizophrenia, and society. Pessimistic caregivers thought they and the patient would suffer a psychotic consequence as a result of long-term treatments that they deemed to be negative.

Overall, the relationship between caregiving, the caregiver's trust in healing, and the duration of the disease can result in a change of convictions. When the caregiver can maintain his or her knowledge and understanding of the psychosis correctly, he or she can maintain their positive convictions. However, if the perceptions are negative, they can result in a change of convictions in the treatment of people with schizophrenia. This might be a reflection of the negative implications of the mental health problems that people with schizophrenia suffered from, the problems that the caregiver faced, and the social support they underwent for years.

A previous study showed the relationship between dissatisfaction with their social networks and the increasing level of psychotic symptoms. Moreover, life satisfaction was positively correlated with social network particularly with family members (Tomini et al., 2016). Another study identified social support has a positive correlation with the quality of life among people with schizophrenia (Prabhakaran et al., 2021). Dodell-Feder et al. (2020) found isolation should become a priority in a community's mental health because it may impact

psychotic-like experiences through the social networks. Therefore, social network served as a protection against a recurrence.

The condition of dissatisfaction with social networks can have an impact on is losing confidence and capability, which is the fourth phase in the process of shackling people with schizophrenia. Loss of confidence and capability is characterized as wrath. Symbols deemed to represent the driving forces of loss of confidence and capability to learn helplessness and obedience to perceived authority from people with schizophrenia. This condition could get more urgent since society felt that they did not have a secure place away from the aggression and destruction of people with schizophrenia.

The participants' ability to understand this loss of confidence and capability required self-efficacy. Self-efficacy is defined as a conviction that one could confidently handle and be competent to take care of certain challenges when treating people with schizophrenia. This condition was very dependent on their quality of life and their physical and mental health that directly impacted their sense of empathy and care. Bad quality of life and poor physical and mental health would result in vulnerability and exasperation. On the contrary, good quality of life and good physical and mental health would result in individual success.

Loss of confidence and capability was often called self-efficacy. Self-efficacy was the conviction that one could do things with confidence and be competent in certain situations (Bandura, 1977). Self-efficacy was the determinant of emotional responses and behaviors towards a stressor (Bandura, 1997), namely the severity of symptoms.

Loss of confidence and capability could make one upset and would negatively impact the treatment process. Low self-efficacy made the caregiver a negative influence, and this influence would result in the loss of confidence and capability (Pasmatzki et al., 2016). Loss of confidence and capability could occur because self-efficacy served to promote emotional endurance and positive judgment (and a cognitive process) and to reduce emotional vulnerability and negative acts (de la Fuente-Arias, 2017; Milioni et al., 2015).

The need for support in independent life would be closely related to an enhanced level of satisfaction. It was crucial for people with schizophrenia and their families to have a job that reflected their needs, hopes, motivation, and satisfaction (Reddy et al., 2016). A study in Indonesia showed that life skills and work productivity of people with schizophrenia could strengthen their ability to live in a community with the application of the community mental health nursing model (Keliat et al., 2020). We believed work would contribute to an enhanced pride and would enhance symptom reduction management, including negative symptoms and positive symptoms (Keliat et al., 2020), getting engaged with their families so they could pursue work, school, and leisure (CAMH, 2016). In the end, all these methods were aimed at enhancing the self-efficacy of people with schizophrenia and their families.

The last phase in the process of shackling people with schizophrenia is restrictions. Restrictions are characterized by uncontrolled fury and rage, and they consisted of committing a punitive act against people with schizophrenia. Symbols representative of the driving forces of restrictions were reward-seeking responses of people with schizophrenia. This condition is worsened by society increasing demand for an urgent feeling of security.

The participants' ability to make restrictions required self-control. Self-control defined as an individual's ability to overcome responses by controlling their behaviors and managing cognitive and emotional responses, at the end of results of which were adaptive behaviors. The self-control concept applied to their experience in taking care of people with schizophrenia, which led to chronic stress. This condition was very dependent on the psychiatric symptom concept, specific burdens of roles, disorders in their spouse's functions, a measured dispositional self-control competency, and self-control on a lighter consequence of burden, fewer memories, and behavior problems.

The most frequent signs and symptoms found in people with schizophrenia were unexplainable anger and aggression. These facts are supported a study conducted by Hodgins and Klein (2017), who stated people with schizophrenia shackled by their ankles showed a history of aggressiveness. These findings support a study conducted by Daulima et al. (2016) who stated most people shackled by their ankles showed negative symptoms, namely anger and hallucination. The study was supported by another study conducted by Hernawaty et al. (2018) on the characteristics of people with mental health problems who were restrained, namely, showing symptoms of violent behaviors, delusion and hallucination, and suicide. These negative symptoms resulted in more violent behaviors (Hoptman et al., 2014). Negative symptoms were aggressiveness, uncontrollable behavior, destruction, and maladaptation (Comparelli et al., 2018). Negative symptoms that became the most important reasons for shackling were violence and agitation. Similar findings from various studies showed several symptoms are frequently displayed by people with schizophrenia before the shackles were removed, including threatening behavior.

Aggressive behaviors often displayed by people with schizophrenia such as social harmfulness acts made other people fear being their victims (Markiewicz et al., 2020). This situation could trigger family members to restrain people with schizophrenia (Laila et al., 2019). Restrictions were regarded as a method to control aggressiveness. The need for a sense of security also led to these restricting acts. Local traditions and cultures also play a crucial role in imposing these restrictions (Fiorillo et al., 2011).

One of the methods to prevent a restricting act was to enhance access to various sources of support. Independent accommodation provides basic security for individuals with mental health and family problems. Daily activity routines and practice would result in a sense of security (Phipps & Ozanne, 2017), thus, restricting threats for people with schizophrenia, their families, and society could be removed.

### **Limitation of this Study**

Our limitation in this study relates to the selection of the sample of participants. All interviews were conducted in East Java as a subset of all provinces in Indonesia. Also, East Java is a large province, and researchers need more time in the interview process. Even so, participants in this study also consisted of five groups (people with schizophrenia, family, cadres [volunteers], and prominent figures), all of whom are closely related to schizophrenia. This study reached data saturation for the twenty-third participant. These findings have implications for increasing the self-efficacy of people with schizophrenia and their families.

### **Conclusion**

The stages of shackling people with schizophrenia, revealed in this study, emphasize shackling people with schizophrenia is a result of the anger expressed by people around people with schizophrenia. In conclusion, we believe the shackling of schizophrenia patients violates human rights. Therefore, it is necessary to prevent and carry out comprehensive management. This study's results can provide broad insight regarding the stages of shackling in people with schizophrenia and become evidence-based on the management and treatment of people with schizophrenia. Understanding this journey can also be the basis for health workers, families, cadres (volunteers), community leaders, and policymakers to establish prevention programs for shackling. So that in the end, it is hoped that people with schizophrenia will not experience shackles.

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### Author Note

Dr. Ns. Heni Dwi Windarwati, S.Kep., M.Kep., Sp.Kep.J. is a lecturer in community nursing department with the Nursing faculty of Brawijaya University, Jl. Veteran, Malang, East Java Indonesia, Postal code 65145. Please direct correspondence to hewinda80@gmail.com.

Prof. Budi Anna Keliat, S.Kp., M. App.Sc. is a professor in Department of Mental Health Nursing with the Faculty of Nursing of Indonesia University, Jakarta, Indonesia, Gedung FIK UI & Laboratorium, Jl. Prof. Dr. Bahder Djohan, Kampus UI Depok, West Java Indonesia. Please direct correspondence to budianna\_keliat@yahoo.com.

Prof. Dr. dr. Raden. Irawati Ismail, Sp.KJ(K), M.Epid. is a professor in Medical Faculty, Indonesia University, Kampus Jaya 29 Cidodol Kebayoran Lama Jakarta Selatan Indonesia. Please direct correspondence to ira\_ismail@yahoo.com.

Adang Bachtiar, M.D., M.P.H., D.S.C. is a senior lecturer in Fakultas Kesehatan Masyarakat, Indonesia University, Kampus Jaya 29 Cidodol Kebayoran Lama Jakarta Selatan Indonesia. Please direct correspondence to adang@post.harvard.edu.

Erna Erawati, S.Kep., Ns., M.N. (Corresponding author) is a lecturer in Department of Psychiatric Nursing, Poltekkes Kemenkes Semarang, Indonesia, Perintis Kemerdekaan Street, Magelang City, Central Java Province, Indonesia, Postal address: 56115. Please direct correspondence to ernaerawati57@yahoo.com.

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