Understanding The Use of Pasung for People with Mental Illness: Experience of Families and Communities, Reasons for Its Use, and Potential Solutions

By

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ABSTRACT

Background. In Indonesia, the term *Pasung* entails the physical restraint through stocks and/or shackles and confinement of the person in the community, beyond the walls of institutions, and often inside their home. Usually, Pasung is applied to people who are considered to be severely mentally unwell, who are perceived to be dangerously aggressive towards others. While Indonesia has established the goal of being free from Pasung since 2010, the incidence of Pasung and its re-occurrence after hospital-based treatment remains high. The continued practice indicates that there are likely complex issues present within Indonesian society, and that a more comprehensive understanding and solution are needed.

Aims. This study aimed to explore the use of Pasung, the experiences of those involved, the perceived reasons for its use, current interventions, and potential solutions, drawing on a range of perspectives to inform improved understanding and proposed approaches to addressing Pasung in the Indonesian community.

Methods. An interpretive ethnographic approach was undertaken in a naturalistic setting in which people live, and in which Pasung is practised. The data included 30 in-depth interviews with Persons in Pasung (PIP), their families, the community, health professionals, non-health professionals, policy-makers, and managers, as well as 135 photographs, 3 videos, and reflexive notes concerning Pasung. Participants in the study were PIP who were part of the Free Pasung Programme in 11 districts in West Java from various geographic locations between 2016 and 2019. The Socio-Ecological Model (SEM) underpinned the study to examine the individual, interpersonal, community, and policy factors associated with Pasung.

Findings. The overarching theme of this research found that Pasung gave the PIP and the systems of support around them, particularly their family, “No room for escape” from its use. The findings inform us how this practice is multidimensional, socially and culturally accepted within the community, and how there are dynamic inter-relationships that exist across contexts associated with the four layers of the SEM that reinforce its use. ‘No room for escape’ is a term used by the author to indicate that Pasung occurs over time for PIP, sometimes for the remainder of their life, which creates barriers to receiving mental health services. This key finding also identifies a lack of accessible alternatives to Pasung, showing that the family and community believe there are no effective, accessible alternatives to these practices. This situation leads to ineffective implementation of the Free Pasung Programme (FPP). The overarching theme of “No room for escape” encapsulates that Pasung, although regarded as a ‘last option’ treatment, is perceived as the only effective, accessible means participants had to manage persons who were deemed as having aberrant behaviour when mental health treatment was not accessible and there were

barriers to accessing mental health services. “No room for escape" implied a major imbalance in power relationships across the four layers of the SEM.

Discussion. The findings show that Pasung is not solely a result of individual symptoms or the refusal of family to accept psychiatric treatment. It can more accurately be attributed to a range of factors across the SEM, including government failure to provide basic mental health services for people with severe mental illness, the ever-present stresses of stigma, the fragmentation of hospital and community services, and the inadequacy of policy. Pasung is a problem that is unlikely to be fully addressed by simply offering mental health treatment in a hospital. Even in Indonesia, where Free Pasung Programmes are being implemented, the emphasis is on providing psychiatric medicine and basic psychoeducation rather than ongoing outreach and/or rehabilitation. Instead, a comprehensive model is required which includes caregiver support, a community development approach to enhance economic independence, a coordinated effort to increase health care adherence, and community education to reduce stigma.

Keywords: Pasung, ethnography, Socio Ecological Model, Person in Pasung, No room for escape, comprehensive model

DECLARATION

I certify that this thesis

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed Muhamad Taufik Hidayat

Date 1 December 2023

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ABBREVIATIONS

AAMH	Australia Asia Mental Health
BCI	Bipolar Care Indonesia
CASP	Critical Appraisal Skills Programme
CEBma	Centre for Evidence-Based Management
CHC	Community Health Centre
CRPD	Convention on the Rights of People with Disabilities
DSM	Diagnostic Statistical Manual
FPP	Free Pasung Programme
GSP	Gerakan Stop Pemasungan the Indonesian Ministry of Social Welfare programme to stop Pasung
HCP	Health Care Professionals
HPA	Health Policy Analysis
JBI	Joanna Briggs Institute
KPSI	Komunitas Peduli Skizofrenia Indonesia
LMIC	Low- and Middle-Income Countries
MDGs	Millennium Development Goals
MoHA	Ministry of Home Affairs
MoH	Ministry of Health
MoSA	Ministry of Social Affairs
MoLH	Ministry of Law and Human Rights
ODGJ	Indonesian term for people with mental illness
ODMK	Indonesian term for people with mental health problems
PIP	Person in Pasung
PIS-PK	Healthy Indonesia Programme through Family Approach (Program Indonesia Sehat dengan Pendekatan Keluarga).
PTF	Policy Triangle Framework
PWMI	People with Mental Illness(s)
RCTs	Randomised Control Trials
SBREC	Social and Behavioural Research Ethics Committee
SDGs	Sustainable Development Goals
SEM	The Socio-Ecological Model
SR	Seclusion and restraints
TheMHS	The Mental Health Services Conference
WHO	World Health Organisation
WJPG	West Java Provincial Government
WJPH	West Java Psychiatric Hospital

GLOSSARY

Behaviour of concern	Any behaviour that causes significant distress or danger to the person living with mental illness or to others. Extremely agitated behaviour, aggression, or violence are examples of these behaviours, which have the potential to cause physical or psychological harm to themselves, another person, or to property around them.
Carer	A person, including a person under the age of 18 years, who provides care to another person with whom they are in a relationship of care.
Consumer	A person who has lived with a mental illness.
Lived experience	A person's experience with mental illness and their pathway to recovery.
Mental Illness	A medical condition that is characterised by a significant disturbance of thought, mood, perception, or memory.
Mental health professionals	Psychiatrists, clinical psychologists, mental health nurses, primary care physicians, clinical social workers, community nurse practitioners.
Pasung	Restraint in community settings such as in the home (non-institutional setting) which entails physical restraint, confinement, stocks, or shackling of the person in the community beyond the walls of institutions.
Policy-makers	Individuals at some level of government or a decision-making institution, including but not limited to international organisations, non-government agencies, or professional associations, who have the responsibility for making recommendations to others.
Unwell	When someone with mental illness is experiencing an episode of mental illness.
Visual	Refers to video and photographs.

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1
INTRODUCTION

This chapter provides a summary of the research undertaken for this thesis, including the background to the research, a statement of the problem being investigated, the research questions and aims, the theoretical framework, the researcher's background, the organisation of the thesis, and an argument justifying the significance of the research. The background to this chapter has been published in the International Journal of Mental Health Systems as part of the systematic review presented in Chapter 3 (Hidayat, M. T., Lawn, S., Muir-Cochrane, E. & Oster, C., 2020. The use of pasung for people with mental illness: a systematic review and narrative synthesis. *International journal of mental health systems*, *14*(1), pp.1-21). The series of questions posed for this research has been submitted as the protocol for a systematic review (Muhamad Taufik Hidayat, Sharon Lawn, Eimear Muir Cochrane, Candice Oster. Systematic Review of Pasung Use for People with mental health conditions: experiences, reasons for Its Use, and potential solutions. PROSPERO 2020 CRD42020157543 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020157543).

1.1 Background

Seclusion and restraint arecommonly used in psychiatric institutions to control people with severe mental illness (the term 'people with mental illness' – PWMI will be used hereafter) who show aggression and violence towards others. The use of seclusion and restraint continues to be widely debated and challenged (Hert et al. 2011; Muir-Cochrane 2022). As indicated by the international literature, seclusion and restraint are not therapeutic in any way, and there have been numerous reports of negative outcomes, despite the fact that psychiatric institutions use them as a last resort in care to ensure the safety of nurses, consumers, visitors, and health professionals alike. The continued use of seclusion and restraint in psychiatry has become a major issue, with many parties, including consumers and carers, calling for their reduction or elimination. As a basic human right, PWMI deserve the least restrictive care possible, and they should not experience trauma or be re-traumatized as a result of hospitalisation (Muir-Cochrane 2018, 2022). However, little is known about their use in non-psychiatric settings, particularly in the community environment such as in the home. Community confinement methods are a global phenomenon and are found in many countries, regardless of the level of country income. However, the practice is most commonly found in Low- and Middle-Income Countries (LMICs) where health resources are inadequate (Guan et al. 2015; Minas & Diatri 2008; Read, Adiibokah & Nyame 2019; Suryani et al. 2011). In Indonesia, this practice is known as 'Pasung*',* which entails the physical restraint, confinement, being placed in stocks, or shackling of the person in the community, beyond the walls of institutions, often inside their homes. Generally, the use of Pasung is related to, and applied to,

people who are considered to be severely mentally unwell; in the context of also being perceived as being dangerously aggressive towards other people (Broch 2001; Minas & Diatri 2008).

Pasung uses one or more combinations of different methods, including mechanical restraint and isolation/seclusion. Mechanical restraint in Pasung usually involves the use of chain shackles, rope, and/or wooden stocks. Isolation usually involves locking people in confined cages and frequently isolated spaces located at a great distance from the community or in a separate hut (Asher et al. 2017; Irmansyah, Prasetyo & Minas 2009; Katuuk, Daulima & Wardani 2019). Both processes can be experienced concurrently; that is, the person can be chained and confined at the same time. Most of the places where the person is confined are dirty, with the PWMI sometimes defecating and urinating without access to a toilet, with no ventilation apart from a small window to insert food and extremely limited human contact. Limited space means the PWMI needs to sit or lie down on the floor for the duration of their confinement. As a result, many of those subjected to Pasung have been found to be under-nourished, physically wasted, and sick from a range of untreated health conditions (Broch 2001; Yusuf & Tristiana 2018).

Although the practice of Pasung has been officially banned in Indonesia since 1977 (MoHA 1999), its practice continues to rise (HRW 2018). This led to the establishment of the Free Pasung Programme (FPP) in Indonesia in 2010 (Indonesia Free from Restraint and Seclusion or 'Free Pasung'), which attempted to reduce the use of community restraint for PWMI (MoH 2010). Furthermore, in 2011, to ensure equal rights for PWMI and that they were not subjected to torture and mistreatment, the government also ratified the internationally recognised Convention on the Rights of Persons with Disabilities (CRPD) (MoSA 2011). This was followed by the ratification of Mental Health Act. 18, enacted in 2014, which also reaffirmed that the perpetrators of deprivation of others would be imprisoned and fined (MoH 2014).

Until recently, there were no epidemiological surveys that accurately conveyed the percentage of people being restrained in the community (Minas & Diatri 2008). Also, the number of PWMI in Pasung might be far more than the number predicted since the majority of PWMI are hidden by their family and not exposed to public view. This is because Indonesian culture and society generally perceive mental illness as a shameful disease due to traditional, religious and cultural beliefs. For example, mental illness is viewed as the result of disrespect for spirits or Gods, and the expulsion of demons is considered an effective remedy (Broch 2001; Nurjannah et al. 2015a; Subu et al. 2022). The Ministry of Health of Indonesia estimated that in their 2014 survey, there had been approximately 57,000 PWMI subjected to Pasung at least once in their lives, and 18,880 were currently in Pasung (MoH 2016a).

The Indonesian government claims that the FPP successfully reduced the rate of Pasung from 18,880 cases to 12,220 in 2018 (HRW 2018). Repeated revisions of the programme by the Indonesian Government (2010-2017 and 2019) have sparked doubt among the community about

the actual number of people still in Pasung and the success of the FPP as claimed by the government. In addition, data released by the Indonesian Institute of Health Research showed a slight decrease from 14.3% to 14% of PWMI who were subjected to Pasung*,* but this did not match the reduction in rates cited by the Ministry of Health (MoH 2018), nor did it appear to account for the increase in population growth in Indonesia during the period 2010-2018, which grew by almost 30 million (from 237 to 265 million), as released by the Indonesian Bureau of Statistics (Badan Pusat Statistik 2019). Other data from the Ministry of Health (MoH) website showed that 10% of those who were in Pasung were released and treated in hospital over a six-year period from 2009-2014. However, there is no data on how many of them were successfully supported through rehabilitation or returned to Pasung in the community (MoH 2016a).

The continued practice of Pasung indicates that there are likely complex issues present within Indonesian society and that a more comprehensive understanding and solution is needed (Minas & Diatri 2008; Read, Adiibokah & Nyame 2009). International evidence has confirmed that PWMI are not predominantly those who commit violence, but instead who are more likely to be victims of violence perpetrated by others (Maramis, Van Tuan & Minas 2011; Minas & Diatri 2008; Read, Adiibokah & Nyame 2009). Examining the use of Pasung is essential to addressing fundamental human rights violations (Drew et al. 2011). To help fill this identified gap, this research aimed to explore the use of Pasung in Indonesia including the socio-cultural meaning of Pasung, the experiences of those involved, the perceived reasons for its use, current interventions and their barriers, and potential solutions. This research aimed to balance the many perspectives on this problem in order to understand Pasung and to inform how Indonesia can develop more effective interventions for PWMI in Pasung, their families, and the Indonesian community. The SEM was selected to underpin the research because of its suitability for understanding this pervasive issue at various social systems levels and exploring any intersections and influences across and between these levels (Bronfenbrenner 1977; CDC 2020; Kilanowski 2017). The SEM was used to examine individual, interpersonal, and community factors as well as policies associated with Pasung and expectations about the management of Pasung to fill gaps in unmet needs.

1.2 Statement of The Problem

Indonesia has one of the highest rates of Pasung in the world. Although Pasung has been banned because it is contrary to human rights, the practice continues to exist within the community, particularly where pervasive negative beliefs about mental illness persist, in the absence of adequate social support and mental health services. Such services are either non-existent or grossly inadequate to meet the needs of the community in many parts of Indonesia. Many persons in Pasung (referred to as PIP will be used hereafter) live in deplorable conditions, but little research has been conducted on the issue.

1.2.1 Pasung as an Acceptable Practice

PWMI often experience human rights violations such as indignity, discrimination, exclusion, and the inability to live independently. As a result, they depend on their families and the community for their basic financial, social, and personal needs. This includes support for food and shelter, and to continue medication and any other treatment for their overall health and wellbeing (Drew et al. 2011). Their risk of being subjected to human rights violations is elevated by the fact that many PWMI live without adequate support from their family (Asher et al. 2017; Cradock, Young & Forquer 2002). In fact, families are the most common perpetrators of the use of Pasung. The literature indicates that Pasung appears to be used as a last resort in the absence of other types of support to help families manage and care for the PWMI. Overall, the family resorts to Pasung due to the interconnection of the elements found in the SEM across individual, interpersonal, community, and policy-related factors (Hidayat et al. 2020). The family and the community also perceived that conducting Pasung was crucial for treating PWMI (Asher et al. 2017; Buanasari, Daulima & Wardani 2018; Laila et al. 2019; Minas & Diatri 2008).

1.2.2 The Disjuncture of FPP and the Need for Ongoing Comprehensive Treatment

A systematic review of the literature (see Chapter 3) highlights the lack of an effective intervention to address Pasung in the community. The existing intervention (the FPP) involves the person being taken to a hospital and being provided with treatment for their mental health over a limited time period, and then being returned to the community without further follow-up for the person, or support being provided to their families and communities. The problems which led to the use of Pasung often quickly reappear after hospitalisation and, as a result, the family and community return to using Pasung (Minas & Diatri 2008; Suryani et al. 2011).

As discussed above, with repeated programmes introduced by the Indonesian Government with the goal of ending Pasung*,* there is presumably a problem in the ongoing treatment of these people. In addition, the lack of availability of sustainable treatment and community support programmes is reportedly hampered by a lack of investment in mental health care and consequent massive workforce deficiencies. There are also few consumer, carer, or other civil-society organisations with a focus on mental health advocacy. Many articles conclude that greater consumer and carer participation and greater cooperation with health and non-health support services are needed (Brooks et al. 2018; Irmansyah et al. 2020); however, they offer little or no further explanation about how to operationalise such initiatives. Another important finding highlighted by several articles is that, while legislation has already been established, its implementation has been poor, with limited or no regulation of policies that aim to address Pasung (Brooks et al. 2018; Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011). This creates inadequate protection of the rights of PWMI, little effort to promote mental health, little in the way of rehabilitation services or efforts to promote social and economic inclusion, and

treatment services that are concentrated in urban areas and often of poor quality, inaccessible, and unaffordable (Maramis, Van Tuan & Minas 2011; Minas & Diatri 2008; Nurjannah et al. 2015a).

More work is needed to develop interventions that address the use of Pasung. These interventions need to include greater family and community participation, and also to evaluate how they might benefit the consumer themselves. While the need for civic engagement in the development of interventions to address Pasung has been identified (Brooks et al. 2018; Irmansyah et al. 2020), including the addition of lived experience perspectives, an understanding of how to do this effectively, and how to involve family and PWMI remains unclear (Lloyd & King 2003).

The current PhD study explored the nature of Pasung, and the reasons given by families and communities for applying such restraint. Moreover, this research sought to understand Pasung from the perspective of PIP, their families, the community, health professionals (e.g., physicians, nurses, psychologists, social workers), non-health professionals (e.g., budgeters, planners), policy-makers (e.g., Ministry of Health, Public Health Officers), and health system managers (e.g., hospital administrators, community health administrators). In addition, this study explored understandings of the implementation of the FPP and its barriers across individual, interpersonal, community, and policy-related factors. This includes how it was conducted and experienced by PIP and families in the community context, and what can be developed to reduce Pasung. A systematic review of the current evidence was conducted as the first step, followed by a policy review and ethnographic research using existing data consisting of videos, photographs, field notes, and interview data collected during the FPP in West Java (2016-2019). The final phase of the research involved a synthesis of all the findings to inform improved understandings and proposed approaches to addressing Pasung in the Indonesian community.

1.3 Research Questions

1. Why does Pasung continue to be practised in the Indonesian community?
2. What is the nature of Pasung as practised by families and communities in Indonesia?
3. How is Pasung perceived and experienced from the perspective of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers?
4. What are current understandings regarding the FPP's implementation, its effectiveness, and how it is practised?
5. How have Indonesia's policies on FPP and mental health influenced Indonesia's efforts towards eliminating Pasung?
6. What are suggested methods and strategies to reduce Pasung across the multiple levels of the SEM?

1.4 Significance of the Research

The existing evidence shows that the practice of Pasung persists, despite the current implementation of the FPP, and claims that the rates of Pasung have reduced (HRW 2018). The continuing practice of Pasung suggests that there continues to be a large gap in our understanding of the reasons given by families and the community, and that there may be unmet needs that are not yet fully recognised. Although some research has suggested greater civic engagement by health professionals with non-health stakeholders, consumers, and carers in community mental health (Irmansyah et al. 2020; Nurjannah et al. 2015a; Suryani et al. 2011), there appears to be a problem in determining what this involvement should look like, its inclusiveness, and the level of participation required and shared by each of these groups. Understanding their perspectives and demands for treatment and support provides an important balance to other perspectives held by professional mental health service providers and policy-makers. Reducing the gap in our understanding of the reasons given by families and the community, and the unmet needs that are not yet fully recognised in relation to Pasung is important, as Indonesia has officially been battling with the practice of Pasung since 1977 (MoHA 1999), and the problem persists despite current efforts to address it.

This PhD research is the first to conduct a comprehensive examination of the social and cultural meanings of the practice of Pasung from the perspective of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers using ethnography as the method of inquiry. It is the first to comprehensively position the analysis of this topic using the SEM which proposes four core principles of Pasung that influence and interact across different levels. Understanding these fundamental principles is crucial for developing multi-level interventions to effectively reduce Pasung.

This PhD research has also used a mix of visual and interview data which extended the use of videography and photograph (photo) analysis that had never been used in prior studies on Pasung in Indonesia. The collection of visual data in the form of videos and photographs is an important way to explore the practice of Pasung, as it is predominantly a hidden and stigmatised practice and is also experienced by people who may not be able to fully express their own perspectives using other forms of communicating their experiences and circumstances through the use of other research methods. The findings of this research have the potential to address what appears to be ‘a blind spot’ in knowledge about Pasung, and to inform health practice in the management and care of PIPs, leading to improvement in the quality of life and experiences of PWMI who experience Pasung.

1.5 Aims of the Research

The broad aim of this research was to explore the use of Pasung in Indonesia, including providing an overview of the social and cultural meanings of Pasung, the experiences of those involved, the perceived reasons for its use, the current intervention and its barriers, and potential solutions. This research aimed to balance the many perspectives on this problem in order to understand Pasung and to inform how Indonesia can develop a more effective intervention for PWMI in Pasung, their families, and the Indonesian community. This broad aim was achieved through the following objectives:

1. To undertake a systematic review of the existing international peer-reviewed literature examining the research evidence regarding the nature of Pasung, how it is experienced from a consumer and carer perspective, the perceived reasons for its use, and the possible solutions proposed to reduce the practice.
2. To conduct ethnographic research exploring the practice of Pasung and how it is perceived from the perspective of PIP, family carers, mental health professionals, and community members. This involved analysis of video, photographs, and interview data previously collected during the FPP implementation in West Java. While in Pasung, many participants in this research could not speak clearly in terms of expressing their experience of Pasung. Some participants had become mute as a consequence of their experience; therefore, visual methods were an important way to capture their experiences. As a result, the use of visual data played a crucial role in this research. The SEM was used as a theoretical framework to gain an understanding of Pasung at various social systems levels, and to explore any intersections and influences across and between these levels.
3. To explore people's understandings of the implementation of the FPP and its effectiveness, how it is conducted, the experiences of consumers and families in the community context, and what can be developed to reduce Pasung.
4. To examine existing policies, plans, and initiatives in Indonesia targeted at eradicating Pasung.

1.6 Conceptual Framework

This research is underpinned by concern for the human rights of PWMI and how they experience stigma and discrimination in care (in the form of Pasung) within their community (Drew et al. 2011; Nurjannah et al. 2015a; Read, Adiibokah & Nyame 2019). Hence, the research explores the interpersonal, community, and care systems' responses to the needs of this group within the Indonesian community. Pasung as a human rights violation is understood within the terms ratified by the internationally recognised Convention on the Rights of Persons with Disabilities (CRPD), which calls for the abolition of torture and mistreatment for all groups who experience disability, including PWMI (Government of Republic Indonesia 1945).

To understand Pasung, this research undertook ethnographic research, informed by the theoretical lenses derived from a systematic review of the existing evidence, used as a predictive and explanatory tool. While the use of existing theory in ethnography is debatable, Cury and Bird (2016 p.201) explained that “pre-existing theory provides valuable assistance when transforming an insight about the world into an idea with explanatory and predictive potential”. The SEM underpinned the research because of its suitability for understanding this pervasive issue at various social systems levels and exploring any intersections and influences across and between these levels (Bronfenbrenner 1977; CDC 2020; Kilanowski 2017). The basic assumption was that a comprehensive approach would be more effective than a single-level perspective (Bronfenbrenner 1977; Kilanowski 2017).

In the case of Pasung, no single factor can clearly generate the reasons for families and communities conducting this practice. All factors (i.e., individual, interpersonal, community, and policy) have potentially had a significant impact on this practice before, during, and after Pasung. The individual level includes biological and personal history factors that increased the risk of the person being subjected to Pasung, i.e., age, marital, sex, employment, education, mental health history, medication history, and aggressive behaviour. Interpersonal relationships consist of the relationships between the person experiencing Pasung and their community, spouse/partner, and family, and in particular the interconnection of a person’s behaviour and perceived risk from family. At the socioeconomic level, adaptation and family burden were also included in this domain. Communities play an essential role in supporting the recovery of a PWMI and also in the overall impact of illness due to stigmatizing, inaccurate beliefs about mental illness. Community factor determined from this review, includes socioeconomic status (both the person and family, and the community surrounding them if reported), geographical area, cultural identity, social inclusion and integration, literacy, and infrastructure. In addition to individual, interpersonal, and community factors, the policy provides a vital context for the practice of pasung and its elimination. The issue of protecting the human rights of persons with mental illness has been a significant concern in many countries, including in Indonesia. These ideas are examined further in Chapter 3.

1.7 Researcher Background and Influence of My Sundanese Cultural Background on the Research

I was born and raised in the Sundanese culture where the study was conducted. Thus, observing the Sundanese culture is always like being ‘at home’ wherever I go. In the Sundanese language, the term ‘psychiatric illness’ is referred to as ‘gering pikir’. The word ‘gering’ means sick people and ‘pikir’ means mind or mental. So, in its complete form, gering pikir means losing one’s sanity. These words, in turn, can only be found in the southern regions of West Java where the language is more euphemistic. In other regions of West Java, the term is coarser; for example, using it with the term ‘gelo’ or crazy (Rosidin & Hilaliyah 2022).

During my childhood, I saw many people in chains, including my neighbour who was also my relative. I had to pass her house to get in and out of my house at least twice a day for school. This was ‘scary’ for me as a child, particularly routinely hearing the sound of chains when she walked or her voice when she screamed. Frequently, I chose different pathways to and from my house to avoid ‘being caught’. By this, I mean being caught in its actual denotative meaning. On one occasion, I was caught by her when she grabbed my shirt. She did not do anything directly harmful to me and only pulled my collar. On reflection, I may have inadvertently run into her territory and disturbed her; hence, her reaction could be understood as very normal, given her situation in Pasung. But for me, it was a traumatic event that then influenced the way I looked at, and saw, people who were deemed as having a mental illness. My experience of living within the Sundanese culture and routinely seeing the practice of Pasung as an insider in some ways placed me in a position of personal bias. The researcher's active participation in the Free Pasung Program as a government officer and a mental health professional, combined with the authentic Sundanese background, granted me an insider's vantage point. This unique perspective allowed for a comprehensive assessment of the program from within. It also bodes well for prospective endeavours dedicated to introducing enhanced programs or approaches aimed at eradicating Pasung, not only within the West Java province, where this research was conducted but also potentially in other regions across Indonesia. As I mentioned earlier in Chapters 1 and later in chapter 5, I therefore made a number of assumptions about the data (that initially limited my ability to question and fully critique what I was seeing), given that I live and have grown up within that culture and the experience of seeing people in Pasung was a ‘normalised’ part of my everyday experience. I am therefore mindful of my past background and my culture and its potential influence on my capacity for achieving trustworthiness in the processes of data collection and analysis.

When I started the current research, the condition of psychiatric patients, particularly those in Pasung, in West Java was very concerning. There is a vast amount of stigma indicated by rejection from the community for the PIP to reintegrate into the community, prolonged hospitalisation rates for PWMI, and untreated physical illness for ex-PIP. People who have been in Pasung and are then freed are often hospitalised for a long period in psychiatric hospitals, moved from one hospital or social unit [where they may receive rehabilitation support] to another, and are treated with multiple psychiatric drugs. Those who are not in hospital or a social unit are often isolated either at home, in a separated place, or in the woods to prevent them from going outside and creating shame for the family. People who are presumed to have mental illness are usually exiled from the community as they are believed to be related to bad spirits which will be described in detail in chapter 2

I set out to study Pasung in the community, not to diagnose anyone or to construct a personal case for PIP based on a particular diagnosis. Instead, I wanted to understand why Pasung was socially

practised in the Sundanese culture. I was not diagnosing the people or treating the people in the context of applying those categories to people in Eastern societies (non-western) that may result in what Kleinman (1987) called a “category fallacy”, defined as “The reification of one culture’s diagnostic categories and their projection onto patients in another culture, where those categories lack coherence and their validity has not been established” (Kleinman 1987 p.1). To sum up this case, the psychiatric symptoms that appear in one cultural context would be absent in other contexts, leading to doubt that cultural expressions of the disorder are comparable (Cohen, A 2004; Kleinman 1987). Furthermore, Andreasen (1997) argued that there are no, or very few, clear biomarkers that have been known to determine mental illness (Andreasen 1997). Nevertheless, there is growing research that demonstrates the influence of other factors on the categorisation of mental illness outside of biological designations, such as socio-cultural, gender, physical health, and political climate factors (Andreasen 1997; Cohen, A 2004; Mezzich et al. 1999).

This study has its roots in my work during the 2012-2019 period when I joined the West Java community mental health team to work closely with PWMI in the community. I then saw the culture around Pasung practice. My background is as a clinician with more than 20 years’ experience working in the psychiatric nursing discipline across many areas, e.g., emergency, the inpatient unit, forensics, adult, child, and adolescent care, out-patients, and the community. In Chapter 5, where I describe the research methodology, I discuss the influence of seeing the practice of Pasung through my clinical lenses alongside my Sundanese background, including the benefits and drawbacks of these perspectives. As well, I describe how the discussions with my PhD supervisors who are non-Sundanese, but come from Western cultural contexts, enhanced the study and made for more robust discussions and reflections.

1.8 Organisation of the Thesis

I present the findings of my PhD thesis in a series of chapters, all of which examine the nature of Pasung and why it is practised in the Indonesian community. Each results chapter incorporates different types of data, such as photos, videos, and interviews, with one chapter being devoted to the overall analysis. The chapters present theory, techniques, and findings and are complete in themselves. As a result, in the methods chapters, the description of the research methods for each type of data contains considerable overlap.

The thesis starts with Chapter 1, the Introduction, which includes the background to the research, the statement of the problem, the research questions and aims, the theoretical framework being used, the researcher’s background, and the organisation of the thesis.

Chapter 2 provides a brief description of West Java Province, the Sundanese culture and religion, and the availability of mental health services and beliefs about mental illness. This overview is a

significant element of this research given that little has been written about Sundanese responses to mental illness and Pasung in particular.

Chapter 3 presents the first systematic literature review on Pasung, providing important context to the existing research and current understandings of Pasung. This systematic review and narrative synthesis of the peer-reviewed international literature was conducted to identify the socio-cultural contexts for Pasung use and interventions to address it. The analysis draws on the socio-ecological framework which focuses on relationships between the individual and their environment.

Chapter 4 provides an understanding of the policy landscape and health care system in Indonesia over time, aiming to examine the development of existing policies, plans, and initiatives in Indonesia targeted at eradicating Pasung. Policy gaps and contextual constraints are identified in order to propose stronger policy solutions. It is interesting to note that there were no articles found that provided a comprehensive view of such policies.

Chapter 5 presents the epistemological stance and research methodology of the thesis, which entails an underlying theoretical epistemological stance to clearly describe and understand the practice of Pasung. This research used Interpretivism as the epistemological stance and Ethnography as the research methodology.

Chapter 6 presents the methods used in the thesis, with interpretive ethnography being described in detail. This chapter also described the location of the research, the population involved in the research, and the three sources of data (photographs, videos, and in-depth interviews) in detail.

Chapter 7 presents the photo analysis, in which photographs of PIPs and their community are examined in order to gain detailed insight into the meanings derived from the practice of Pasung. Photo analysis had never been previously used in a similar study on Pasung in Indonesia. This part of the overall study was conducted in a non-institutional setting, and the findings made a significant contribution to knowledge of Pasung specifically, and mental illness in general.

Chapter 8 presents a videography aimed at capturing the complexities of Pasung in the community. Videography is the combination of ethnography focused on natural social situations, the context of the video data taken, and video data analysis. So far, no single research approach has been able to properly develop an accurate narrative of Pasung and this finding added a significant contribution to knowledge of the practice.

Chapter 9 presents the interview analysis, including interviews with PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers. This chapter delves into the experiences of, and reasons for, Pasung of PWMI in community settings in West Java in order to develop viable interventions, particularly in light of the existing FPP intervention.

Chapter 10, the discussion chapter, includes detailed visual and interview data to gain a rich and deeper understanding of Pasung. In this process, pre-existing theory from the systematic review provided valuable insights about Pasung. I discussed the findings under four key themes that arose from the data. The data were organised into four broad components that were guided by the SEM framework.

Chapter 11 presents the conclusion, and the strengths and limitations of the research. This chapter provides a summary of the thesis and a solid argument for its significance, which includes recommendations for future work, a critical analysis of what needs to change, implications for clinical practice, and inclusion of the unique needs of the PIP.

The next chapter discusses the West Javanese context, providing a closer look at Sundanese culture and help-seeking behaviour as well as beliefs about illness. This overview is a significant part of this research given that little has been written about Sundanese responses to mental illness and Pasung in particular.

2
WEST JAVA, SUNDANESE CULTURE, HELP-SEEKING BEHAVIOUR, AND WEST JAVA MENTAL HEALTH SYSTEM

A community's health care system is built through organising beliefs about illness, decisions about specific episodes of illness, and the expectation and evaluation of certain types of care. Understanding the type of health care system in a community can provide insight into the interconnectedness of how people perceive and respond to illness, including norms controlling treatment selection and evaluation, roles, power dynamics, interaction settings, and institutions (Ito, Setoya & Suzuki 2012; Jung 2016; Minas & Cohen 2007). Indonesia is a developing country with a population of 250 million people (Badan Pusat Statistik 2019), and mental health services are being developed nationwide through general psychiatric coordination. The current scope of such services is significant, reaching structurally into the majority of the 34 provinces of this vast island archipelago. Within each service region, it is clear that only a small proportion of persons choose to use the available mental health services, with the Ministry of Health stating that in West Java, only 36.6% of those with a mental illness seek support through mental health services. In general in Indonesia, only about a third (38%) of mentally-ill patients attend treatment and are not neglected (MoH 2018, 2019a). This chapter provides a brief description of West Java Province, Sundanese culture and religion, as well as providing an overview of the availability of mental health services and beliefs about mental illness. This overview is a significant part of the research given that little has been written about Sundanese responses to mental illness and Pasung in particular.

2.1 West Java Province

As an administrative province, Jawa Barat (West Java) was formed in 1925 during the Dutch colonial occupation. The previous name was Pasundan or Soendalanden or Tatar Pasundan. Most people living in this part of Java are Sundanese, and the majority language used in daily activity is Sundanese. West Java is located on the island of Java, with the sea forming a border on the southern and northern sides. In the north, Jawa Barat is bordered by Jakarta, the capital of Indonesia, Central Java to the east, and Banten to the west. The mountain area, which includes a number of active volcanoes, stretches from west to east and makes the soil fertile for agriculture (Ekajati 2005; Kosoh, Suwarno & Syafei 1994; Pemerintah Provinsi Jawa Barat 2017).

Figure 2-1: Map of West Java Province (Pemerintah Provinsi Jawa Barat 2017)

West Java is the most populous province in Indonesia with a population approaching 50 million, or more than 20% of the total Indonesian population, with the ratio of men to women being approximately equal. West Java is divided into 27 districts, with an average population density of 1,365 people per square kilometre. Among the 27 cities in the province, the capital city Bandung is one of the most populous cities in the world (currently 48th) with nearly 50,000 people per square mile (Badan Pusat Statistik 2021).

The population of the city's main buffer zone, which includes Bogor Regency, Bogor City, Bekasi Regency, Bekasi City, and Depok City, totals 11,930,991 people, or 26% of West Java's total population. As a result, it can be estimated that a quarter of West Java's population lives in the capital city's buffer zone. Meanwhile, the population of Greater Bandung (Bandung Regency, West Bandung Regency, Bandung City, and Cimahi City) is 8,670,501 people, or 18% of West Java's total population, implying that Bandung Raya, the province's capital, is home to over one-fifth of the province's population. When the population of the buffer zone of the Capital City and Greater Bandung is added together, the overall population of West Java is 20,601,492 persons or 44% of the total population. Two-thirds of the total population live in urban areas (Badan Pusat Statistik 2019; Pemerintah Provinsi Jawa Barat 2017).

2.2 Sundanese Culture and Religion

The Sundanese are an ethnic group from West Java Island, Indonesia, covering the provinces of West Java and Banten. Sundanese people have spread across many areas of Indonesia, while West Java has the greatest population of Sundanese in Indonesia. Despite being the largest tribe

in West Java, the Sundanese are one of the lesser-known tribes, with the name frequently mis-spelled as ‘Sudanese’; even auto-correct on a computer will transform it to ‘Sudanese’ (Dixon 2000). As per the Indonesian Bureau of Statistics (Badan Pusat Statistik), the Sundanese tribe comprises 36,701,570 individuals, or 15.50% of Indonesia's total population (Badan Pusat Statistik 2010).

The name Sunda is derived from the Sanskrit words ‘sund’ and ‘sudsha’. The word means ‘bright, brilliant, white, and sparkling’. The terms for Sunda can also be found in Balinese and Kawi (Old Javanese). The meaning is nearly identical: clean, pure, holy, spotless, without blemish. The origin of this word, according to Sundanese people, is the practice of everyday life according to Kasundaan which serves as a guide to life's virtues. Sundanese characters include cageur, which means healthy, bageur, which means good, truth, which means true, singer, which means introspective, wanter, which means courageous, and smart, which means intellectual. The Sundanese have used the Kasundaan characters since ancient times, specifically during the Salakanagara Kingdom, and the Tarumanegara, Sunda-Galuh, and Pajajaran eras, and even now. Meanwhile, in AD 397, King Purnawarman used the term Sunda to refer to the capital of the Tarumanegara Kingdom, whose influence was waning. The Tarumanegara Kingdom was renamed the Sunda Kingdom in AD 680 by Tarusbawa, a 14th-century prince of Tarumanegara (Ekajati 2005).

Sundanese people are mountain enthusiasts, sometimes known as orophiles or ‘urang gunung’. This name is attached to the Sundanese from the geographical area of West Java which is a mountainous area, with most of the population working as farmers and cattle breeders (Danasasmita 2006; Sujati 2019). At present, the majority of Sundanese people are Muslims, although the Sundanese tribe's progenitor is the Pajajaran Country, which is a Hindu kingdom. Therefore, it is not surprising that in their religious practice, many villages still employ a cultural cross-over between Islam and Hinduism. This can be seen, for example, in rituals that begin with spells in local languages, which are subsequently incorporated into prayers using Arabic words and verses from the Qur'an, which is not seen in pure Islamic practice (Rosidi 2005). There are now a variety of areas that are used for ritual and religious purposes by the community, particularly in regard to sacred tendencies towards ancestral spirits and places that are deemed sacred. In some ways, people's current religious activities still reflect the continuity of prior religious models and patterns. These patterns are also evidenced as part of the purification of mentally-ill people, as they are believed to be related to bad spirits (Mustapa 2022).

In terms of traditions being taught and passed on, the primary source of teaching in Sundanese society is by parents, teachers, and elders. Although there may not be a well-developed formal hierarchical political system, leadership is frequently recognised. Their method of teaching the children is by reciting the narratives of the ancestors using folklore, or with a range of frightening

and taboo or rebellious prohibitions. A common example of a taboo restriction (pamali) is that children should not go out at night, as doing so will result in sicknesses caused by demons. Some people continue to believe in spirits, sacred tombs, divination, and demons. If their children cut their nails at night, the parents will undoubtedly mention taboo, as this is thought to have an effect on a person's soul. People who cut their nails at night are thought to be agitated, insane, or sad (Mustapa 2022; Rosidi 2005; Sujati 2019). This taboo has influenced Sundanese help-seeking behaviour and their perspectives on mental illness, which will be described in the following sections.

2.3 Mental Illness and Help-Seeking Behaviour

Mental illness has a complex system of meaning; it is generated by culture and thus becomes a cultural entity. Cultural meaning systems are systems of knowledge that are internally rational and always constructed in a systematic way in order to be handed on. Language, forms of art and expression, behavioural standards, religion, social and political structures, economic systems, legal systems, and views about illness and healing are all part of the body of knowledge. Thus, a cultural meaning system frames a society's cognitive realities in order for individuals inside the community to symbolically represent the world for themselves and others. Thus, a society's culture shapes how its members perceive and feel about illness (Kleinman 1987, 1988; Yang et al. 2007).

Not only mental illness, but also the practice of mental health can be seen as a cultural system with symbolic meaning entwined with particular configurations of social institutions and modes of interpersonal interaction (Kleinman 1988; Lesmana, Suryani & Tiliopoulos 2015). Therefore, one needs to be conscious of how illness is defined and stated from the Sundanese perspective when employing concepts of psychiatric illness to explain behaviour, illness, and wellbeing. This means that in order to define behaviour and formulate illness in a particular cultural context, one needs to be aware of the various conventions surrounding people, behaviour, deviance, illness, medical practice, and institutionalised forms of care that are present in the contexts in which the phenomena of ill-health exist.

Cultural aspects are rarely, or very infrequently, considered in mental health treatment procedures. In cross-cultural situations, health professionals frequently overlook or underestimate such elements, resulting in intervention measures that may interfere with traditional means of healing (Fernando 2014; Lesmana, Suryani & Tiliopoulos 2015). Each culture has its own set of health and illness beliefs, perceptions, and ideals. Researchers have long been interested in what encourages people to use health services and what inspires them to change their health behaviours. A multiplicity of research addressing specific aspects of this issue has been conducted in a variety of countries. Most discussions of mental illness fall into one of two descriptive and ideological domains: that of a biological disease, in which patient and family complaints are regarded as subjective reports that should be translated into objective data by clinicians, who will then

determine whether these reports constitute valid signs of a pathological process. Second, the cultural context, is where illness is defined culturally as the ill person's and family's recognition, naming, and experience of the process of identifying signs and indicators inside the individual that are considered abnormal or that deviate from wellness (Bains 2005; Biswas, Gangadhar & Keshavan 2016; Clark 2014; Conrad & Slodden 2013).

Some cultures may attribute the start of mental illness to demonic possession, the evil eye, black magic, or the breaking of taboos, in which case traditional healers, elders, or other influential members of the community would be responsible for fixing the issue. Religion and spirituality play a significant role in these perceptions by contrasting suffering with a higher-order good, and as a result, the jurisdiction that lies within the system is used to find the answers (Bains 2005; Biswas, Gangadhar & Keshavan 2016; Broch 2001). The Sundanese, for example, perceive that life has multiple elements, including how people relate to God, to one another as individuals, to society, to nature, and to their pursuit of both physical prosperity and non-physical fulfilment. For instance, Sundanese people hold the belief that deviant behaviour is connected to ancestral trance and ‘Karuhun’, the ancestor who is thought to watch over the land, who occasionally manifests in physical form (Danasasmita 2006; Ekajati 2005).

The belief of mental illness being a form of bad evil results in treatment being sought through traditional techniques. Various curative measures may be offered concurrently during the diagnosis to improve the odds of recovery. Help from spirits is sought in order to heal disease. The spirits or local practitioners (dukun) may recommend massage (urut), blowing (splashing holy water through the mouth), and herbal medicinal offerings (Danasasmita 2006; Ekajati 2005). In times of illness, individuals and their families do not consider whether medical systems are more or less efficient, but rather what the available health care options are (Widayanti et al. 2020). In addition, in terms of whether or not people are motivated to seek treatment, how they manage their symptoms, how supportive their families and communities are, and where they seek help (from a mental health specialist, primary care provider, clergy member, and/or traditional healer) depends on the cultural meanings of health and illness (Winkelman 2008).

Pasung, on the other hand, has been heavily linked with PWMI, as many of these people show aggressive behaviour (Broch 2001; Hidayat et al. 2020; Minas & Diatri 2008; Suryani et al. 2011). For the Sundanese, aggressive behaviour is considered troubling because the culture emphasises calmness and speaking in a low tone (Danasasmita 2006; Ekajati 2005). Aggressive or violent behaviour also raises concerns about patients roaming or escaping, and the likelihood of suicide, particularly in the absence of family supervision. This condition is exacerbated if families have financial issues when the breadwinner is unable to work due to illness (Daulima, Rasmawati & Wardani 2019; Eka & Daulima 2019; Katuuk, Daulima & Wardani 2019). The stigma experienced by people with mental illness might also have a harmful impact on social and cultural attitudes,

such as a misunderstanding of the mental disease leading to the practice of Pasung. Pasung is regarded as an acceptable norm, and the community believes that allowing those with mental illnesses to remain locked in Pasung for the remainder of their lives is preferable because they feel that letting the person go will generate adverse issues in the community (Hartini et al. 2018; Hidayat et al. 2020; Minas & Diatri 2008). Hence, individuals with disturbing behaviours, such as PIPs for example, are more likely to be perceived as dangerous and have the potential to injure others and should be kept out of the community.

Understanding mental illness through the frame of culture will determine the pattern of help-seeking behaviours by individuals and families of PIP. This is important as care for the person relies on family support situated within a communal culture. People seek health care by determining when and whom to consult, whether or not to cooperate, whether to switch between treatment options, whether care is successful, and whether they are satisfied with the quality of care (Kleinman 1988; Widayanti et al. 2020). Individuals first confront disease with their families, recognise the indicators of illness, assign a name and a value to the illness, assess specific sick roles (acute, chronic, impaired, medical, spiritual, and so on), and then decide what to do and what type of treatment would be beneficial. When a disease enters either the professional or the folk realm, decisions regarding where and when to seek care, how long to stay in care, and how to evaluate therapy are all regardless made in the family context (van der Sanden et al. 2016; Widayanti et al. 2020). Family members share their lives as well as their responsibilities and tasks; in this setting, the family may develop a system of beliefs that govern their daily lives. Individual autonomy and independence may have different connotations in different families based on the culture formed inside the family (Kleinman 1988; van der Sanden et al. 2016).

Western sociological and social psychological research in this area have demonstrated that adopting oversimplified models of help-seeking behaviour based on the following rationalistic assumptions is incorrect: that symptoms of disease or ‘risky’ behaviours are always identified and/or defined in terms of health; that recognition of symptoms will necessarily or automatically result in help-seeking behaviour; and that help-seeking behaviour will always take the form that scientific research supports. If it is erroneous to make such assumptions in relation to industrial societies with highly developed and accessible health care systems then, as anthropologists warn us, particular care needs to be taken to avoid transferring simplistic models of help-seeking behaviour to developing countries with very diverse cultural, political, and economic characteristics (Becker, Brown & Ainlay 1986; Salan & Maretzki 1983; Winkelman 2008).

The inappropriateness of adopting rationalistic approaches to help-seeking behaviour can be illustrated in relation to Pasung-related help-seeking behaviour in West Java, Indonesia. There has been a growth in such research over the past decade, particularly in Asia, prompted primarily through concern about the role of mental illness, but not specifically in relation to Pasung

(Lesmana, Suryani & Tiliopoulos 2015; Widayanti et al. 2020). Families are in charge of monitoring the growth of the illness and evaluating how far a person's health deviates from normalcy or healthiness. The family will also decide where to seek help and what kind of care to get. When some attitudes, emotional expressions, or behaviours of family members do not fit social standards and values, and there is some worry about the nature of the behaviour, families may see them as deviant (Kleinman 1988; Lesmana, Suryani & Tiliopoulos 2015; Widayanti et al. 2020). In Sundanese culture, these difficulties have historically been addressed by local religious authorities, community leaders, and/or traditional healers/shamans (dukun), even though not specifically in relation to mental illness (Danasasmita 2006; Sujati 2019).

However, views about mental illness and the availability of traditional healers are not the only factors preventing PIP from getting appropriate treatment. Although West Java has the highest rate of psychosis of Indonesia’s 34 provinces, surpassing 200,000 cases spread across 27 cities with approximately 14% having been in Pasung at least once in their lives, and 30% having been in Pasung in the last three months (MoH 2018), there are only limited mental health services, particularly at the community level. In West Java, mental health services are provided through a hybrid system in which government-funded and privately-funded health clinics co-exist. There are numerous mental health care options: colonial-era psychiatric institutes co-exist with American-style outpatient psychiatry clinics incorporated in general hospitals. Despite almost every Regency hospital having an outpatient clinic, only 2 of these hospitals have an inpatient ward for mental illness. This burden is shared by the province's network of around 1,072 primary care or community health centres (Puskesmas). However, only 44% of Puskesmas provide community-based mental health treatment, including public education, counselling, basic psychiatric services, house visits, community outreach, and referrals to specialist care. These tasks are usually performed by nurses who have completed Community Mental Health Nursing certification, or by general practitioners working at a Puskesmas. Recently, certain regencies, notably in the urban regions, have begun to hire clinical psychologists to work in Puskesmas (MoH 2018, 2019a).

Although the expansion of Western-style mental health services continues, with more districts beginning to train doctors, nurses, and community volunteers in primary mental health services, there is still limited information on whether the target audiences are aware of the availability of these services, aligned with the philosophy of these services, or find it socially acceptable to access them. This strongly suggests that districts and municipal governments should build more mental health facilities, such as mental health hospitals, clinics, and community services, as specified by the Mental Health Act No. 18 of 2014 provinces article 47-49 (MoH 2014). In order to respond to specific local concerns in accordance with national policy objectives, strategies, and priorities, local governments must also construct their own plans and programmes (MoHA 1999). In practice, as in many developing nations, local governments face an ambiguous path forward, as well as the combined challenge of coping with both pre-existing chronic problems which require

additional resources, and a concurrent load of emergent problems. However, this strategy does not always translate into the effective provision of mental health services at the local government level. The implementation of mental health reform at the local level is complex, especially in West Java, which has the highest prevalence of mental health issues and is the most populous province in Indonesia (Patmisari 2014).

In conclusion, the help-related behaviour of the population in West Java is complicated by the fact that it is a multicultural, ethnically diverse province, although the main tribe is Sundanese, with a wide range of health providers. Despite the widespread availability of professional health providers in West Java, informal health providers or non-conventional health providers constitute a large component of health services (MoH 2018, 2019a; Salan & Maretzki 1983). In the Indonesian context, these informal health providers are regulated under Health Law and classified as biologically-based therapies (traditional therapies based on natural substances); physical therapies with tools (e.g., acupuncture, acupressure, and cupping therapy); physical therapies without tools (e.g., massage); and mind-body therapies (e.g., hypnotherapy and meditation) (MoH 2009b). Traditional medicine, according to Article 1, number 16 of the Health Law, is therapy and/or treatment with techniques and substances that relate to empirically inherited experiences and abilities that can be accounted for, and implemented in line with, societal standards (MoH 2009b). With this service mostly available in all regions, a proportion of people choose not to use the available mental health services which are in fact quite scarce. Because these traditional providers are widely available, the use of complementary and alternative treatments is also common. This complicates efforts to identify the elements that influence help-seeking behaviour.

The next chapter presents a systematic literature review on Pasung that provides important context to the existing research and current understandings of the practice. This systematic review and narrative synthesis of the peer-reviewed international literature was conducted to identify the socio-cultural context for the use of Pasung and interventions to address it. The analysis draws on the socio-ecological framework, which focuses on relationships between the individual and their environment.

3
THE USE OF PASUNG FOR PEOPLE WITH MENTAL ILLNESS: A SYSTEMATIC REVIEW AND NARRATIVE SYNTHESIS

This chapter provides important context to the existing research and current understanding of Pasung. This systematic review and narrative synthesis of the peer-reviewed international literature was conducted to identify the socio-cultural context for the use of Pasung and interventions to address it. The analysis draws on the socio-ecological framework, which focuses on the relationships between the individual and their environment. This chapter is a green copy (accepted manuscript) of the article published in the International Journal of Mental Health Systems: Hidayat, M.T., Lawn, S., Muir-Cochrane, E. and Oster, C., 2020. The use of Pasung for people with mental illness: a systematic review and narrative synthesis. *International journal of mental health systems*, *14*(1), pp. 1-21.

3.1 Methods

3.1.1 Search Strategy

The following search strategies were undertaken in September 2019 to locate peer-reviewed articles. The search terms were developed in consultation with an expert librarian. The search involved the following databases: MEDLINE, PsycINFO, CINAHL, Scopus, ProQuest, Ovid Emcare, and Google Scholar. The relevant peer-reviewed articles were searched using only the 'P' from the PICO tool to identify the main concepts. This was because we constructed a full PICO, initially applying it within MEDLINE and then translating it into PsycINFO, PsycArticle, Scopus, ProQuest, Ovid Emcare, and Google Scholar. However, this produced a very large number of potential sources (270,017), most of which were irrelevant to the purpose of the review and because they could not distinguish appropriately between seclusion and restraint, as used in Western health care systems and Pasung. The review did not limit the timeframe on publications, as there were very few articles on this topic and we believed, therefore, that there was significant value in including an extensive search timeframe.

3.1.2 Inclusion Criteria

The inclusion criteria were based on all studies of the following:

1. Pasung-based populations (with or without a firm diagnosis of mental illness) in the community setting
2. Peer-reviewed literature published in the English or Indonesian languages available up to, and including, 2019
3. Reports on empirical studies, systematic reviews (both quantitative, qualitative, and mixed-methods studies), and other identified reviews (e.g., narrative, scoping, rapid)

4. Focus on interventions, including those that aimed to: (1) improve diagnosis, investigation, treatment, monitoring, and management of Pasung; (2) improve Pasung management programmes for consumers and carers, health promotion interventions, and interventions designed to improve treatment compliance; and (3) improve health care processes, e.g., engagement, follow-up, and appointments with mental health services or psychotherapists; and (4) improve consumer and carer involvement.

3.1.3 Exclusion Criteria

Exclusion criteria were all studies:

1. Not available in the English or Indonesian languages
2. Non-peer-reviewed literature
3. Editorials, opinion pieces, letters to the editor, books or book chapters, conference posters, conference proceedings, formal media, and social media
4. Seclusion in a hospital-based, shrine (spiritual/religious/holy place to cure a person deemed mentally ill), or other social institution
5. Not specific to Pasung-based populations

3.1.4 Screening Process

The titles and abstracts of all articles were screened and double-checked based on the agreed inclusion and exclusion criteria. Full-text peer-reviewed papers were further double-screened, with checks of the reference lists of included studies for any further potentially relevant papers and included if consensus was confirmed by the researchers. At this stage, we also activated an alert for further publications until 31 December 2019. Two authors (MTH and SL) independently reviewed the titles and abstracts; then all four authors (MTH, SL, EM, CO) reviewed the full texts against the inclusion/exclusion criteria and performed the quality ratings. For sources that were in Bahasa, the first author undertook each of the screening steps, with collaboration from one PhD student and one Master of mental health nursing specialist who also spoke fluent Bahasa; each of these individuals performed independent selection and rating. The research team then undertook detailed discussion, making a final determination about the inclusion of these studies. Several of these sources had an English language abstract also available, which aided in understanding the overall intent and steps undertaken for each study. Disagreements were handled by discussion until the authors reached an agreement. We were all being reflective and engaged in conversation about cultural biases. If full agreement could not be reached, SL made the final decision on inclusion/exclusion. Agreement on the final included sources and ratings was reached following robust research team discussion.

3.1.5 Data Extraction and Analysis

Data extraction was led by the first author and checked by all research team members. The following data were extracted for each peer-reviewed empirical study: author(s), year, country,

study type, aims and methodology, population(s)/setting, number of participants/ methods of recruitment, data collection and data analysis methods, main findings, and limitations. For reports and discussion papers, the extracted information included: author(s), date, country, main purpose, how Pasung was defined, study population demographics and characteristics, and proposed solutions. The Socio-Ecological Model (SEM) was then used to generate a theoretically informed deductive synthesis. We wrote a detailed narrative synthesis summarising each study's findings within the context of the highlighted themes. We also described the research designs, participants, interventions, and key findings. We then compared and contrasted the conclusions from different research, comparing and contrasting the data's similarities, differences, and trends.Quality Rating

All studies underwent quality rating using internationally recognised rating scales matched to study type. For interventional studies, we used the CASP (Critical Appraisal Skill Programme) (CASP 2018). For the before and after studies, we used the relevant JBI (Joanna Briggs Institute) tool (JBI 2015), and for the survey, the Critical Appraisal for Surveys from the Centre for Evidence-Based Management (CEBma 2015) were used as no instrument was available from the suite of CASP tools to rate these two study types. All quality rating instruments were used to evaluate the methods, results, and value of each study. However, this was not intended to exclude low-quality studies but to evaluate the quality of the evidence.

Four reviewers (SL, EM, CO and MTH) assessed the English language articles (n=24). All articles were reviewed independently by at least two reviewers, with any differences in ratings discussed by the group before reaching a consensus. CO and MTH reviewed one Case Control study, four Before-After studies, one Cross-Sectional study, and twelve Qualitative studies. SL and EM reviewed twelve Qualitative studies and five Survey studies. For articles only available in Bahasa (n=10), quality ratings were undertaken by MTH and two further reviewers who were native Bahasa speakers. A similar process was undertaken for resolving any differences in ratings. MTH then met with SL to discuss and moderate the ratings. This involved MTH reading out (translating) pertinent sections of the full papers to SL, and SL asking detailed critical questions to clarify the stance taken. Most articles in Bahasa also included an English version of the study abstract, which aided this process.

3.1.6 Underpinning Model

The SEM underpinned this systematic review analysis because of its suitability for providing an understanding of this pervasive issue at various social systems levels and exploring any intersections and influences across and between these levels. The SEM is a theoretical framework used to analyse the complex interplay between individuals as well as their social and physical surroundings in areas such as psychology, public health, education, and environmental studies. This approach emphasises the need of evaluating several layers of impact on human behaviour and relationships, spanning from individual influences to wider social and policy context (Glanz,

Rimer & Viswanath 2008; Kilanowski 2017). In addition, no single factor could clearly generate the reasons for family and community conducting this practice. A range of factors have potentially had a significant impact on this practice before, during, and after Pasung. Therefore, using SEM was appropriate as the model incorporates a number of different lenses. The SEM was used to examine the four-layer factors adopted by the Centres for Disease Control (CDC) (CDC 2020); i.e., individual, interpersonal, community, and policy factors associated with reasons for Pasung and expectations about the management of Pasung to fill gaps in unmet needs. Understanding the many different levels of impact on behaviour allows treatments and programmes to be devised to target issues at each level, resulting in more complete and successful strategies for promoting positive behaviours and well-being, and, in this case, reducing Pasung practice.

3.2 Results

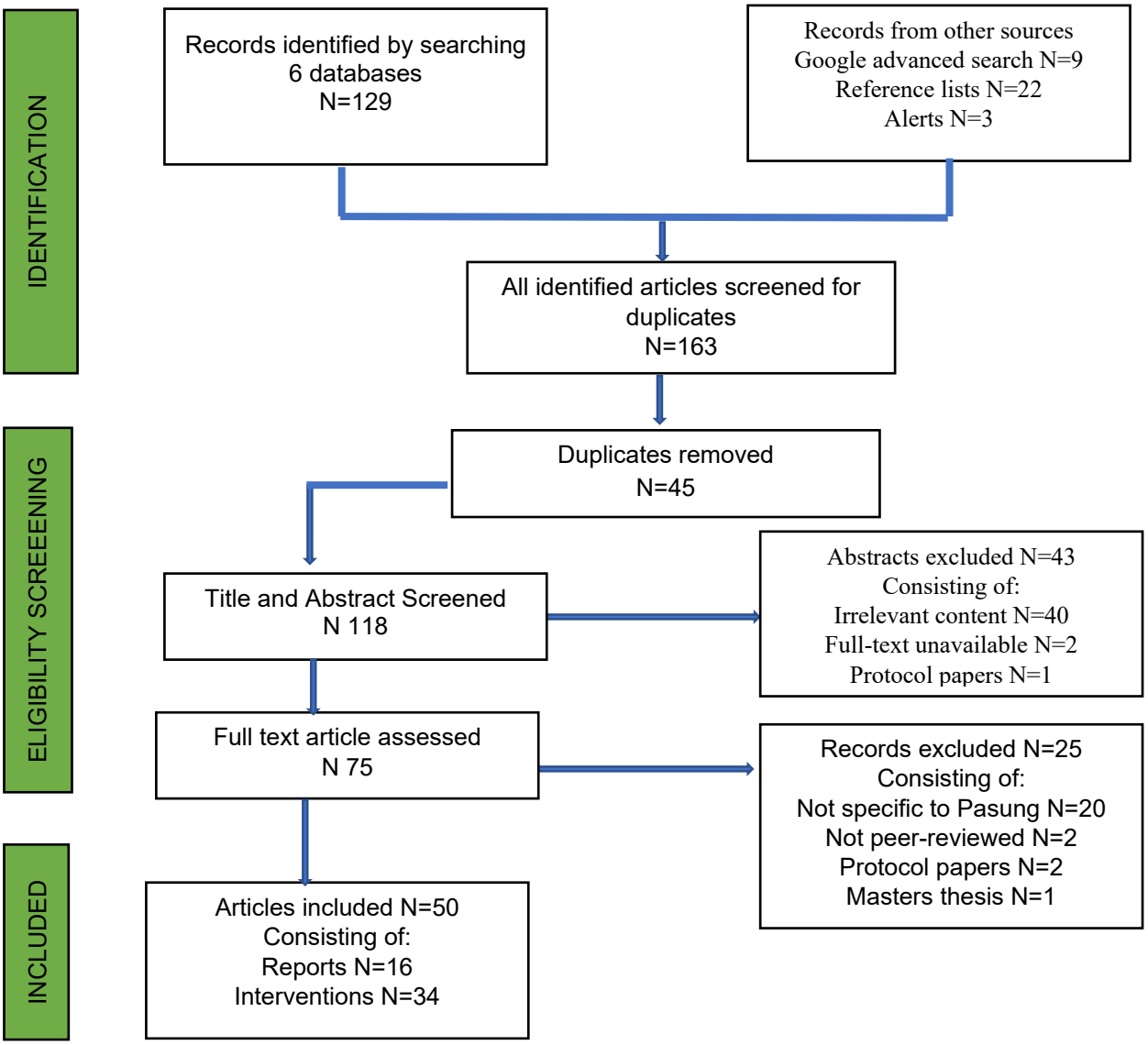


Figure 3-1: PRISMA Representing the Number of Records Retrieved at Each Stage of The Review

3.2.1 Data Characteristics

The database search retrieved 163 records in combination (Figure 1). After removing duplicates (n=45), there were 118 abstracts and titles in total (84 primary papers, 22 from reference lists, 9 from Google Scholar, and 3 from alerts). The review of the titles and abstracts resulted in the exclusion of a further 43 records (40 irrelevant papers, 2 with full-text unavailable, and 1 protocol paper). For the remaining 75 articles, full-text papers were reviewed for eligibility against the inclusion and exclusion criteria. Of these, 25 were excluded, with 20 articles not specific to Pasung, not peer-reviewed (2 articles), 2 protocol articles, and 1 thesis. In total, 50 peer-reviewed articles were included in the final review (see Supplementary Files 1 and 2 for Details of Studies: Tables 1 and 2).

Most studies were conducted in Indonesia (68%) followed by Asian and African countries (Table 1). Of the 50 articles, 16 were reports/discussion papers and 34 were empirical studies of which more than half were qualitative, followed by fewer survey studies and those using other quantitative designs, with no randomised controlled trials (Table 2).

Table 3-1: Number of Articles by Country

Country	N	%
Indonesia	34	68
Ghana	2	4
Ethiopia	1	2
Japan	1	2
Singapore	1	2
China	2	4
East Timor	1	2
India	2	4
Philippines	1	2
Somalia	1	2
Chad	1	2
LMIC	2	4
Pakistan	1	2

Table 3-2: Summary of Empirical Studies by Type of Methods, Intervention Type, and Quality Rating

	N
Type of Methods	
Before-After	4
Case-Control Type	1
Cross-sectional	1
Survey	7
Qualitative	21
Quality Rating	
Good (8-10)	11
Fair (3-7)	11
Poor (1-4)	12
Intervention Type	
Psychoeducation as a single method and in combination with decision care-making	2
686 Programme (China) unlocking programme	1
Community-based programme with the culturally sensitive and respectful mental health model	1
Indonesian Free Pasung Programme with community mental-based approach	1

3.2.2 Results of the Quality Rating Process

1. Qualitative Studies

There were 21 qualitative studies which comprised 14 articles in English and 7 in Bahasa. The CASP qualitative studies quality assessment tool contained 10 questions. Only 1 study was assessed as meeting sufficient quality across all 10 criteria. For Question 1: 'Was there a clear statement of the aims of the research?' and Question 2: 'Is a qualitative methodology appropriate?', most of the studies fulfilled the criteria except for 2 where the goal of the study was unclear. In Question 3: 'Was the research design appropriate to address the aims of the research?', 17 studies met the criteria, with insufficient detail in 4 studies to confirm whether this criterion was met. In Question 4 'Was the recruitment strategy appropriate to the aims of the

research?', 15 studies met this criterion, with insufficient detail about how recruitment occurred and the appropriateness of the sample selection (inclusion and exclusion criteria) in 6 studies. In Question 5, 'Was the data collected in a way that addressed the research issue?', only 13 studies stated in sufficient detail how the data was collected; for example, through audio-recording, focus group discussions, or in-depth interviews. However, across the 21 studies, few clearly explained the setting or detail about specific questions, or the interview guides used by the researchers, with none explaining how saturation was reached. For Question 6 (about the relationship between the researcher and the participant), only 2 studies provided specific detail; the relationship was unclear in 16 articles, with 3 studies providing no information about this criterion.

Question 7 assessed the ethical considerations, with almost half the studies (n=9) making no mention of, or providing insufficient detail about, the ethical issues. Some studies stated they had gained ethics approval, but there was no further explanation about how the researchers protected privacy and confidentiality or gained the consent of the participants. This was particularly notable for those studies available only in Bahasa. For Question 8 (about the rigour of the data analysis), only 10 studies met this criterion, with 9 stating the type of data analysis used (e.g., thematic analysis, Colizzi's method), but providing very limited information about the analysis processes followed, and 2 studies providing no information.

Most qualitative studies (n=14) available in English provided an adequate statement of findings (Question 9), and some information about the strengths and limitations of the results. However, all studies available only in Bahasa did not mention this, and only described theories and ideas that supported their arguments and not the opposite view. In addition, the articles did not mention how the credibility and dependabilityof the findings were assured, or the triangulation processes. For Question 10 (How valuable is the research?), most studies (16 out of 21) were assessed as valuable, with this being unclear in only 5 studies, due largely to insufficient detail in the discussion, and limited or no mention of the implications for future research or the potential for wider application of the findings.

2. Before-after studies

There were 4 before-after studies (quasi-experimental) with 9 questions from the relevant JBI assessment tool used to rate their quality. Across all the articles, few of the criteria were met and many were unclear. For instance, in Question 2, 'Were the participants included in any comparisons similar?', Question 3, 'Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?', and Question 7, 'Were the outcomes of participants included in any comparisons measured in the same way?', these criteria were unclear for all these studies. As well, most studies had no control group (Question 4). Other weaknesses included the lack of complete follow-up, lack of detail about follow-up when it was reported, and limited or no information about strategies to deal with the lack of follow-up. The

appropriateness of the statistical approach was unclear for 3 of the 4 studies. This result then impacted outcome reliability, with only 2 of the 4 studies meeting this criterion.

3. Survey studies

There were 7 studies which used a survey design, consisting of 2 in Bahasa and 5 in English. The CASP quality rating scale for surveys comprised 12 questions, however, Question 12 (Can the results be applied to your setting/organisation?) was not used due to its lack of relevance for this review. No studies met all the criteria; only 3 of the 7 studies met most of the criteria, and the remaining 4 studies met between 2-4 criteria. Only 2 studies provided confidence intervals.

4. Cross-sectional studies

The JBI scale for assessing cross-sectional studies consisted of 8 questions. Only 1 study was included, with only 3 of the 8 meeting the criteria. The inclusion criteria were not clearly defined, subject setting was not clearly described, and the researchers failed to describe confounding factors and strategies to deal with these. However, the studies did mention how the researchers aimed to maintain validity and reliability, used the selection criteria for the selection of participants, and used a valid outcome measure.

5. Case-Control studies

The CASP assessment tool was used to rate the single included case-control study which met 9 of the 11 criteria. The size of the treatment effect and the management of potential confounding variables were unclear.

6. Key Findings

The key findings are presented in Table 3. These informed the narrative synthesis that follows.

Table 3-3: Key Findings

No	Author + Title	Findings
1	Alem (2000). Human rights and psychiatric care in Africa with particular reference to the Ethiopian situation. Acta Psychiatrica Scandinavica, 101(399), pp. 93-96.	Care provided in Ethiopia does not seem to be in accordance with the UN Declaration of Human Rights. As most LMIC countries are unable to fulfil the basic needs of their citizens, it appears that the mental health system in Ethiopia will not change in the foreseeable future.

No	Author + Title	Findings
2	Anto and Colucci (2015). Free from Pasung: a story of chaining and freedom in Indonesia told through painting, poetry and narration. World Cult Psychiatry Res Rev, 10(34), pp. 149-67.	The story of Anto who was shackled several times since he was young. Anto achieved good grades at school. However, he was very shy and lacked confidence and was bullied during his school years (fancy boy); this led him to have low self-confidence. As a teenager, he suffered from depression which became worse over time. The symptoms reappeared when he was working at a paper factory and also while he was at university. The family decided to place him in Pasung as they were afraid Anto would hurt himself or disturb the neighbours. After 3 times in Pasung, he was finally freed by the Free Pasung Programme from the local psychiatric hospital and shared his story with others, using various forms of art to express his experiences and to help them to be free from Pasung.
3	Asher et al. (2017). “I cry every day and night; I have my son tied in chains”: physical restraint of people with schizophrenia in community settings in Ethiopia. Globalization and health, 13(1), p. 47.	Most of the participants with schizophrenia and their caregivers had personal experience with the practice of restraint (Pasung). The main explanations given for restraint were to protect the individual or the community and to facilitate transportation to health facilities. These reasons were underpinned by a lack of care options, the consequent heavy family burden, and a sense of powerlessness among caregivers. While there was pervasive stigma towards people with schizophrenia, lack of awareness about mental illness was not a primary reason for restraint. All types of participants cited increasing access to treatment as the most effective way to reduce the incidence of restraints.
4	Broch (2001). The villagers’ reactions towards craziness: An Indonesian example. Transcultural Psychiatry, 38(3), pp. 275-305.	Stigma was central to how people in the village reacted to the mentally-ill person (gila betul). Most villagers believed that the person was possessed and dangerous, and that mental illness was an evil spirit (Jinn) that should be cured by spiritual or traditional healers. Some of them also thought that mental illness was a disease.

No	Author + Title	Findings
5	Buanasari, Daulima and Wardani (2018). The experience of adolescents having mentally ill parents with Pasung. Enfermeria clinica, 28, pp. 83-87.	Pasung use with parents with mental illness had a clear psycho-social impact on adolescents. Role changes occurred when the teenager became a breadwinner and caregiver of the parent. The experiences felt by adolescents involved changes to every aspect of their lives in relation to their roles, and their psychological and social conditions. Three themes: 1. Changed life due to having a mentally-ill parent in Pasung 2. Reciprocity as the reason for taking care of the parent 3. Positive meaning of life with having a mentally-ill parent in Pasung.
6	Daulima, Rasmawati and Wardani (2019). Penurunan Kemampuan Kepala keluarga dalam memenuhi kebutuhan ekonommi keluarga: Study fenomology pengalaman orang dengan gangguan jiwa pasca Pasung. Jurnal Keperawatan Indonesia, 22(2), pp. 139-146.	The family breadwinner felt a lack of confidence due to a role change after having their family member in Pasung. In addition, the family had more problems with family finances as they now had to take care of the person. This meant someone needed to look after the person all the time and could not go to work. Another reason why the person became a burden was the high cost of medication and treatment. However, the neighbours and the environment were fully supportive of the breadwinner to continue working by giving support for casual work like domestic chores. This support increased their confidence and was a strong basis for them to continue their role as head of the family.
7	Daulima (2018). Preventing Pasung by mentally-ill patients' families. Enfermeria clinica, 28, pp. 256-259.	Validity and reliability results showed that the content of this instrument is valid once improvements had been made to statement item numbers 16 and 17. It was also shown to be reliable by the consistency of the responses with an alpha value of 0.729. That is, responses to the instrument are consistent and are reliable measures of the level of intention of the mentally-ill patient's family to use Pasung.

No	Author + Title	Findings
8	Dewi, Daulima and Wardani (2019). Managing family burden through combined family psycho-education and care decisions without Pasung therapies. Enfermeria clinica, 29, pp. 76-80.	The study demonstrated that family burden was significantly lower among those who received the combination of the two therapies (family psycho-education and care decisions without Pasung) compared to only family psycho-education ($p < 0.05$). These therapies decreased the family burden into the low category.
9	Eka and Daulima (2019). Factors related to Pasung on people with mental illness. International Journal of Nursing and Health Services (IJNHS), 2(2), pp. 36-41.	Ten studies were found. There were 3 main factors related to Pasung: 1. Factors that originated from the person such as aggression, wandering, and homicide. These behaviours were triggered by lack of adherence to medication due to financial problems and health service inaccessibility. Proposed solutions were educating the person about medication compliance 2. Factors that originated from the family such as financial burnout, emotional instability, helplessness, lack of knowledge, dissatisfaction with health services, and the fear that the person would do harm to others or the self. Families decided to use Pasung as a treatment after family discussions and pressure from the community; hence, perceived community stigma was a prominent factor in their decision-making. Proposed solutions were family education about medication compliance to overcome stigma about its use 3. Factors that originated from the community including stigma and discrimination, which caused increased family burden. This meant families often decided to use Pasung instead of mental health services. The community also commonly played the main role in deciding to use Pasung. Proposed solutions were community empowerment; in particular, empowerment of community leaders with influence in decision-making (although only limited descriptions of empowerment processes were provided).

No	Author + Title	Findings
10	Firdaus (2016). Pemenuhan Hak Atas Kesehatan Bagi Penyandang Skizofrenia di Daerah Istimewa Yogyakarta (Rights Fulfilment on Health of People with Schizophrenia In Special Region of Yogyakarta). Jurnal Ilmiah Kebijakan Hukum, 10(1), pp. 87-103.	1. There are local regulations in Jogjakarta, Indonesia to protect people with schizophrenia and to reduce the practice of Pasung in the form of gubernatorial regulation number 81/2014 aiming to improve mental health knowledge 2. Community-based services have been used in several mental health services with using community volunteers to identify people with schizophrenia in their local community area 3. There are some obstacles to fulfilling the rights of mentally-ill people, as mental health is not the main priority considering the small size of the budget and the number of cases where many mentally-ill people are wandering the streets and are neglected in the nursing homes.
11	Guan et al. (2015). Unlocking patients with mental disorders who were in restraints at home: a national follow-up study of China's new public mental health initiatives. PLoS One, 10(4), p.e0121425.	96% of patients were diagnosed with schizophrenia. Prior to unlocking them, their total time in Pasung ranged from 2 weeks to 28 years, with 32% having been locked up multiple times. The number of persons regularly taking medicines increased from 1 person at the time of unlocking to 74% in 2009 and 76% in 2012, and showed sustained improvement in patient social functioning and significant reductions in family burden. Over 92% of patients remained free of restraints in 2012.
12	Hall et al. (2019). Social inclusion and exclusion of people with mental illness in Timor-Leste: a qualitative investigation with multiple stakeholders. BMC public health, 19(1), p. 702.	People with mental illness in Timor-Leste were found to face widespread, multi-faceted sociocultural, economic, and political exclusion. They were stigmatised as a consequence of beliefs that they were dangerous and lacked capacity, and experienced instances of bullying, physical and sexual violence, and confinement. Several barriers to formal employment, education, social protection, and legal systems were identified. Experiences of social inclusion for people with mental illness were also described at the family and community levels. People with mental illness were included through family and community structures that promoted unity and acceptance. They also had opportunities to participate in activities

No	Author + Title	Findings
		surrounding family life and livelihoods that contributed to intergenerational wellbeing. Some PWMI benefitted from disability-inclusive programming and policies, including the disability pension, training programmes, and peer support.
13	Hartini et al. (2018). Stigma toward people with mental health problems in Indonesia. Psychology research and behaviour management, 11, p. 535.	The results show that better knowledge about mental health was associated with lower public stigma toward PWMI. Significant differences in stigma toward people with mental illness were also found across groups according to age, sex, experience of contact, history of mental illness, attitudes toward Pasung, marital status, and income level. Age was negatively correlated with stigma; people were more tolerant as they got older. Married individuals were more tolerant. A history of mental illness in the family equated to greater tolerance. No marked differences in level of stigma were found across groups according to education level.
14	Rasmawati, Daulima and Wardani (2018). The experience of people with mental disorders in social function adaptation after suffering from Pasung. Enfermeria clinica, 28, pp. 275-279.	Pasung has a physical and psychosocial impact on PWMI in adapting to society. Four themes: a) Withdrawal from others as an initial manifestation of release from Pasung; b) Bio-psychosocial changes after Pasung that act as an impediment to performing social functions; c) Improved social function through the optimisation of support systems; and d) Satisfaction with life as a result of social adaptation.
15	Idaiani and Raflizar (2015). Faktor Yang Paling Dominan Terhadap Pemasungan Orang Dengan Gangguan Jiwa Di Indonesia (Factors Contributing to Shackling Practice of Psychotic People in Indonesia). Buletin Penelitian Sistem Kesehatan, 18(1), pp. 11-17.	The most profound factor that contributed to Pasung's practice was low socio-economic status. Low socio-economic status families have 2-3 times greater risk than middle- and high-income families. In contrast, a geographic area with inaccessibility to health facilities and high mental health literacy has no significant relationship with Pasung.
16	Irmansyah, Prasetyo and Minas (2009). Human rights of persons with mental illness in Indonesia: more than legislation	The focus of the Indonesian Constitution on rights pre-dated the Universal Declaration. Indonesia has ratified relevant international covenants and domestic law provides an adequate legal framework for human rights

No	Author + Title	Findings
	is needed. International journal of mental health systems, 3(1), p. 14.	protection. However, human rights abuses persist, are widespread, and go essentially unremarked and unchallenged. The National Human Rights Commission has only recently become engaged in the issue of protection of the rights of persons with mental illness.
17	Jones et al. (2009). Severe mental disorders in complex emergencies. The Lancet, 374(9690), pp. 654-661.	Services created by non-government organisations in these contexts are a drop in the ocean compared with what is needed. In all areas mentioned, most PWMI remain unrecognised, untreated, and unable to access services. Non-government agencies are not a substitute for effective government strategy and action. But they might sometimes be a stimulus; for example, emergency mental health services developed by the International Medical Corps and other national and international agencies have sometimes become seeds for effective longer-term models of care in a number of countries.
18	Katuuk, Daulima and Wardani (2019). Families' experience caring for mentally ill patients with re-Pasung. Enfermeria clinica, 29, pp. 270-274.	Three themes were expressed by the family who applied Pasung to a family member, e.g., 1. The helpless feeling of the family in adapting to the mental state of a Pasung person as the family is unable to provide continuous medication. The family must share the funding for the treatment in addition to other family members' needs like school and food. 2. Security was the main reason to justify re-Pasung and to cover up guilty feelings for re-Pasung 3. As a substitute for re-Pasung and feeling guilty, families fulfilled basic needs and reduced the length of time in Pasung by releasing the PIP for temporary close supervision
19	Laila et al. (2018). Perceptions about Pasung (physical restraint and confinement) of schizophrenia patients: a qualitative study among family members and other key stakeholders in Bogor Regency, West Java Province, Indonesia	Family members and society in general perceived that Pasung is necessary for security reasons due to the patient's aggressive behaviour (e.g., physical violence towards family members, damaging neighbours' property, and stealing food). The family often did not respond to the patient's request to be released from Pasung. They felt

No	Author + Title	Findings
	2017. International journal of mental health systems, 12(1), p. 35.	insecure and helpless when the person was not in Pasung and wandered away from the house. Family members had financial constraints that stopped them from seeking mental health care, and they were also dissatisfied with the available services. Health care workers underlined the poor knowledge and misconceptions about schizophrenia in the community.
20	Laila et al. (2019). Factors associated with Pasung (physical restraint and confinement) of schizophrenia patients in Bogor regency, West Java Province, Indonesia 2017. BMC Psychiatry, 19(1), p. 162.	The person's aggressive or violent behaviour (AdjOR: 4.49, 95%CI: 2.52–8.0), unemployment (AdjOR: 2.74, 95%CI: 1.09–6.9), and informal employment (AdjOR: 2.5, 95%CI: 1. 1–5.84) in the family, and negative attitude of the family towards the patient (AdjOR: 2.52, 95%CI: 1.43–4.43) were associated with Pasung. The patient's aggressive or violent behaviour (PAR = 44.3%), and unemployment in the family (PAR = 49.3%) were the predominant factors for the use of Pasung by the family.
21	Maramis, Van Tuan and Minas (2011). Mental health in southeast Asia. The Lancet, 377(9767), pp. 700-702.	In most countries in Southeast Asia, mental health spending is no more than 2% of the health budget, with 80-90% going to mental hospitals. There are massive workforce deficiencies; few consumer, carer, or other civil-society organisations with a focus on mental health advocacy; inadequate protection of the rights of people with mental illness; few efforts to promote mental health; little in the way of rehabilitation services or efforts to promote social and economic inclusion; and treatment services being concentrated in urban areas, often of poor quality, inaccessible, and unaffordable.
22	Marthoenis et al. (2016). Mental health in Aceh, Indonesia: A decade after the devastating tsunami 2004. Asian Journal of Psychiatry, 19, pp. 59-65.	Mental health services in Aceh have been improved compared to their condition before the tsunami, with development programmes focused on the procurement of policy, improvement of human resources, and enhancement of service delivery. The case of Aceh is a unique example where conflict and disaster, and the need for security, serve as the catalysts for the development of a mental health care system. Despite these

No	Author + Title	Findings
		improvements, some issues such as stigma, access to care, and political fluctuations remain challenging.
23	Miller (2012). Who needs psychiatrists?	In Aceh, provincial health authorities are creating a community mental health programme that shifts much of the work traditionally done by psychiatrists to general practitioners, nurses, and village volunteers. In rural areas, where resources are limited, training and delivery of care by less specialised health workers shows promise as an effective way to manage demand for support by rural communities where people with mental health conditions are under-served and at greater risk of experiencing Pasung.
24	Minas and Diatri (2008). Pasung: Physical restraint and confinement of the mentally ill in the community. International Journal of Mental Health Systems, 2(1), p. 8.	Fifteen cases of Pasung, approximately even numbers of males and females and almost all (n=13) with a diagnosis of schizophrenia were identified; 9 had previously received psychiatric treatment. Duration of restraint ranged from 2 to 21 years. Travel was the major cost of treatment component cited as unaffordable (the nearest available treatment was 6 hours away by boat and then road). The most common form of Pasung was in a small room or hut. Reasons are given for Pasung: violence, coming to harm by running away or wandering off, concern about suicide, and unavailability of a caregiver. Affordable and equitable access to basic mental health services is seen as the only effective and sustainable solution.
25	Molodynski, O'Brien and Burns (2017). Key international themes in coercion. BJPsych International, 14(3), pp. 61-63.	Coercion remains a dominant theme in mental health care and a source of major concern in many countries. While the presence of coercion is ubiquitous internationally, it varies significantly in nature and degree in different countries and is influenced by a variety of factors. Recent reports have raised concerns about physical restraint and the increasing use of legislation in high-income countries. At the same time, a recent Human Rights Watch report on Pasung (the practice of tying or restricting movement more generally) in Indonesia has served to highlight the plight of

No	Author + Title	Findings
		many in middle- and lower-income countries who are subject to degrading and dehumanising 'treatment'.
26	Ndetei and Mbwayo (2010). Another side of African Psychiatry in the 21st Century-chaining as containment: guest editorial. African Journal of Psychiatry, 13(1), pp. 3-5.	Lack of knowledge of the cause of mental illness, or the fact that such conditions can be treated may lead to mistreatment of patients with mental illness. It is possible that chaining is practised more widely, and in more countries, than is realised. There is therefore a need for an audit to determine just how common this practice is – a practice which has no place in contemporary African psychiatry.
27	Nurjannah et al. (2015a). Human rights of the mentally ill in Indonesia. International nursing review, 62(2), pp. 153-161.	'Connecting care' as the core category to describe a model of care that involves health professionals and non-health professionals, such as family members. Four main factors influence care-providers' decision-making: competence, willingness, available resources, and compliance with institutional policy. Health professionals are influenced most strongly by institutional policy when deciding whether to accept or shift responsibility to provide care. Non-health professionals base their decisions largely on personal circumstances. Jointly made decisions (between the various stakeholders) can be matched or unmatched. Unmatched decisions can result in forced provision of care, increasing risk of human rights violations.
28	Patel and Bhui (2018). Unchaining people with mental disorders: medication is not the solution. The British Journal of Psychiatry, 212(1), pp. 6-8.	A rights-based approach must enforce well-established international human rights conventions, and scale up comprehensive community services around the needs and preferences of people affected by mental illness.
29	Patel, Goel and Desai (2009). Scaling up services for mental and neurological disorders in low-resource settings. International health, 1(1), pp. 37-44.	The plan proposed is based on the socio-cultural, epidemiological, and health system contexts of a specific location in one country. Although 'one size does not fit all' in health-system interventions, such a plan may serve as a blueprint for other contexts, following appropriate modification and adaptation to

No	Author + Title	Findings
		ensure its feasibility, acceptability, and relevance.
30	Patel et al. (2018). The Lancet Commission on global mental health and sustainable development. The Lancet, 392(10157), pp. 1553-1598.	Three measures are proposed: first, balancing the focus on treatment, rehabilitation, care, and recovery with an equal emphasis on the promotion of mental health and the prevention of mental illness, particularly interventions early in the life course; second, adopting a staging approach to the identification and diagnosis of mental illness, recognising the potential benefits of intervention at each stage; and third, embracing diverse global experiences of mental health and disorder, to tailor the range of interventions more appropriately and to promote mutual learning. Key terms for defining the scope of mental health are also proposed.
31	Puteh, Marthoenis and Minas (2011). Aceh Free Pasung: Releasing the mentally ill from physical restraint. International Journal of Mental Health Systems, 5(1), p. 10.	Fifty-nine former Pasung patients were examined. The majority (88.1%) of the patients were male, aged 18 to 68 years. The duration of Pasung varied from a few days to 20 years, with a mean duration of 4.0 years. The reasons for applying Pasung were many, with concerns about danger being the most common. The great majority (89.8%) had a diagnosis of schizophrenia.
32	Rahman, Marchira and Rahmat (2016). Peran dan motivasi perawat kesehatan jiwa dalam program bebas Pasung: studi kasus di Mataram. Berita Kedokteran Masyarakat, 32(8), pp. 287-294.	Nurses had been carrying out their role as executors of nursing care policy, as the direct nursing to caregivers, and were providing direct nursing care to people who had experienced Pasung and their families, as well as continuing therapy for ex-Pasung sufferers, and as educators, collaborators, and also educating the family. The nurses faced a difficult challenge in implementing FPP: 1. Family and community rejection 2. An emotional expression such as grieving, frustration, or giving up 3. The absence of a caregiver 4. Illiteracy in mental health 5. Unavailability of anti-psychotic drugs 6. No partnership or multi-sectoral coordination 7. Multiple tasks

No	Author + Title	Findings
33	Rasmawati, Daulima and Wardani (2018). Studi Fenomenologi Pengalaman Hidup Orang Dengan Gangguan Jiwa Pasca Pasung Yang Mengalami Perceraian. Journal of Islamic Nursing, 3(1), pp. 100-105.	PIP potentially lost support from families, in particular spouses, due to their incompetence in fulfilling their basic needs, their aggressive behaviour, and by judging they would not recover like a 'normal' person. Divorce has an additional impact on PIP. Grieving is the first response to separation from children and the spouse. Most of the respondents were left by their spouses due to their mental health problems. The problem became worse when the person could not find a new partner due to their mental illness and financial barriers.
34	Read, Adiibokah and Nyame (2009). Local suffering and the global discourse of mental health and human rights: An ethnographic study of responses to mental illness in rural Ghana. Globalization and Health, 5(1), p. 13.	Chaining and beating of the mentally-ill was found to be commonplace in homes and treatment centres in the communities studied, as well as the withholding of food ('fasting'). However, responses to mental illness were embedded within spiritual and moral perspectives, and such treatment provoked little sanction at the local level. Families struggled to provide care for severely mentally-ill relatives with very little support from formal health services. Psychiatric services were difficult to access, particularly in rural communities, and were also seen to have limited effectiveness. Traditional and faith healers remained highly popular despite the routine maltreatment of the mentally-ill in their facilities. Caution is suggested when taking a moral perspective on rights and responsibilities in the context of Pasung use in this context, as this may be used to justify the maltreatment of people with mental illness, as this research has suggested.
35	Reknoningsih, Daulima and Putri (2014). Studi Fenomenologi Pengalaman Keluarga dalam Merawat Pasien Paska Pasung. Medica Hospitalia: Journal of Clinical Medicine, 2(3).	Most caregivers were poorly educated (primary level and not educated). There were five themes found: 1. The family felt physically exhausted and emotionally distressed caring for PIP. 2. The family's emotional burdens and being physically exhausted were reasons given for re-restraining their family member. 3. Further family difficulties arose due to the burden of Pasung management, and the person's aggressive behaviour. As a result, re-Pasung was the main option for the family.

No	Author + Title	Findings
		4. The families have internal and external support for caring for PIP. Either material support like money and staple foods or external support like free insurance and free medication. 5. However, families get more spiritual understanding as part of caring for the person while in Pasung in the form of experience of spirituality, closer to God and recognition.
36	Riany, Cuskelly and Meredith (2016). Cultural beliefs about autism in Indonesia. International Journal of Disability, Development and Education, 63(6), pp. 623-640.	The interviews revealed five related themes about autism: 1. Understanding autism; 2. Causes of autism (traditional cultural beliefs about pregnancy, belief in karma and God's plan); 3. Beliefs about how best to care for a child with autism (traditional and medical treatments, education, good parenting); 4. Reactions to having a child with autism (self-blame, shame, expectations of stigma); 5. Parenting a child with autism (impact of shame, parenting practices, and use of coercion. Overall, despite many understandings of the underlying medical causes of autism, their traditional cultural beliefs led many to stigmatise children with autism and their family, creating increased isolation in the community.
37	Malik and Bokharey (2001). Breaking the chains. Psychiatric Bulletin, 25(7), pp. 273-275.	A total of 100 patients in Pasung at shrines were treated, with the age range from under 9 to those above 70 years, with most aged between 10 and 29 years. Most of the persons had mental illnesses such as schizophrenia, depression, and epilepsy.
38	Saribu and Napitulu (2009). Is There Any Regulation to Protect People with Mental Disorders in Indonesia (Case Study of Pasung). Indonesian J. Int'l L., 7, p. 516.	The Indonesian legal system/national laws which regulate the rights of PWMI including: 1. Law No. 23 of 1992 concerning health 2. Law No. 39 of 1999 concerning human rights 3. Law No. 4 of 1997 concerning a person with disabilities 4. Penal code of Indonesia (could Pasung be categorised as a delict (violation of law)? 5. Indonesian criminal procedure code (Pasung could be classified as a criminal

No	Author + Title	Findings
		deed; however, up until now, no perpetrators of Pasung have been punished by the courts.
39	Stratford et al. (2014). Introducing recovery-oriented practice in Indonesia: The Sukabumi project–an innovative mental health programme. Asia Pacific Journal of Social Work and Development, 24(1-2), pp. 71-81.	The Ministry of Social Affairs (MoSA) has been able to utilise the extensive experience and skills of its Australian partners to enhance the implementation of the plan. The success of the collaboration of Mind and Australia Asia Mental Health (AAMH) programme with MoSA has been achieved through a rigorous concern to ensure that concepts of psychosocial rehabilitation and approaches such as the recovery approach which originated in developed Western nations are relevant and applicable to the Indonesian context.
40	Suharto (2014). Budaya Pasung dan dampak yuridis sosiologis (studi tentang upaya pelepasan Pasung dan pencegahan tindakan pemasungan di kabupaten wonogiri). IJMS-Indonesian Journal on Medical Science, 1(2).	1. The age of people in Pasung is between 13-70 years, dominated by males (3:1), with the length of illness from 2-35 years, the incidence of relapse from 1-7 times during the illness, and the average duration of Pasung being 8.5 months. 2. The majority of families resorted to Pasung as the treatment due to the high costs of medications. This was in relation to the direct costs of buying medications and paying mental health staff, and the indirect costs of transportation (most mental health services are located in the central city which sometimes took a day's journey to go back and forth). 3. Most caregivers were parents (mostly their mother), aged 50 or more, low levels of education (primary level and uneducated), working as farmers/gardeners/Warong. There is a significant relationship between education level and age of the family with the social function of the family. 4. Pasung practice is not solely negligence of family to give care to their family member, but also the failure of government to provide mental health services at the primary level.
41	Suhron (2017). Effect Psychoeducation Family on Ability Family in Treating People With Mental Disorders (ODGJ) Deprived (Pasung). Journal of Applied Science and Research, 5(1), pp. 41-51.	The mean score before family psycho-education intervention was 21.6, and after the mean increased to 29.1. The Wilcoxon test showed ρ value = 0,000 <α = 0.05 which meant there were differences in the ability of

No	Author + Title	Findings
		families to care for PWMI before and after family psycho-education.
42	Suhron, Yusuf and Subarniati (2018). Assessment Potential of Families Increasing Ability to Care for Schizophrenia Post Restrain at East Java, Indonesia. Indian Journal of Public Health Research & Development, 9(10).	Caregivers were mostly female, average age was 27, one-third of caregivers were not working, more than three-quarters (83%) gained primary education level or lower, more than three-quarters (80%) lived in a remote area, and nearly half were parents. Cultural values affected the family's role which indirectly affected the ability of the family in caring for the person.
43	Suryani et al. (2011). Treating the untreated: applying a community-based, culturally sensitive psychiatric intervention to confined and physically restrained mentally ill individuals in Bali, Indonesia. European Archives of Psychiatry and clinical neuroscience, 261(2), p. 140.	The development of a community-based, culturally sensitive, and respectful mental health model can contribute to positive mental health outcomes. The traditional medical, hospital-based, psychiatric model currently practised in Indonesia, and arguably in other countries, possesses an inherent inability to provide a holistic and equitable service to this population and in this cultural context. After 19 months of holistic treatment, none of the patients were confined in Pasung, and only 2 required further intensive treatment. Community education forums and workshops to educate them about mental health issues in a meaningful and respectful language that was aligned with their culture and customs were effective (500 per month attendance). Mutual support groups for families and community members were also established.
44	Tanaka et al. (2018). A qualitative study on the stigma experienced by people with mental health problems and epilepsy in the Philippines. BMC Psychiatry, 18(1), p. 325.	The findings highlight the culturally and socio-economically specific contexts, consequences, and impact modifiers of experiences of stigma. Participants emphasised that PWMI face stigma because of cultural traits such as the perception of mental health problems as a disease of the family, and the tendency to be overly optimistic about the severity of the mental health problem and its impact on their life. Furthermore, stigma was experienced under conditions where mental health care was not readily available and people in the local community could not resolve the PWMI's mental health crisis. Experience of stigma reduced social networks and opportunities for

No	Author + Title	Findings
		PWMI, threatened the economic survival of their entire family, and exacerbated their mental health problems. An individual's reaction to negative experiences can be fatalistic in nature (e.g., believing it is God's will). This fatalism can help PWMI to remain hopeful. In addition, traditional communal unity alleviated some of the social exclusion associated with stigma.
45	Tay et al. (2017). The ties that bind–A case report about restraining a mentally unwell family member at home for over a decade. Asian Journal of Psychiatry, 26, pp. 146-148.	The first case report examines the prolonged use of Pasung in a developed urban setting. Illness factors, family dynamics, stigma, lack of mental health literacy, and cultural roles contributed to her chaining. Despite Singapore's excellent infrastructure, highly educated public, accessible professional psychiatric treatment, and overall modernity, there remains a minority of psychiatric patients who are beyond the reach of the treatment team.
46	Ulya (2019). Coercion (Pasung) and people with a mental disorder in Indonesia: Bioethics and health law. International Journal of Law and Psychiatry, 66, p. 101477.	Pasung and mental illness produce a vicious cycle which is difficult to break, particularly when the person is part of the family. On the one hand, family is the key to caring for the person, but on the other hand, the family have limited resources and sometimes is exhausted by their caring responsibilities. Pasung is more common in rural locations and among lower socio-economic groupings. Stigma towards mental illness is prominent. When adopting an ethical viewpoint, Pasung must not be used as a substitute for treatment as it violates human dignity and human rights. The basic moral principles in bioethics show that ill-treatment and coercion fail to adhere to four basic rules (i.e., respect for autonomy, beneficence, non-maleficence, and justice). There is no justification for the view that unregulated coercion is a form of treatment for mental illness. Any attempt to justify such coercion violates the principles of national and international health law. More integrated community programmes are needed to address stigma and to support families.

No	Author + Title	Findings
47	Vijayalakshmi, Reddemma and Math (2012). Gender-related differences in the human rights needs of patients with mental illness. Journal of Nursing Research, 20(2), pp. 90-98.	Gender differences were clearly evident. Subjects enjoyed a satisfactory level of fulfilment in the physical dimension of human rights needs, which included food, housing, and clothing. Men expressed lower satisfaction than women with perceived human rights needs fulfilment in the emotional dimension. This included fear of family members (# 2 =9.419, p G .024) and being called derogatory names (# = 8.661, p G .034). Women expressed lower satisfaction than men with perceived human rights needs fulfilment in social and ethical dimensions. This included the freedom to leave the home (# 2 =11.277, p G .010), and sexual abuse by family members (# 2 =9.491, p G .019). Men felt more discriminated against than women due to perceptions of mental illness in the community domain (# 2 =10.197, p G .037).
48	Wirya (2017). Rezim Kebenaran Rasionalisme dalam Diskursus Kegilaan dan Tindakan Pendisiplinan Pasung sebagai Kejahatan. Jurnal Kriminologi Indonesia, 9(2).	Four considerations are proposed: 1. The discourse of madness in this article is defined as a set of statements that has institutional strength, which means a set of statements that have a profound influence on the way we act and think individually. The act is to do Pasung. 2. Pasung is a part of madness discourse formed by the power, knowledge, and social structure of the community, and Pasung is deemed a rational act to control someone whom they call crazy. 3. This research showed that the discourse of madness that promotes the truth regime of rationalism and produces Pasung as part of the control of those deemed as ‘crazy’ is a crime that must be dealt with through a replacement discourse. 4. Even though psychiatric therapy has tried to eliminate and replace this current discourse, psychiatry itself assumes the insane as an object that needs to be controlled.
49	Wulandari, Daulima and Wardani (2019). The fight against stigma in the recovery process of post-Pasung mentally ill	Several themes were identified: 1. The reluctance to be re-Pasung. The patient refuses to be subjected to Pasung and stating that Pasung was a horrible experience. 2. The demand to have interaction with other

No	Author + Title	Findings
	patients. Enfermeria clinica, 29, pp. 295-299.	people. The patient wished to interact freely and make friends. 3. The sense of being ignored due to stigma. The patient felt exiled, sad, and traumatised because of stigma.
50	Yusuf and Tristiana (2018). Fenomena Pasung dan dukungan keluarga terhadap pasien gangguan jiwa pasca Pasung. Jurnal Keperawatan Padjadjaran, 5(3).	1. Most of the caregivers were parents, followed by spouses and other relatives. 8 of 9 respondents were poorly educated (primary level) and were casual workers (farmers, gardeners) with some being unemployed. 2. Most patients had been subjected to Pasung for 1 to 24 years. 3. The intention of the family using Pasung was to control patient aggressive behaviour (toward others, themselves, and the neighbourhood), for curing, to avoid wandering, and because they could not continue to care for the patient. The family also had no other options as they had to work to feed their family and the PIP. In addition, they had limited financial resources and endured the high costs of treatment. 4. The decision to use Pasung came from families, neighbours, and the community. The community and the family work together to build shelter for Pasung like creating a hut making a window from iron. 5. The impacts of Pasung were atrophy, contracture, and psychological aspects (depression, isolation, trauma, hate).

3.2.3 Narrative Synthesis using the Socio-Ecological Model

3.2.3.1 Individual level

Sixteen articles discussed individual level factors as a risk and/or primary cause for the practice of Pasung. The individual level included biological and personal history factors identified in the literature that increased the risk of the person being subjected to Pasung, e.g., age, marital status, sex, employment, education, mental health history, medication history, and aggressive behaviour. The literature identified that people subjected to Pasung were predominantly male, aged 18-60 years with a previous mental illness, unemployed, a past history of Pasung, and a low level of education. Although two articles reported similar rates of Pasung for males and females, overall there was no correlation between sex and Pasung practice. However, in most articles, males were more likely to be subjected to Pasung. Approximately 3 out of 4 people in Pasung were male (Laila

et al. 2019; Puteh, Marthoenis & Minas 2011; Suharto 2014). Younger men with schizophrenia were at greater risk of being subjected to Pasung than young women (Laila et al. 2019; Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011). Although the association remains unclear, this use of Pasung in young men appears to be related to more aggressive behaviour or violence developed at a younger age (Laila et al. 2019; Minas & Diatri 2008).

In most of the articles, a PIP was more likely to be single with almost 30% being divorced. However, it was not possible to state a direct correlation between having a mental illness and marriage breakdown from the available data (Laila et al. 2019). Nevertheless, one study (Rasmawati 2018) suggested that many people who experienced Pasung had been left by their spouse or partner because of having a mental illness and experiencing personal hardship.

Most people in Pasung had a mental illness history, with 89-96% diagnosed with schizophrenia (Guan et al. 2015; Puteh, Marthoenis & Minas 2011), with the duration of illness ranging from 1 to 35 years. Despite studies finding that Pasung was predominantly experienced in adult populations, some studies also found that Pasung occurred in school-age children (those around 13 years old) while some were older than 60 years of age (Puteh, Marthoenis & Minas 2011; Suharto 2014).

Defining how long the person was in Pasung was problematic because it was unclear when Pasung initially began and whether the person had been released for short periods and then placed back in Pasung, as explained by Asher et al. (2017). Reports of duration varied across studies, with Laila et al. (2019) stating that individuals had been subjected to Pasung from 1 day to 12 years (mean 1.3 years). Another study showed a longer duration of Pasung, up to 24 years (Yusuf & Tristiana 2018). The history of Pasung use is also important to highlight as some articles reported that more than 30% of individuals subjected to Pasung had past experience of being restrained one or more times (Asher et al. 2017; Guan et al. 2015; Katuuk, Daulima & Wardani 2019; Puteh, Marthoenis & Minas 2011).

Most Pasung use with people with a history of mental illness was believed to be because they had failed to continue their medication (Minas & Diatri 2008). Medication non-adherence was suggested to be the cause of illness relapse in 96.8% of patients and the exhibiting of aggressive behaviour (Laila et al. 2019). Treatment drop-out was also reported by Minas and Diatri (2008) who found that 9 out of 15 people in Pasung had previous treatment with mental health services. Medication non-adherence was also seen to be related to the inability of the family to provide regular medication to their family member due to factors including cost and the lack of availability of family members to assist PWMI to go to mental health services (Katuuk, Daulima & Wardani 2019). Another factor identified as a root cause of medication discontinuation was refusal by the PWMI, with Asher et al. (2017) reporting that the PWMI was usually restrained (tied up) in the journey to the health facilities as they often refused to be medicated.

Laila et al. (2019) reported that PWMI with aggressive or violent behaviour were five times more likely to be subjected to Pasung than non-aggressive PWMI. The study by Reknoningsih, Daulima and Putri (2014) echoed the above finding and restated that aggressive behaviour led the family to use Pasung on more than one occasion with relatives. Other studies confirmed that violence was a reason for the family using Pasung (Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011).

In addition to individual level factors relating to the demographic and behavioural characteristics associated with Pasung, we also identified literature reporting the effects of Pasung on individuals. As a result of the prolonged duration of Pasung, some people were severely negatively impacted, both physically and mentally. A few studies mentioned the impacts of Pasung (Asher et al. 2017; Buanasari, Daulima & Wardani 2018; Helena, Daulima & Wardani 2018; Rasmawati 2018; Yusuf & Tristiana 2018), but none precisely measured the physical and psychological impacts of Pasung for the PWMI, their family, or the community in the long- or short-term. Asher et al. (2017) reported that two PWMI had physical injuries resulting from restraint, including bruising, contracture, and deformity of the leg. The injuries primarily happened because the PIP could not move freely or because they were held in wooden stocks in one position for a long time.

Similarly, another study by Yusuf and Tristiana (2018) found that many PWMI subjected to Pasung in Indonesia experienced atrophy and contracture, mostly in the lower limbs. Another finding was that many PMWI experienced cachexia (wasting syndrome) due to being undernourished or denied food and water. One study also reported that the person in chains was often tied without access to food (Read, Adiibokah & Nyame 2009). The impacts of Pasung were not only physical; studies reported that they also involved the PIP experiencing psychological problems. Yusuf and Tristiana (2018) noted that PIPs experienced depression, isolation, and hatred towards those who had put them in Pasung. Many of the respondents in this qualitative study also reported being traumatised by the experience of Pasung and avoided contact with other people as a result. In another paper, community leaders and community health workers also highlighted the detrimental psychological impacts of being restrained, and acknowledged that it could make the illness worse or increase the risk of violence towards others, including those the PWMI knew very well (Asher et al. 2017)

3.2.3.2 Interpersonal

Interpersonal relationships consisted of the relationships between the person experiencing Pasung and their community, spouse/partner, and family, and in particular, the interconnection between the person’s behaviour and the risk perceived by the family. At the socio-economic level, adaptation and family burden were also included in this domain.

Reported reasons for using Pasung were similar to studies conducted within Asia and Africa where PWMI were tied up for extended periods of time in order to give them medication, transport them to health facilities, or where the caregiver was no longer available (Asher et al. 2017; Suharto 2014;

Yusuf & Tristiana 2018). The family were also the most common perpetrators of Pasung towards their family members who were mentally-ill. This finding was highlighted by two high quality articles. The first article, a quantitative study by Laila et al. (2019), stressed that family members were the dominant actors in implementing Pasung, with mothers being most likely (32.46%), followed by fathers (27.19%), and elder siblings (9.65%). A second study by Asher et al. (2017) also found that family members were the main people responsible for instigating Pasung. The two articles were conducted in low- to middle-income countries (LMICs): Africa (Ethiopia) and Asia (Indonesia). However, the findings from these studies were not likely to be representative of the complete picture of the use of Pasung in LMICs because both were conducted with small samples and in very localised research sites.

Carers of PWMI in Pasung were reportedly poorly educated (Reknoningsih, Daulima & Putri 2014). Reknoningsih, Daulima and Putri (2014), highlighted that families using Pasung were predominantly female, the mother was usually aged over 50, and some family members being unemployed or daily hire workers such as gardeners or farmers. Similarly, three further articles described the carer as uneducated or as having a low level of education (Suharto 2014; Suhron, Yusuf & Subarniati 2018; Yusuf & Tristiana 2018) and living in a rural area. Despite the relationship between carer education and the practice of Pasung being unclear overall, one study suggested that education levels were strongly correlated with social support for the PIP (Suharto 2014). As an example, families were reported to frequently reject requests from the PIP to release them. This was done out of fear that the person would wander and create a further burden for the family. As a replacement for Pasung, the family sometimes released the person and used close monitoring and observation to prevent them from wandering (Katuuk, Daulima & Wardani 2019; Laila et al. 2018).

Perceived risk and safety from aggression were other critical findings frequently identified as interpersonal factors that increased the use of Pasung (Buanasari, Daulima & Wardani 2018; Guan et al. 2015; Hall et al. 2019; Laila et al. 2019; Minas & Diatri 2008; Read, Adiibokah & Nyame 2009). These articles identified that the use of Pasung was initiated to protect the family and the community and to protect the PWMI themselves. For example, Asher et al. (2017) described Pasung as a choice taken by the family to protect the individual and to make it easier to facilitate transportation to health facilities. This was supported by Hall et al. (2019) who also found that the PWMI often experienced bullying, and physical and sexual violence by surrounding communities when the person was wandering. Broch (2001) agreed with this finding, stating that PWMI were often ridiculed by the community (mostly children) who called out the words ‘gila betul’ (‘crazy’ in Indonesian). These experiences triggered PWMI to act aggressively, forcing caregivers to restrain the person at home to avoid further problems for the family, community, and the person themselves.

A further interpersonal reason for the use of Pasung identified in the literature was to address the burden of caring for the family member in Pasung. As reported in nine articles, family members experienced stress and felt powerless as a consequence of caring for the PIP, feeling they had to manage the burden alone (Asher et al. 2017; Buanasari, Daulima & Wardani 2018; Daulima 2018; Daulima, Rasmawati & Wardani 2019; Dewi, Daulima & Wardani 2019; Laila et al. 2018; Rasmawati, Daulima & Wardani 2018; Read, Adiibokah & Nyame 2009; Reknoningsih, Daulima & Putri 2014; Yusuf & Tristiana 2018). For example, Read, Adiibokah and Nyame (2009) asserted that families were characterised mainly as being powerless, with extremely limited options, and sometimes driven to act out of fear. Similar findings were reported by Yusuf and Tristiana (2018), who stated that the decision to use Pasung came after a long discussion with, and pressure from, the community. However, the primary person responsible for making the decision was the main caregiver as a practical response to a challenging situation.

Due to family members' need to have an income, Pasung was also sometimes used to control the PWMI to allow the caregiver to attend work. Helena, Daulima and Wardani (2018) also identified that the family experienced a psychosocial change after their family member was placed in Pasung, mainly if the person had previously been the head of the household or the primary breadwinner. In these circumstances, other family members now had to find new ways of gaining income for the family or taking on the role of head of household (Buanasari, Daulima & Wardani 2018; Daulima, Rasmawati & Wardani 2019). Consequently, many families with a PWMI lived in poverty. Low socio-economic status for families was identified as a risk factor for the use of Pasung. Idaiani and Raflizar (2015) claimed that families from low socio-economic backgrounds had a 2-3 times greater risk of using Pasung on their PWMI family members.

In such situations, the role of the family also had to change, not only because the person was unemployed, but also because of the person's lack of confidence due to their diagnosis of mental illness (Helena, Daulima & Wardani 2018). The person's condition was reported to worsen due to increased feelings of guilt about not being able to fulfil their commitments and role within the family with consequent loss of dignity (Read, Adiibokah & Nyame 2009). As a result, many PWMI lived alone or their partner had left them (Rasmawati 2018).

The lack of accessible and affordable treatment options appears to underlie many of the caregivers' narratives. While stigma is another factor that will be discussed separately, its existence was indicated by the assumption that PWMI were likely to be violent or aggressive, and thus had to be in Pasung. Another finding from four articles (Buanasari, Daulima & Wardani 2018; Laila et al. 2018; Laila et al. 2019; Yusuf & Tristiana 2018) was that Pasung was described as a last resort after the family believed that the medication given by mental health services was not helping the PWMI, given the experience of relapse and prolonged illness despite treatment.

3.2.3.3 Community

The community plays an essential role in supporting the recovery of PWMI and also in the overall impact of illness due to stigmatising, inaccurate beliefs about mental illness. Community factors determined from this review include socio-economic status (both the person and their family, and the community surrounding them if reported), geographical area, cultural identity, social inclusion and integration, literacy, and infrastructure.

Several studies reported that myths and beliefs in the general population about mental illness were associated with the increased use of Pasung (Asher et al. 2017; Broch 2001; Eka & Daulima 2019; Hall et al. 2019; Hartini et al. 2018; Marthoenis et al. 2016; Rasmawati 2018; Riany, Cuskelly & Meredith 2016; Tanaka et al. 2018; Tay et al. 2017). PWMI were often considered to be dangerous and/or possessed by demons. This included, for example, the belief that mental illness was related to the person having supernatural abilities, or resulting from disturbed spirits or black magic. These stereotypes increased discrimination and ostracisation by those around the PWMI (Asher et al. 2017; Broch 2001; Read, Adiibokah & Nyame 2009; Tay et al. 2017). Other studies reported that some families also believed that the existence of mental illness for the PWMI was god's will (Riany, Cuskelly & Meredith 2016; Tanaka et al. 2018). They viewed having a family member with a severe mental illness as their destiny because of their past sins or as a temptation. Some family members blamed themselves for having someone in their family with mental illness (Riany, Cuskelly & Meredith 2016; Wulandari, Daulima & Wardani 2019).

Instead of getting proper medical treatment, PWMI in some communities were isolated from social life because they were considered a 'family disgrace' and dangerous. As a result, the community and/or the family often sought the help of spiritual healers and traditional healers as the first choice for treatment (Asher et al. 2017; Tanaka et al. 2018; Tay et al. 2017; Ulya 2019). These three articles reported that all families of those in Pasung had used traditional medicine, either by a dukun (shaman) or a spiritual healer. Unlike the information provided by health workers who treated mental illness as a disease, traditional practitioners often provided misinformation to the family about the causes of illness.

Misleading information was exacerbated by a low level of mental health literacy, which was reportedly associated with Pasung, although the nature of the relationship remains unclear (Asher et al. 2017; Idaiani & Raflizar 2015; Tay et al. 2017). Mental health literacy is linked with stigma, which has been identified as one of the predictive factors of Pasung. A study by (Hartini et al. 2018) showed that better mental health literacy was associated with lower negative stigma towards PWMI. In addition, better knowledge of mental illness was thought to prevent the community from mistreating PWMI (Ndetei & Mbwayo 2010).

Inaccessibility of health care, particularly mental health care, was found to be a further community level risk factor. Some authors identified that health care inaccessibility was the main reason why PWMI were restrained in Africa (Asher et al. 2017; Read, Adiibokah & Nyame 2009). Similarly, in Asia, mental health care access was a key issue around the practice of Pasung. Lack of access as the core driver of Pasung practice was reported in three articles (Guan et al. 2015; Minas & Diatri 2008; Suryani et al. 2011). Although these articles were of poor quality, they were consistent in identifying that Pasung occurred in communities where formal mental health care was inaccessible and where there was a lack of antipsychotic medication.

While some authors identified a lack of access to mental health care as a significant factor, others found this not to be the case. For example, Suharto (2014) found that the majority of families resorted to Pasung due to the high cost of medications, which included the direct costs of buying drugs and paying mental health staff as well as the indirect costs of transportation. Although this article was of poor quality, it presented multiple perspectives, including that of the families. Tay et al. (2017) reported similar access to care issues in an urban setting in Singapore where mental health access was available, but where traditional restraints were still carried out. Likewise, Laila et al. (2019) conducted research into Pasung in one city in West Java where the community had access to mental health care. The article found that people still used Pasung as an option for care despite more than 2/3 of participants having Indonesian National Insurance, meaning they could use mental health facilities free of charge.

Results regarding the geographical spread of Pasung use were also contradictory and inconsistent. In many articles, most people in Pasung lived in rural areas with poor access to mental health services (Asher et al. 2017; Marthoenis et al. 2016; Puteh, Marthoenis & Minas 2011; Read, Adiibokah & Nyame 2009). One article reported that more than 80% of individuals lived in low socio-economic and remote areas (Suharto 2014). In contrast, another study conducted in a rural setting in Singapore by Tay et al. (2017) found that Pasung could also be found in urban areas with modern infrastructure and accessibility to mental health facilities. Despite these researchers finding only one case in a metropolitan area, they concluded that both rural and urban areas had incidents of Pasung. Idaiani and Raflizar (2015) also proposed that geographical area and access to mental health service had no relationship with the practice of Pasung in Indonesia. Furthermore, Ndetei and Mbwayo (2010) stressed that the practice of chaining occurred globally in more countries than those that had been documented.

Apart from its influence on the family in conducting Pasung, the community also played a role as an external form of support, both for the family and the PIP. In one report, neighbours offered casual work for the breadwinner who had a family member in Pasung (Daulima, Rasmawati & Wardani 2019). The neighbourhood provided similar support by facilitating the person to get free insurance and free medication (Reknoningsih, Daulima & Putri 2014).

3.2.3.4 Policy

In addition to individual, interpersonal, and community factors, policy provides a vital context for the practice of Pasung and its elimination. The issue of protecting the human rights of PWMI has been a significant concern in many countries, including Indonesia (Nurjannah et al. 2015a). However, mental health is not a primary focus compared to physical health in Indonesia. One article reported that in most South-East Asian countries, mental health was not the main priority. As an indicator, the budget spent on mental health was less than 2% of the total health budget, allocated predominantly to psychiatric hospitals. The article also highlighted that there were very few efforts in prevention, promotion, and rehabilitation of mental health. Many mental health programmes, including a community-based approach which was primarily concentrated in urban areas, were found to be of poor quality (Maramis, Van Tuan & Minas 2011).

In LMICs, policy support for mental health problems identified in the literature was inadequate, or if it existed, implementation was problematic (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011; Miller 2012; Patel, Goel & Desai 2009; Patel et al. 2018). While there has been policy prohibiting Pasung in Indonesia, there has also been a lack of policy, procedure, and funding at the local level. Two studies argued that having legislation only was not enough to enable the protection of human rights for PWMI. Instead, real action from government across the central government, the provincial government, and the district level was needed (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011). For instance, a country such as Indonesia implemented its Mental Health Act in 2014, but regulation at the local level to apply this Act was absent. In contrast to this argument, Firdaus (2016) stated that policy had been developed at the local level in Indonesia and that the issue related instead to insufficient funding in the implementation of the policy. For instance, in the Mental Health Act and local regulation, it had been stated that Pasung perpetrators would be fined or imprisoned; nevertheless, in the implementation, no sanction had been given to the perpetrators.

As a result of these complex policy problems, Pasung has usually been identified as being due to the family's failure to provide appropriate treatment with an expectation that the family knows how to manage the PWMI and avoid Pasung (Irmansyah, Prasetyo & Minas 2009; Wulandari, Daulima & Wardani 2019). In addition, proper policy implementation, including consumer and carer involvement, is yet to occur (at the time of writing), with little or no further explanation about how to operationalise such cooperation. In addition to consumer and carer involvement, it has been identified that implementation should be in accordance with the improvement of coordination among all stakeholders, including health professionals, non-health professionals such as those in social affairs, non-government organisations, and the community (Nurjannah et al. 2015a; Wirya 2017).

In Indonesia, the Bebas Pasung Programme (Free Pasung Programme) has involved the provision of community-based mental health services alongside intensive education campaigns (Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011; Suryani et al. 2011). None of the articles measured the effectiveness of the programme or how it was delivered. Also, different approaches were taken to the delivery of the programme in each district or province. For instance, in Bali, Suryani et al. (2011) used a community-based programme with a 'culturally sensitive' intervention. The authors claimed that the model successfully decreased Pasung in the Bali region. In Jogjakarta, Firdaus (2016) studied a community-based service with community volunteers, and Rahman, Marchira and Rahmat (2016) added a community nurse to their community-based approach.

In other countries, for example in Somalia (Read, Adiibokah & Nyame 2009), the Chain Free Initiative supported by the World Health Organization (WHO) aimed to reduce the number of people restrained in hospital and community settings partly through increasing access to mental health care. In a study in China by Guan et al. (2015), 271 people with mental illness who were restrained at home were identified by the Chinese '686 programmes'. After receiving a package of interventions including 'unlocking' by a team of mental health professionals, admission to a psychiatric hospital was undertaken where required, with follow-up by a community mental health team. This study reported that 92% of people remained unrestrained after seven years of follow-up (Guan et al. 2015). However, such an intensive programme is not generalisable to countries such as Ethiopia or Indonesia with highly limited mental health resources and where free universal health care is not available. Another social inclusion programme and policy was implemented in East Timor (Hall et al. 2019), aiming to educate the community to enhance community acceptance of persons with a disability, including PWMI. The study claimed that the programme increased the opportunity for PWMIs to participate in community activities that increased their wellbeing.

Despite studies reporting interventions that had been tested and implemented, this review of the literature highlights the lack of an effective intervention to address the practice of Pasung in the community in Indonesia. The existing intervention, the 'FPP', involves the person being taken to hospital and being provided with treatment for their mental health over a limited period, and then being returned to the community without further follow-up for the person or support provided to their families and communities. The problems which led to the use of Pasung often quickly reappear after hospitalisation, with the family and community returning to using Pasung (Minas & Diatri 2008; Suryani et al. 2011).

3.3 Discussion

This systematic review is the first to examine all available peer-reviewed literature to date to identify the characteristics and the main reasons behind the practice of Pasung. This review revealed a limited number of articles available on this topic. Our quality rating of the included

papers revealed that few were of good quality, and many were limited in their discussion and interpretation of the findings.

The reviewed studies were mostly conducted in Indonesia with other research from Asian and African countries. From these regions, three countries are among the most populous in the world (China, India, and Indonesia), while two are high income countries (Japan and Singapore). In most LMICs across Asia and Africa, mental health care, particularly community mental health care, is scarce. Hence, understanding the reasons behind Pasung practice is an important consideration in developing appropriate programmes to reduce Pasung.

Analysed through the lens of the SEM, the review identified a range of factors across the individual, interpersonal, community, and policy levels, demonstrating the interconnection of factors within and between these levels. At the individual level, while the diagnosis was unknown for a small number of participants or subjects discussed within the studies, the majority of PIPs had been diagnosed with a severe mental illness (Laila et al. 2019; Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011). PWMI, particularly those with schizophrenia and aggressive behaviour, were at higher risk of being placed in Pasung compared to those without violent behaviour (Laila et al. 2019). They were five times more likely to be at risk of demonstrating violent and aggressive behaviour compared to the general population. This risk increased to 16 times higher when the person had a comorbid condition such as substance misuse (Cornaggia et al. 2011).

However, a history of mental illness is not the only factor leading to Pasung. The review identified further individual level characteristics including aggressive and violent behaviour, discontinuing medication, and past confinement history being associated with Pasung. It was not always clear whether it was mental illness or aggressive behaviour that was correlated primarily with Pasung. The findings support this argument, given that roughly 10% of persons diagnosed with other conditions such as dementia, epilepsy, intellectual disability, and autism that might be unrelated to mental illness or with comorbidity with mental illness, but showed aggression or ‘being a social nuisance’ because they wandered around, were also in Pasung (Minas & Diatri 2008; Riany, Cuskelly & Meredith 2016). Thus, Pasung could be used for anyone who tended to be violent irrespective of their diagnosis.

We highlight the finding of aggression, as it has many forms including verbal, physical, or self-injury, and ranging from intentional to unintentional. Of these, verbal aggression was frequent (Stanford et al. 2003). In one study, only 3 out of 15 cases of Pasung were due to physical violence; the remainder were categorised as due to past aggressive behaviour with no further explanation (Minas & Diatri 2008). This finding is in line with previous research which described that verbal aggression was common both in acute care and in residential settings for PWMI (Cornaggia et al. 2011). The number was similar for persons who had dementia (Enmarker, Olsen & Hellzen 2011; Keene et al. 1999) and persons with intellectual disabilities (Crocker et al. 2006).

However, as most of the articles were qualitative, it is difficult to determine whether a majority of cases of Pasung use were due to verbally aggressive behaviours. Further research is needed to understand how this type of aggressive behaviour impacts Pasung use, and how it might impact the delivery of prevention interventions for Pasung.

There are many individual and situational factors for why PWMI may act aggressively (Bulgari et al. 2018; Cornaggia et al. 2011). Based on the findings, individual factors leading to Pasung were discontinued medication, past confinement history, and being predominantly male, single, having a low level of education and low socio-economic status (Idaiani & Raflizar 2015; Laila et al. 2019; Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011; Rasmawati 2018; Riany, Cuskelly & Meredith 2016). These findings aligned with a previous study which described the risk factors for aggressive behaviour among psychiatric patients as including being of a younger age, male, not being married, having previous mental illness history, and having a history of violence or self-destructive behaviour (Dack et al. 2013). However, another study by Steinert (2002) argued that gender, diagnosis, and substance use played a minor role in predicting violence in the community, while a history of previous violence played a significant role. The study also suggested that the role of environmental factors could lead to violence and has been mostly underestimated.

Alongside individual-level factors, environmental factors were also found to be important. This literature review demonstrated that the family were most likely to use Pasung on a family member, usually instigated by the parent or elder sibling (Asher et al. 2017; Laila et al. 2018; Yusuf & Tristiana 2018). Families believed that the use of Pasung was essential to keep the PWMI safe (Asher et al. 2017; Laila et al. 2018; Yusuf & Tristiana 2018). In addition, the family were faced with a difficult choice between Pasung on the one hand and the person wandering or becoming a social nuisance on the other (Read 2012; Yusuf & Tristiana 2018). Therefore, Pasung was usually described as a pragmatic action, where the decision to use it came after a lengthy discussion with relatives and community leaders. Nevertheless, in the end, the main person responsible for making the decision was the primary caregiver.

However, positioning the problem of Pasung on the caregiver within a policy lens, including the decision to put the family as the perpetrator in prison, seems unjust. For example, Minas and Diatri (2008) reported that when mental health services were available, the families in their study were willing to unchain the person and accept all treatment for them when it was offered. Evidently, treatment for people with mental illness proved to be optimal when the family were involved in the care and support. The role of the family has proven to be very important in improving medication adherence, preventing recurrence, restoring social roles, and preventing health and economic impacts for caring for mentally-ill family members (Cradock, Young & Forquer 2002; Kikkert et al. 2006; Read, Adiibokah & Nyame 2019).

This review also identified the economic strain placed on families with a family member with a mental illness. This is because the long duration of illness means the PWMI cannot earn an income, and this was exacerbated by the costs of accessing and paying for medications required for treatment. PWMI often require other family members to care for them at home, denying the opportunity for the carer to also have an income (Asher et al. 2017; Buanasari, Daulima & Wardani 2018; Laila et al. 2018; Laila et al. 2019). The evidence highlighted that caregivers often take on the burden of caring for the person without help from other relatives and the community, meaning it is ultimately their decision whether or not to use Pasung.

Another interpersonal factor was mental health literacy, although there was conflicting information on this issue. Many families obtained information about mental illness and the type of treatment, whether medical or alternative, from relatives, neighbours, and the community. While this can be understood as a form of social support to families, the information was sometimes inaccurate, with mental illness often associated with the occult. Two articles (Laila et al. 2019; Tay et al. 2017) argued that this contributed to the practice of Pasung, while Asher et al. (2017) and Idaiani and Raflizar (2015) disagreed. In line with the above, Jorm (2000) stated that mental health knowledge in the community was often ignored by the public and, as a result, many PWMI were only brought to treatment settings once they were in a chronic state of mental health.

Furthermore, there is a shortfall of interventions to overcome the problem except psycho-education to prevent Pasung. Indeed, although most caregivers were poorly educated and sometimes had not had a formal education, the relationship between low literacy and an increased likelihood that caregivers would use Pasung is still debatable. In contrast to physical health, which is observable with signs like pain or swelling, recognition of symptoms of mental illness is more difficult to understand for the general population. Despite the contrasting arguments, a previous study by Hartini et al. (2018) showed that strong literacy, both of individuals and the community in terms of mental health knowledge, tended to reduce stigma. Mental health awareness is essential to increase the acceptance of the community, minimise stigmatising beliefs about PWMI, and potentially also to reduce Pasung practice.

To some extent, families behaved and treated the mentally-ill family member based on the social and cultural norms of the community in which they lived. For example, in several studies, the community believed that PWMI were aggressive, dangerous, and would not return to ‘normal’ (Asher et al. 2017; Rasmawati 2018; Tanaka et al. 2018; Tay et al. 2017). Even when no aggressive behaviour was evident, the community perceived the person would behave violently. This negative belief adversely affected the person’s ability to cope with the problem and increased their stress (Eka & Daulima 2019; Kommana, Mansfield & Penn 1997; Kurihara et al. 2000; Wulandari, Daulima & Wardani 2019). Thus, for security reasons, the community shackled the person (Laila et al. 2018; Yusuf & Tristiana 2018).

Inaccessibility of access to services, particularly in rural areas, was also seen as a significant problem (Asher et al. 2017; Guan et al. 2015; Minas & Diatri 2008; Read, Adiibokah & Nyame 2009; Suryani et al. 2011). Despite the assumption that Pasung should be less evident in urban areas where mental health facilities are easily accessible, it still exists in these areas (Laila et al. 2019; Tay et al. 2017). However, most of the articles found that PIPs live in remote areas, and mostly in low-middle income areas (Asher et al. 2017; Broch 2001; Buanasari, Daulima & Wardani 2018; Irmansyah, Prasetyo & Minas 2009; Laila et al. 2018; Laila et al. 2019; Nurjannah et al. 2015a; Read, Adiibokah & Nyame 2009; Yusuf & Tristiana 2018). In addition, in many LMICs, psychiatric hospitals are only located in the capital city or in more densely populated areas which are often inaccessible for people who live in rural areas, due to problems with transport, time, cost, and the capacity of the hospital itself to cater to the needs of these communities.

Furthermore, in Indonesia, for example, nearly 90% of government health funding is dedicated to psychiatric hospitals, with very limited focus on prevention or early intervention support services in the community (Maramis, Van Tuan & Minas 2011). This situation is exacerbated by the limited number and ability of community workers and the limited number of specialists and treatment facilities. In LMICs, policy support for mental health problems is inadequate, and where it does exist, implementation is problematic (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011; Miller 2012; Patel, Goel & Desai 2009; Patel et al. 2018). Another phenomenon that needs attention is the focus on psychiatric hospitals as the main spearhead, with the community bringing people with mental health conditions to these facilities. Inevitably, the mental health services will be inadequate at the primary care level; where they do exist, the quality is often inadequate. Systems for coordination and post-discharge follow-up clinical support are also inadequate, creating unnecessary cycles of illness relapse.

The studies identified in this review were predominantly experience-based, focusing on individuals in Pasung and their families. However, families are heterogeneous; hence, future research must account for structural, cultural, economic, and social variation within the family. For instance, do higher-income families also use Pasung? If not, why? In addition, most of the empirical studies did not consider the pressures placed on families when caring for the PIP, such as interpersonal stresses, family burden, finances, and other family member needs. Further research could explore these issues in detail. These issues must also be built into support and treatment programmes for this population. There is a mismatch between consumer and family preferences and the services offered; in other words, in what families expect/demand and what is offered by existing support programmes. More longitudinal research is needed, ideally connecting multi-disciplinary professionals/stakeholders and those with lived experience at all levels.

Family psycho-education programmes are available, but existing programmes vary widely, with inconsistencies in how they are delivered, their content, who conducts them, and where they are

conducted (in hospitals or in the community). More understanding is needed about the best approaches for delivering psycho-education to families with lived experience of Pasung. The diversity of approaches and the limited strength of evidence found within the studies reviewed here suggest that currently there is no single approach that suits all family situations, and that a diversity of approaches is likely to be warranted in order to address Pasung. More work is needed in general to develop interventions that address the use of Pasung; these interventions need to include family and community participation and also need to evaluate how they might benefit the consumer themselves. While the need for civic engagement in the development of interventions has been identified, such as the inclusion of lived experience perspectives, an understanding of how to do this effectively and how to involve the family and the person subjected to Pasung remains unclear (Irmansyah, Prasetyo & Minas 2009; Nurjannah et al. 2015a; Suhron, Yusuf & Subarniati 2018; Suryani et al. 2011; Wirya 2017).

3.4 Limitations

The main limitations of the studies were in relation to methodological design and the absence of RCTs, although the use of RCTs in Pasung is ethically problematic. Most studies using qualitative methods had relatively small samples, unclear or poorly administered analysis methods, and an absence of underpinning theory. Therefore, the findings cannot be generalised to broader populations or settings. As a result, this review demonstrates that there is no clear evidence to suggest which interventions are best suited to overcome the use of Pasung.

This systematic review focused on studies published in English and Indonesian, which may have limited understanding of the findings of studies of Pasung reported in other languages. Research predominantly included in this review was undertaken in Indonesia, with a smaller number of studies conducted in other parts of Asia and Africa. In addition, most studies were conducted in LMICs.

3.5 Conclusions

Pasung seems to be the last resort for families of mentally-ill family members who show, or are perceived to be at risk of, aggressive and violent behaviour. This situation is exacerbated by limited community care and support, stigma, inaccessibility of mental health services, economic burden, and limited regulation of policies that aim to address Pasung. The findings highlight the lack of an effective intervention to address the practice of Pasung in the community. Family psycho-education programmes are available, but existing programmes vary widely, with inconsistencies in how they are delivered, their content, who conducts them, and where they are conducted (in hospitals or in the community). More understanding is needed about the best approaches for delivering psycho-education to families with lived experience of Pasung. Given the historical context of religious and traditional beliefs about mental illness, incorporating religious or traditional healers into psycho-

education appeared to be a promising approach. It can be a delicate and difficult procedure that calls for careful consideration of ethical, professional, and cultural boundaries. However, when done thoughtfully and respectfully, it could enhance the effectiveness of mental health interventions, especially in communities where traditional beliefs and practices are deeply ingrained. While the need for civic engagement and culturally sensitive approaches in the development of community-based interventions, including the inclusion of lived experience perspectives, has been identified, an understanding of how to do this effectively, and how to involve family and the person subjected to Pasung remains elusive. A comprehensive understanding is needed, to balance the many perspectives in order to understand Pasung, and to inform the building of a more suitable model of care for the person with severe mental illness to reduce the practice of Pasung. To achieve this understanding, it is firstly important to understand the existing policy landscape, particularly in shaping current mental health service provision and systems of care. These are examined in the next chapter entitled, Indonesia Free from Pasung: a policy analysis.

4

INDONESIA FREE FROM PASUNG: A POLICY ANALYSIS

Despite various policies enacted to abolish Pasung, Indonesia has made very modest progress in reducing this practice. The policies have been reviewed in Chapter 3: Systematic Review as one of the issues associated with Pasung. However, of the seven articles that discussed the policies, three focused on the human rights issues surrounding Pasung (Firdaus 2016; Irmansyah, Prasetyo & Minas 2009; Nurjannah et al. 2015a), while the other four discussed the punishments for those who implemented Pasung (Saribu & Napitulu 2009; Suharto 2014; Ulya 2019; Wirya 2017), and none provided a comprehensive view of the policies. This policy analysis examined the existing policies, plans, and initiatives in Indonesia targeted at eradicating Pasung. Policy gaps and contextual constraints were identified in order to propose stronger policy solutions. A total of 18 policy documents were examined, including government news releases and organisational archives. A content analysis was undertaken of national level policies that addressed Pasung within the context of the health system, the social system, and human rights since the establishment of Indonesia. This was followed by a case study analysis of policy and programme responses, particularly in West Java Province. The policy analysis presented in this chapter has been published in the International Journal of Mental Health Systems.

4.1 Introduction

Human rights violations against people with mental illnesses are widespread in both the community setting and in mental health facilities in many countries (Drew et al. 2011). One example of violations is the use of seclusion and restraint (SR), with Human Rights Watch reporting that at least 60 countries use these practices (HRW 2020) in their mental health institutions and in the community. Seclusion and restraint are controversial and ethically complex practices used in psychiatric institutions to manage the behaviour of PWMI who pose a risk to themselves or others. Seclusion involves confining a person in a room alone, while restraint involves using medication, devices or physical force to restrict a person's movement (Chieze et al. 2019; Goulet, Larue & Dumais 2017; Muir-Cochrane 2022; Muir-Cochrane, Baird & McCann 2015; O'Hagan, Divis & Long 2008). These interventions are typically used in emergency situations and as a last resort when all other interventions have failed (Chieze et al. 2019; Scanlan 2010; Van Doeselaar, Sleegers & Hutschemaekers 2008). SR is also typically counterproductive, with harmful repercussions for both patients and mental health professionals because they damage trust and engagement with services and promote coercive care over therapeutic care (Muir-Cochrane, Baird & McCann 2015; Scanlan 2010; Van Doeselaar, Sleegers & Hutschemaekers 2008). Seclusion and restraint is also widespread in the community setting where In Indonesia, SR in the community is known as

Pasung, which is frequently used, prompting significant human rights concerns (Broch 2001; Hidayat et al. 2020; Minas & Diatri 2008).

Pasung is a ‘long-standing custom’ in West Java, and in Indonesia more broadly. Dutch psychiatrists published extensively about the issue of Pasung in Indonesia as early as the 1920s, nearly a century ago and before Indonesia’s independence. During the colonial period, the Dutch East Indies' mental health care policy was based on the mental hospital, which provided custodial care. Independent Indonesia inherited four extremely big mental institutions, around ten acute-care clinics in major cities, and an agricultural colony in 1949 (Pols 2006). Pasung has traditionally involved a person who is agitated or considered at high risk of doing harm, either to themself or others, being shackled using a wooden log (Anto & Colucci 2015; Broch 2001; Minas & Cohen 2007). Frequently, this shackle is anchored to a concrete floor or wall (Broch 2001; Minas & Cohen 2007). Currently, Pasung has grown to include purpose-built cages and similar structures within the home or community designed for containment.

In Indonesia, the policy to ban Pasung was issued in 1977 with the release of a Home Affairs Ministry regulation (MoHA 1999). Despite this regulation being in existence for more than four decades, Pasung still exists in the Indonesian community and has been somewhat overlooked. In 2010, the Indonesian government through the Ministry of Health launched the Indonesia Free Pasung Programme (FPP), which aimed to eliminate the use of community SR for people with serious mental illness (MoH 2014). This was followed by the ratification of Mental Health Act. 18, which has been in effect since 2014 and reaffirmed that those who deprive others of their rights would be imprisoned or fined (MoH 2014).

There have been no epidemiological surveys that have accurately expressed the percentage of people in the population subject to Pasung until recently (Minas & Diatri 2008). In Indonesia, the majority of people with mental health issues are hidden by their families and not exposed to public view. This is because mental illness is highly stigmatised and viewed as a shameful affliction in Indonesian culture and society (Broch 2001; Nurjannah et al. 2015b).

The Indonesian government claims that the Free Pasung Programme has successfully reduced Pasung based on rates estimated by Human Rights Watch from 18,880 cases in 2010 to 12,220 cases in 2018 (HRW 2018). The Indonesian government's repeated revisions of the Free Pasung Programme (2010-2017 and 2019) have sparked doubt among the community about the true number of people still in Pasung and the success of the FPP as claimed by the government. The number of individuals in Pasung could be significantly higher than estimated. Furthermore, according to data provided by the Indonesian Centre for Health Research, the number of people with serious mental illness who were subjected to Pasung decreased somewhat from 14.3% to 14%, but this does not match the fall in rates stated by the MoH. It also does not appear to reflect Indonesia's population growth from 2010 to 2018, when the country's population increased by

about 30 million (from 237 to 265 million) (Badan Pusat Statistik 2019). According to data from the MoH website, 10% of those in Pasung were released and treated in hospitals over a six-year period from the start of 2009 to the end of 2014. However, there is no evidence on how many people with serious mental illness were successfully rehabilitated or returned to their communities and Pasung.

Since the introduction of the Pasung policy, there has been limited research into how the policy has been positioned to bring about change and what the policy actors perceive to be the challenges (Hidayat et al. 2020; Hunt, Guth & Setiyawati 2021; Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011). Among this research, some has been focused on the content (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011) while other research has been centred on actors and decision-making (Nurjannah et al. 2015b). Nevertheless, the political, economic, and social contexts in promoting or inhibiting Pasung policy at the national and sub-national levels have been largely unexplored.

Using Health Policy Analysis (HPA) (Walt & Gilson 1994), otherwise known as the Policy Triangle Framework (PTF) (O'Brien et al. 2020; Walt et al. 2008), this policy analysis intends to contribute to addressing this knowledge gap. This framework has been widely used in many countries, particularly Low and Middle-Income Countries (LMICs), to address a variety of health policy issues, including health sector transformations and population health (Gilson & Raphaely 2008; Walt & Gilson 1994; World Health et al. 2018). It focuses on four key aspects: the policy content; the people involved in policy change; the procedures involved in producing and implementing change; and the context in which the policy is created. The framework is premised on the idea that policy derives from, and is shaped by, political and social processes (Buse 2012; Walt & Gilson 1994).

The HPA is a simplified portrayal of a complicated set of inter-relationships in which actors as individuals, or as members of groups or organisations, are influenced by the context in which they live and work; context is influenced by many factors such as political instability or ideology, history, and culture, as well as how the policy-making process – how issues get onto policy agendas and how they fare once there – is influenced by actors and their positions in power structures (Walt & Gilson 1994). The context variables that have shaped Pasung policy, the actors involved, the content of the policy and institutional provisions, and the approaches and policy processes are examined in this chapter. The findings of this chapter will be used to inform the challenges and accomplishments to the appropriate change agents, such as relevant government agencies, and will contribute to the body of knowledge on Pasung, hence strengthening the links between research and policy.

4.2 Methods

4.2.1 Sampling Frame of Included Literature

All policies that aimed to address Pasung, whether in English or Indonesian, with full-text available and which had been issued by the government of Indonesia from 1945 onwards, including the Indonesian Constitution, laws related to the right to health in Indonesia, human rights, and social welfare for people with mental illness subjected to Pasung, were included. For the availability of targeted Pasung policy documents and publications, we mostly relied on online resources, searching the websites of the MoH, the Ministry of Social Affairs (MoSA), the Ministry of Home Affairs (MoHA), the Ministry of Law and Human Rights (MoLH), the Human Rights Watch (HRW) commission report, and the West Java Provincial Government (WJPG).

4.2.2 Search Strategy

Web-based searches of national and provincial websites, including the MoH, MoSA, MoLH, MoHA, the HRW Commission report, and the WJPG website, were conducted to identify all public policy documents relevant to Pasung. Searches were conducted in September 2021. All potentially relevant information was downloaded for analysis. Search terms included “Pasung”, “mental illness”, “mental health”, “policy development”, “policy implementation”, “policy evaluation”, “disability”, “Pasung policy”, and “health policy”. We included 17 national policy documents and 1 provincial-level policy document in our analysis.

4.2.3 Data Extraction and Analysis

The data extraction began by identifying, describing, and categorising current and previous policies aimed at overseeing Pasung practice. We compiled and reviewed the content of all national policies dating back to 1945, looking for particular policy content pertinent to Pasung and then went on to analyse and explain the reasons for their impact (or lack thereof) on Pasung. We tracked the evolution of policy content over time, as well as the extent to which the aforementioned shifting policy framework influenced implementation.

The analysis then moved to the provincial level where the study was located, which is West Java Province's health policy and strategy papers. Understanding how decentralisation reforms impacted policy creation and execution, a review of provincial Pasung prevention plans and implementation policies was considered relevant. West Java was chosen because it is one of the provinces with the highest prevalence of mental health problems according to National Health Research in 2013 (MoH 2013). Despite a minor drop in 2018 (using a different instrument compared to the previous one in 2013), West Java is also regarded as having among the highest number of PIPs in Indonesia, given the fact that it is the most populated province in the country (Badan Pusat Statistik 2019; MoH 2018).

The context, content, mechanisms, and actors that shaped these policies were examined using the HPA. The term ‘context’ refers to national, regional, or even global political, economic, social, and cultural elements that may influence health policy. The reviewed content of the policies refers to what areas of health care it covers and what is not covered. The mechanisms through which these policies were formed, implemented, or reviewed are referred to as the policy process. Individuals, communities, groups, institutions, and the government are examples of actors who have an impact on health policy. Finally, the data were read for familiarisation, and then iteratively read again to identify any new trends. Context, actors, content, and processes were among the key categories of codes examined and classified based on Walt and Gilson's established codes and themes (Walt & Gilson 1994; Walt et al. 2008).

4.3 Result

4.3.1 Policy Documents Identified

In total, 18 policy-related documents were identified. In this section, each document is described in relation to its relevance to Pasung. We divided the context of Pasung policy into three periods of time considering that Indonesia has had three eras since independence in 1945. The first era is called the ‘Old Era’, starting from 1945 to 1965; the Second Era called the ‘New Era’, began in 1966 after the rebellion of the Communist parties in which thousands of civilians and army personnel died, up until 1998; and, the third era which is called the ‘Reformation Era’, starting from 1999 to the present (Hosen 2004; Pols 2006; Sutarto 2008; Warren 2005). Table 1 shows the chronology of the policies and plans evaluated for relevance to Pasung.

Table 4-1: **The Timeline of Major Policies of Relevance to Pasung**

No	The Policy	Year	Era
1	The Constitution of the Republic of Indonesia	1945	First Era
2	The Indonesian Penal Codes (enacted by Law No. 1 of 1946)	1946	
3	Mental Health Act	1966	Second Era
4	Ministry of Home Affairs decree of 1977	1977	
5	Law on Health No. 23 of 1992	1992	
6	Human Rights Act Number No. 39	1999	Third Era Part 1 Before the Enactment of Mental Health Act No. 18 of 2014
7	The Amended 1945 Constitution	2000	
8	Law on Indonesia Social Security Scheme No. 40	2004	
9	Law on Health No. 36	2009	
10	Towards Indonesia Free of ‘Pasung’ Ministry of Health	2010	
11	Law on Social Security Agency No. 24	2011	
12	Mental Health Act No. 18	2014	
13	The law concerning the Rights of Persons with Disabilities No. 8	2016	

14	Ministry of Health Ministerial Decree on Health Indonesia through Family Approach (PIS-PK) No. 39	2016	Part 2 Global Policy shift from Millennium Development Goals (MDGs) (2000-2015) to Sustainable Development Goals (SDGs) (2015-2030)
15	Stop Pasung movement (Gerakan Stop Pemasungan/GSP)	2017	
16	Ministry of Health Ministerial Decree on Stop Pasung No. 54	2017	
17	Ministry of Health Ministerial Decree on Minimum Services Standard on Health No. 4	2019	
18	West Java Regional Regulation of mental health	2018	Local policy

4.3.2 The First Era after the Proclamation (1945-1965)

Context: After the proclamation of independence in 1945, the new Indonesian state inherited a health system that had been destroyed by years of combat, including Japanese occupation and the revolutionary battle against the Dutch (Neelakantan 2013; Pauker 1980). There was a severe scarcity of clinicians in the country, who were largely concentrated in the country's major cities, where only a small percentage of the people lived. The Indonesian Ministry of Health also had to manage the recurrence of epidemic diseases as well as endemic diseases (Neelakantan 2013).

Indonesia adopted a mental health system similar to that of the United States, focused on a clinical biomedical paradigm. American psychiatry dominated mental health treatment from then on, setting the groundwork for modern, open-style institutions and out-patient care. Most Indonesian psychiatrists undertook training at Western universities after independence and applied their expertise on the topic in their own country (Porath 2008). Since the mid-1960s, the biomedical paradigm has been the foundation of psychiatric thinking. The medicalisation of mental health issues tends to background the patient's subjective experience of the condition in favour of delivering accessible mental health care within a complicated health system. The Directorate of Mental Health in Indonesia is in charge of this. However, several factors have hindered effective implementation of mental health care, including the government's inadequate health infrastructure, political volatility, inadequate funding, inadequate healthcare infrastructure, including hospitals, clinics, and transportation facilities, shortages of qualified healthcare professionals, inadequate healthcare planning, and ineffective policy implementation. People in rural and remote locations, in particular, have limited access to mental health treatment (Pols & Wibisono 2017; Porath 2008). While there is no field per se and relatively little research that has focused on the historical perspective of Pasung both before and after Indonesia's independence, in the broad sense we propose here, there is an extensive range of research on seclusion and restraint in psychiatric settings that provides important insights into how these practises are known, how to promote or ban the use of this SR, or at least understand the interventions to end this practise.

Content: There were two policies issued during the old era, the 1945 Constitution of the Republic of Indonesia, and The Penal Code of 1946. The details are below:

4.3.2.1 The Constitution of the Republic of Indonesia

The 1945 Constitution of the Republic of Indonesia (Government of Republic Indonesia 1945), also known as Undang Undang Dasar 1945, is the foundation of all law in Indonesia. It was written before Indonesian independence in August 1945 and was named shortly after independence was proclaimed, following Dutch colonial rule and then Japanese occupation during World War Two. The constitution was a brief document consisting of 37 articles, six of which dealt specifically with human rights (Articles 26-31) as shown in Table 1. However, only one Article (Article 27 verse 2, in bold text) was directly related to Pasung:

> Every citizen is entitled to work and a living that is commensurate with their status as human beings.

It is worth noting that the Constitution's obligations to human rights predate the 1948 United Nations Universal Declaration of Human Rights. The above rights were to be established by law, but might also be restricted by law. For example, every citizen has a right to a living that is consistent with their status as human beings, but if they are declared mentally ill, they may be forced to live in a mental hospital as other laws may allow family or community members to transfer someone to the hospital without their consent.

4.3.2.2 The Penal Code of 1946

In the Penal Code of 1946 (Government of Republic Indonesia 1946), three Articles dealt with mental illness and, to a lesser extent, seclusion and restriction. Despite the fact that the penal code prohibits a person from being deprived of liberty, someone who allows a mentally-ill person to be abandoned alone might be imprisoned and punished.

a. Indonesian Penal Code Article 333, verse 1
   “Any person who deprives a person of liberty purposely and unlawfully, or proceeds to deprive a person of liberty, faces a maximum sentence of eight years in jail”.
b. Article 10
   “For the sake of peace and public order, or to heal the mentally ill person himself, close relatives of a mentally ill person may petition the chairman of the district court to have the person treated in a mental health facility”.
c. Article 491
   “Anyone who is obligated to care for a mentally ill person who is hazardous to himself, or others faces a maximum fine of 750 rupiahs if they let that person roam around unaccompanied”.

This meant that a family's options for caring for someone with mental illness were limited. On the one hand, they were prohibited from depriving a person of their liberty, but on the other, they could not allow the person to roam as they would encounter severe consequences. When the family could not send the individual for treatment because it was either inaccessible or the hospital was

overcrowded, they might have chosen to hide the sick family member, with Pasung being one of the few options available to the family.

Actors: The MoH, through the Directorate of Mental Health, oversaw the majority of the policies, while the psychiatric institution served as the frontline at the local and state levels. In this era, the community (i.e., the family) was partially engaged with the responsibility of guarding persons with mental ill-health, while the person themself lost their autonomy to make decisions about their medical treatment. Yet the MoLH established rules outside of the health system, such as penal codes, that constrained how the family should care for an ill relative. With the dominance of the biomedical system on the one hand, and the penal code on the other, lack of access to mental health support and lack of community support continued to leave families with limited care options.

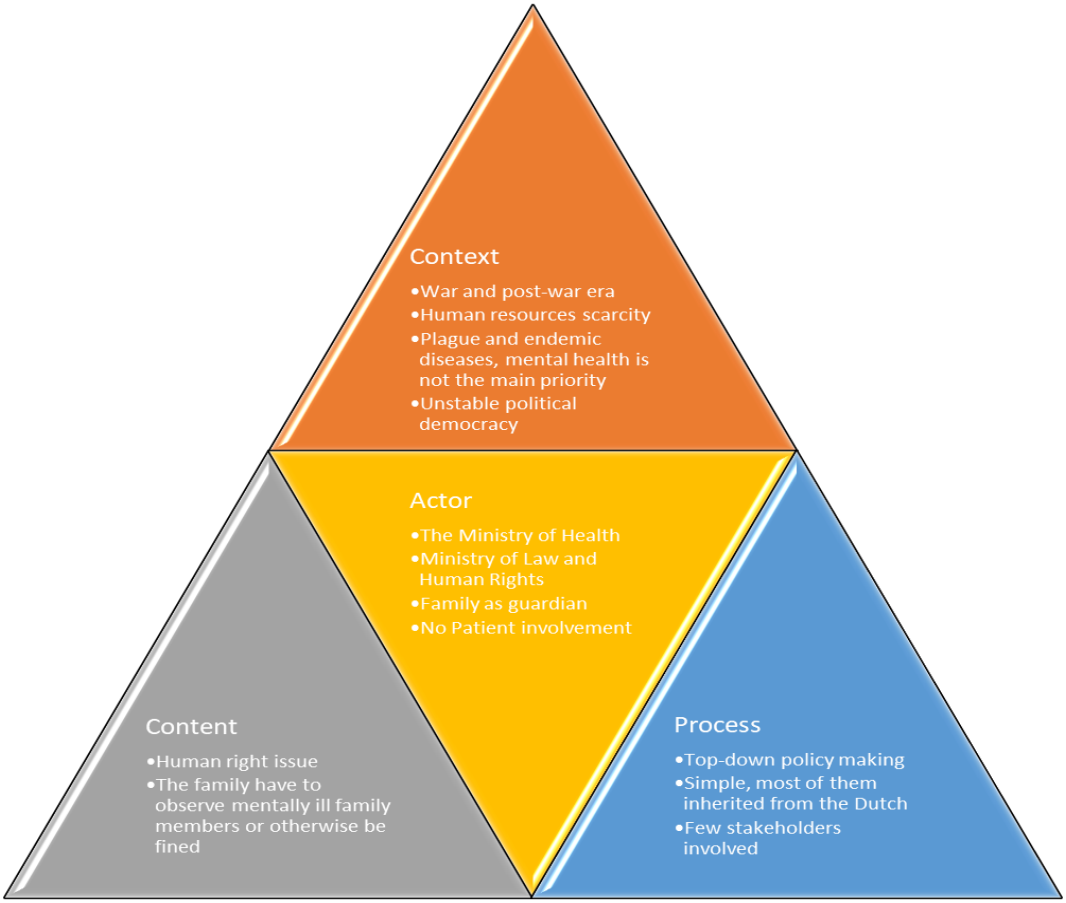


Figure 4-1: Health Policy Analysis on Pasung in The First Era of Indonesia 1945-1965

Process: During the first era, Indonesia became a legally established nation. As previously stated, much of the policy was passed down from the Dutch, including the Indonesian penal codes, which were taken from the Wetboek van Strafrecht (WvS) and were enacted by the Penal Codes Legislation No. 1 of 1946 (Government of Republic Indonesia 1946). It was reasonable that much of the policy-making process was top-down during this period. This circumstance was exacerbated by war, turmoil, and the economic crisis (Dick 2002; Green 2005; Wicaksana 2021).

In terms of health policy, the MoH developed legislation and policies at the national level in conjunction with a variety of stakeholders. The responsibility for producing implementation plans with specified targets, indicators, funds, and timetables rested on the provincial departments of health. Provincial agencies were also in charge of monitoring and evaluating national policy and legislation that had been implemented. Provincial districts (divisions of provinces) were in charge of implementing interventions at the local level in accordance with national and provincial priorities (Green 2005).

4.3.3 The second Era/New Era (1966-1998)

Context: The three approaches of prevention, treatment, and rehabilitation were proclaimed by the Directorate of Mental Health in 1966 as the foundation of a comprehensive mental health care system. At this time, the Indonesian government chose a paradigm similar to that of the previous era, in which the major players were the psychiatric institutions. This was demonstrated by the establishment of an even greater number of psychiatric institutions in Indonesia, in addition to the four psychiatric hospitals (Bogor, Grogol, Lawang, and Magelang) inherited from the Dutch as part of their colonial rule in Indonesia. The number of patients across these hospitals doubled in 1970, and a range of therapeutic approaches were introduced (Pols 2006; Porath 2008; Salan & Maretzki 1983).

Content: Three primary articulations ruled mental health and specific policy to prohibit isolation and restriction throughout the second era. Contrary to popular belief during this period, which viewed mental illness as hazardous and requiring constant monitoring, the government supplied a more comprehensive approach during this time, although only inside the confines of the institutions. Three policies relating to this era are detailed below:

4.3.3.1 Mental Health Act No.3 of 1966

The first Mental Health Act for Indonesia was issued in 1966 (MoLH 1966) at the beginning of what is known as the new order era. This first Mental Health Act was a brief regulation and consisted of only 7 Chapters and 14 Articles. The government began to see mental health as a problem for national development, particularly health development. The Act influenced the policy agenda at the time to view mental health through a predominantly biomedical lens, as mentioned in the first Article where the definition of mental health was linked with the definition of mental health in medical science:

> Mental health according to the current understanding of medical science is a condition that allows a person to acquire an optimal physical, intellectual and emotional development and that development goes in harmony with the situation of other people.

Furthermore, in Article 1, Sub-paragraph (b), mental illness as defined in Sub-paragraph (a), is a disturbance in mental function that leads to mental health issues. The regulation mentioned neither Pasung nor restraint and seclusion. However, it regulated the circumstances of a person who could be admitted to hospital. In Article 6, the regulation mentioned that admission to a hospital without the patient's consent was against the law:

> If a patient is required to be treated in hospital, then from a legal point of view the right to freedom of movement of the patient is limited. As such that action can be categorized as criminal conduct unless the restriction on freedom of movement is based on law.

Despite the legislation urging persons to respect the human rights of the person in terms of freedom of movement (Article 6), other Articles within the Act did not do so. For example, Article 5 mentioned that coercion was in place where the doctor who treated the person had the authority to send the person to a hospital without their agreement. To make it a legal action, consent could be obtained from one of the following: the patient if she/he was deemed to have enough capacity to give consent; or, where this was not the case, the parent, spouse, or the guardian of the patient. In the case of an emergency or disturbing the peace and public security, the police or the judge, as specified in Article 5, could refer the patient to hospital. The words "disturbing public security" were not defined clearly in Article 5; therefore, this Article might have been used to commit a person to a mental health facility without their consent. For the sake of safety, a family or community may consign someone who was regarded as mentally-ill to a mental institution and prohibit them from returning to the community.

4.3.3.2 Home Affairs Ministerial Decree PEM.29/6/15 on 11 November 1977

This Home Affairs ministerial directive (MoHA 1999), written to the governors at all provincial levels throughout Indonesia, asked the public to avoid shackling persons with mental illnesses and to create public awareness about the importance of providing care for patients in psychiatric hospitals. The letter also included directives for sub-district and village chiefs to take proactive measures to deal with patients in their communities. Despite the fact that the policy was only at the ministerial level, the government, which was governed by authoritarians, had a great desire to implement it. At the time, the majority of governors were army major generals. This is why the Ministry of Home Affairs took the lead in the Pasung movement rather than other ministries (Rinakit 2005).

4.3.3.3 Law on Health No. 23 of 1992

In the Law on Health policy issued in 1992 (MoH 1992), there were no specific Articles or verses mentioning Pasung. Four articles covered the issue of mental health and what the government's responsibility for each community was to prevent, promote, and treat mental illness. In this policy, governments were beginning to change the ethos of mental health by emphasising the importance

of community to support the overall health of its members. In addition, the definition of mental health, which covered social and productivity aspects, showed commitment to tackling the link between poverty, unemployment, and mental health (see Table 4.2, Article 1).

Moreover, in this policy, the government tried to implement mental health services in an integrated way, as seen in Articles 10, 24, and 25. Despite the boundaries and definitions of prevention and promotion in this policy being vague in relation to the cure and treatment of mental illness, policy-makers attempted to pave the way for the identification of the need for mental health services to be implemented comprehensively (see Article 24, verse 2).

Table 4-2: Chapters and Articles Relevant to Mental Health in Law on Health No. 23 of 1992

Chapter	Article
1: General Terms	Article 1 (1) Health is a state of complete physical, mental, and social wellbeing that enables a person to be socially and economically productive
VI: Health service	Article 10 To achieve an optimum health status for the community, health services are carried out with promotive, preventive, curative, and rehabilitative which are carried out in a comprehensive, integrated, and sustainable manner. Article 11 (1F) Health services as mentioned in verses 10 including mental health
Chapter VII Mental Health	Article 24 (1) Mental health is implemented to obtain an optimum both intellectually and emotionally (2) Mental health includes the promotion and prevention of mental health, prevention and treatment of psychosocial problems and mental illness, and curative and recovery of people with mental illness (3) Mental health is implemented at all levels by individuals, the family, school, work, and community, supported by mental health service facilities and other facilities Article 25 (1) The government shall provide treatment and care, recovery, to people with mental illness after the hospital treatment and/or treatment into the community (2) The government initiates, assists, and fosters community activities in the prevention and management of psychosocial problems and mental illness, treatment and care, recovery and shelter of former people with mental illness into the community Article 26 (1) Person with mental illness who possibly disturb public order and security must be treated and cared for in mental health service facilities or other health service facilities (2) Treatment and care for people with mental illness can be carried out at the request of the husband or wife or guardian or family

	members of the patient, or at the initiative of the official responsible for security and order in the local area or a court judge if in a case there is a suspicion that the person concerned is a person with a mental disorder (3) The government is responsible for establishing and operating a national education system that is governed by law

Despite many improvements in mental health policy in general, this policy remained unchanged in nature, similar to the Penal Codes and Mental Health Act of 1966, where coercion is used in situations where a doctor or authority determines that someone needs to be hospitalised (see Table 2, Article 26, verses 1 and 2). Psychiatrists (doctors) were given significant power in mental health legislation, which gave them the right and responsibility to hold patients and force them to take medication or undergo other therapy.

Actors: Similar to earlier eras, the MoH controlled the bulk of policies through the Directorate of Mental Health (previously the Department of Mental Health), despite the leading organisation to combat Pasung being the MoHA. Out-patient psychiatric clinics integrated into general referral hospitals were more common than psychiatric institutions during this era. A number of treatment approaches, including prevention, treatment, and rehabilitation, were also implemented as the cornerstone of a comprehensive mental health care system (Pols 2006). To overcome Pasung, the government attempted to enlist the help of other stakeholders, such as the MoHA. However, there was only partial implementation of the policy, with the family, and local schools, workplaces, and communities largely taking up this burden with the help of mental health professionals and other organisations. For example, unlike physical health, mental health was not taught in schools. While the family's obligation to protect mentally-ill individuals continued, the patient's autonomy to make decisions about their medical treatment without being affected by both their health care provider and carer was minimal.

Process: Indonesia's internal and international policies, including health and mental health, remained dominated by economic nationalism throughout the Suharto administration. The nationalist agenda had many forms and manifestations, but the essence remained the same as in the previous era (Wicaksana 2021). Since the New Order's inception in 1966, military ideology emphasised the pursuit of economic development as a means of rescuing the country from the politico-economic disasters that occurred under the old era. From spoiler to essential supporter, the military adjusted its role. The military's main role as a key supporter was to provide advice and policy recommendations to the president, as well as to criticise the government (Honna 2018; Rinakit 2005). Most institutions, it should be noted, adopt top-down team management. This is how any ministerial and provincial level with an executive ladder was set up. This structure dismissed the involvement of civilians (Neelakantan 2013; Rinakit 2005). The context, content, actors, and process elements within the Second Era are summarised in Figure 4.2

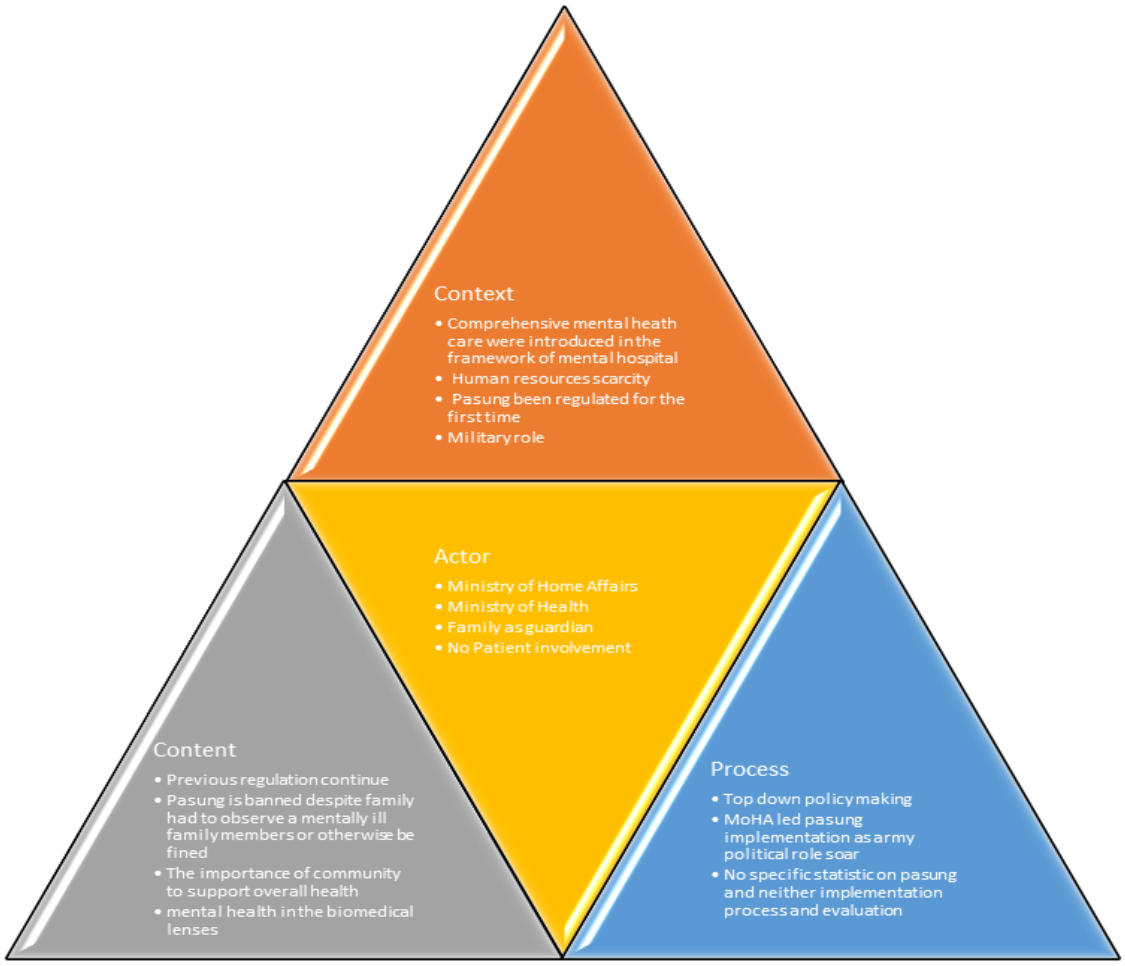


Figure 4-2: Health Policy Analysis on Pasung in the Second Era of Indonesia 1966-1998

4.3.4 The Third Era/Reformation Era (1999-present)

Context: In the early reformation era, the resistance and students' movements arose from the so-called urban middle class, resulting in a new civil movement. This had never been seen before; the government had previously faced few substantial challenges from either the military or civil society (Aspinall 2014a; Hosen 2004; Rinakit 2005).

The health sector was one of the most important government initiatives in this era. The government enacted health-related legislation, including Health Law No. 36 of 2009. This was followed by the enactment of Law No. 18 of 2014, which dealt with mental health. With the passage of the Law on Indonesia Social Security Scheme No. 40, and the Law on Social Security Agency No. 24, the transition from voluntary to mandatory social schemes began to support funding for health and mental health. Global policy had also shifted from MDGs (2000-2015) to SDGs (2015-2030) in this era. In the MDGs, mental health was not specifically mentioned, but in the SDGs, there are some articles (goals) that specifically mention mental health. Furthermore, during this era, the care offered by dukuns, or indigenous healers, had also been given special consideration. Traditional medicine, according to Article 1, number 16 of the Health Law, was therapy and/or treatment with techniques and substances related to empirically inherited experiences and abilities that could be

accounted for and implemented in line with societal standards. Moreover, pharmaceutical preparations in the form of traditional medicines and cosmetics, as well as medical equipment, had to comply with the norms and/or requirements set out in Article 105 of the Health Law.

Content: Compared to the previous era, the government issued four times as many policies in relation to health and disability which had a broader definition that included mental illness, mental health, and a particular policy to prevent isolation and confinement. The above-mentioned improvements reflect recent policy advancements in Indonesia, indicating that there is some political momentum for establishing a better mental health care system.

The following policies were put in place during this era.

4.3.4.1 The Amended 1945 Constitution (Amendments)

The 1945 Constitution of the Republic of Indonesia (Government of Republic Indonesia 1945) has been amended four times during the Reformation Era, most notably in 1998 (Government of Republic Indonesia 1998) with the insertion of the Human Rights Article. It now contains a dedicated chapter solely for human rights in Chapter XA. Three verses (Articles 28B, 28G, and 28I) underline the protection against violence and torture or other treatment that degrades human dignity. As an example, Article 28G states:

> Every person has the right to be free of torture and other degrading treatment that degrades human dignity.

4.3.4.2 Human Rights Act No. 39 of 1999

The fulfilment of the right to health for persons with a mental disorder links with Indonesia's human rights obligations. The Human Rights Act No. 39 of 1999 (MoLH 1999) was issued long before Indonesia ratified the Convention on the Rights of Persons with Disabilities (CRPD) (MoSA 2011) in 2011 (see the law on CRPD No. 19 of 2011). In Chapter II of this Act, the basic principle of Article 4, verse 1 mentioned that every person has the right to life, the right not to be tortured, the right to personal freedom, thoughts, and conscience, the right to religion, the right not to be enslaved, the right to be recognised as a person and as equal before the law, and the right not to be prosecuted on the basis of retroactive law. These are human rights that cannot be reduced under any circumstances by anyone.

Furthermore, Article 9 states that: (1) Everyone has the right to live, maintain life, and improve their standard of living; (2) Everyone has the right to live in peace, security, happiness, and physical and spiritual prosperity; and (3) Everyone has the right to a great and healthy living environment. By issuing this legislation, the government wished to emphasise that torture, including seclusion and restraint of people suspected of having mental illness, was an act contrary to human rights. The use of seclusion or physical restriction as a technique for a hospital's administrative convenience or in-patient ward management is regarded as a violation of human rights. The Article stressed that

staff can only administer seclusion for brief periods of time as a method of crisis management or when it is the only way to prevent urgent or impending harm to the patient or others.

During this era, there were no regulations in place that expressly addressed people with disabilities. Existing regulations were dispersed and covered areas such as education, health, accessibility, and employment that affected people with disabilities. It was also at this time that new phrases were coined and first applied to people with impairments. 'People's disability' and 'handicap' were two examples of these phrases, and they applied to a variety of disabilities (blindness, quadriplegia, and impaired speech). At the end of the era, the term "Persons with Disabilities" emerged in the regulations.

4.3.4.3 Law on Indonesia Social Security Scheme No. 40 of 2004

The Law on Indonesia Social Security Scheme No. 40 of 2004 (MoLH 2004) was a game-changing step towards meeting the Indonesian government's goal of Universal Health Coverage (UHC). Article 3 of this regulation stated that “Social security is a form of social protection to ensure that all people can meet their basic needs for a decent life”.

The Indonesian social security programme is currently undergoing a fundamental overhaul in order to improve the existing system's performance for beneficiaries, and to expand social security coverage to more people, including those with psychosocial disabilities. The Indonesian government paid the insurance premiums for those in need and those with psychosocial disabilities, as stated in Article 20: “Participants in health insurance are anyone who has paid contributions or has had contributions paid for them by the government.” Furthermore, Article 21 (3) of this Law stated, “Participants who have a permanent total disability and are unable to pay their contributions are reimbursed by the government.”

By the enactment of this Law, participants could get promotive, preventive, curative, and rehabilitative services. This was stated in Article 22 which mentioned “Benefits of health insurance are individual services in the form of health services that include promotive, preventive, curative, and rehabilitative services, including medicines and consumable medical materials needed.” This regulation also encouraged people to seek treatment at the nearest health facilities, as all community centres and hospitals cooperated with this system, which is mentioned in Article 23: “Health insurance benefits as referred to in Article 22 are provided to government-owned or private health facilities that cooperate with the Social Security Administering Body.”

4.3.4.4 Law on Health No.36 of 2009

The Law on Health policy issued in 2009 (MoH 2009a) had similar concerns to the previous Law on Health policy issued in 1992 in terms of Pasung regulation, where we found no information directly regarding Pasung. The content regarding mental health in Chapter IX consisted of 9

Articles (see Table 4.3). The difference between the previous and the 2009 Law in Health policy is described in several Articles below:

Article 144 (3) and Article 147, verse 1. The responsibility is stated not only by the government, but also local government and the community to hold shared responsibility for implementing the mental health service. This version was issued after the reformation and decentralisation eras where all Indonesian provinces and districts had autonomy in relation to managing funding and local resources, while the central government managed the overarching policy and some of the resources. Moreover, community involvement was introduced to increase the coverage of mental health services. The government moved its thinking to be more wide open to the community being involved in the mental health service, such as the mental health at work and mental health at school initiatives.

Article 146 described how education and information regarding mental health are a must to protect the human rights of people with mental illness. Due to stigma, discrimination, and a lack of legal protection, individuals are exposed to human rights breaches in the community and in a range of services. Improved media reporting and public education were deemed useful strategies to reduce human rights concerns.

Article 146 (2) is another example of where human rights issues were included in the policy document, as exemplified in verse (1) which aimed at avoiding violations of the human rights of a person considered to have a mental health disorder. Article 148, verse 1 further stated that people with mental illness have equal rights to other citizens.

The minimum standard requirement for mental health facilities started to be regulated under this law, which mentioned in Article 147 (3) that specific health service facilities were required to demonstrate standard requirements that were in accordance with those mentioned as being needed in the regulation to effectively treat and care for people with mental health illness.

During this third era of reform, policies focusing on disadvantage and social exclusion have emerged from the new determination to address the links between poverty, unemployment, and mental illness. This was covered in Article 149 (1), in which people with mental health issues who are neglected, homeless, threaten the safety of themself and/or others, and/or disturb the order and/or security of the general public are required to receive treatment and care in mental health facilities.

Despite many improvements, in this policy, psychiatry continues to separate mental illness from the person’s broader social and environmental context and surroundings. Mental health issues and psychosocial problems are both defined as abnormal personal experiences. Social and cultural variables are secondary at best, and may or may not be considered (see Article 1, definition of

health). This is partly due to the fact that the majority of psychiatric contacts take place in hospitals and clinics where the treatment focus is only on the person‘s clinical symptoms, whether through medication or psychotherapy (see Article 147 (2-3), Article 149 (1, 2, 3), and Article 150 (1).

Table 4-3: Chapters and Articles Relevant to Mental Health in Law on Health No. 36 of 2009

Chapter	Article
1: General Terms	Article 1 (1) Health is a state of complete physical, mental, and social wellbeing that enables a person to be socially and economically productive
IX: Mental Health	Article 144 (1) Mental health service is aimed to ensure all people can have a healthy life, free from fear, stress, and other symptom related to mental illness (2) Mental health services, as referred to in verse (1), consists of the prevention, promotion, cure, and rehabilitation of patients with mental illness and psychosocial problems (3) Mental health services, as referred to in verse (1), are the joint responsibility of the government, local government, and the community (4) Government, local government, and the community are responsible for creating mental health services at the highest possible level and ensuring the availability, accessibility, quality, and equity of mental health services, as referred to in verse (2). (5) The government and local governments are obliged to develop community-based mental health services as part of integrated mental health services, including accessibility to a community for mental health services Article 145 The government, local government, and the community should ensure mental health services are available at all levels including the preventive, promotive, curative, and rehabilitative, and also in the workplace as referred to in Article 144, verse (3). Article 146 (1) The public has the right to obtain accurate information and education regarding mental health (2) The rights, as referred to in verse (1), are aimed at avoiding violations of the human rights of a person who is considered to have a mental health disorder (3) The government and local governments are obliged to provide information and education services on mental health Article 148 (1) People with mental illness have the same equal rights as other citizens (2) The rights, as referred to in verse (1), include equal treatment in every aspect of life unless the laws and regulations state otherwise Article 149

Chapter	Article
	(1) People with mental illness who are neglected, homeless, threaten the safety of themselves and/or others, and/or disturb the order and/or security of the general public are required to receive treatment and care in health care facilities (2) The central government, local government, and the community are obliged to give treatment and care at mental health facilities for people with mental illness who are abandoned, homeless, threatening the safety of themselves and/or others, and/or interfering with public order and/or security (3) The central government and local governments are responsible on equal distribution of mental health facilities by actively involving the public actively (4) Central and local government responsibility, as referred to in verse (2), includes financing of the poor Article 150 (1) Mental health examination for the benefit of law enforcement (Visum et Repertum Psychiatricum) can only be done by psychiatrists at mental health facilities (2) Determination of the legal competence status of a person who is suspected of having a mental illness can only be conducted by a doctor who has the expertise and competencies in accordance with professional standards Article 151 Further provisions regarding mental health services will be regulated through government regulation

4.3.4.5 'Towards Indonesia Free of Pasung' of 2010

To deal with the increasing number of people in Pasung, the MoH launched a campaign known as 'Towards Indonesia Free from Pasung', or Indonesia Bebas Pasung, in October 2010 (MoH 2010). Apart from the increasing incidence of Pasung, this campaign was based on increasing advocacy and encouragement from many organisations including human rights organisations, mental health organisations, and extensive media input. The regulations used as the basis of the campaign were the Mental Health Act of 1966 (MoLH 1966), the 1992 Health Law (MoH 1992), and the Letter of the Ministry of Home Affairs 1977 (MoHA 1999), which ordered the public not to implement shackles for people with mental health issues, and to raise public awareness to hand over care for these individuals to mental hospitals or other mental health facilities. The letter also contained instructions for all governors, mayors, and district and village leaders to actively take steps to deal with PIPs in their area.

The MoH added that in order to meet the needs of people with mental health issues who were confined and neglected, comprehensive efforts were needed from the health, economic, and social institutions of society. This programme was known as Indonesia Bebas Pasung (FPP). This effort regulated the role of government, local governments, and the community. The MoH further

stressed that the central government and local (provincial and district) governments were responsible for the equitable distribution of mental health service facilities by encouraging the participation of the community, including the financing of treatment and care for people with mental health issues for the poor. The government and local governments were not only to find cases of Pasung and then release them, but also to provide education to the public to discourage them from using Pasung.

Community health centres were empowered to become the first place of contact and delivery of mental health services, and it was legislated that they had to provide the necessary treatment. General hospitals had to provide beds to treat people with mental health issues that required treatment. Psychiatric hospitals, apart from being referral centres, also had to become centres for mental health development for health services in their area. Community participation was expected to enable the identification of individuals with mental health issues in the community, avoid shackles, and encourage community members to seek treatment and carry out control. The programme also targeted decision-makers, non-government organisations, professional organisations, community leaders, health leaders, special groups, related sectors at the central and regional levels, and individuals who experienced chronic diseases and people with mental health issues (MoH 2010).

4.3.4.6 Law on Social Security Agency No. 24 of 2011

To achieve the goals outlined in Law No. 40 of 2004, the government established an administrative body in the form of a legal entity based on the principles of mutual cooperation, non-profit, openness, prudence, accountability, portability, mandatory participation, trust funds, and the results of managing social security funds entirely for programme development and the best interests of participants. In Article 2, Law No. 24 of 2011 (MoLH 2011), this social security agency was divided into two parts: the health agency and the worker's agency. The formation of this social agency body actually took slightly longer than expected as mandated in Article 52 of Law No. 40 of 2004 which stated, “All provisions governing the Social Security Administering Body as referred to in paragraph (1) are adjusted to this Law no later than 5 (five) years after this Law is promulgated.” It took seven years to establish the administering body.

In relation to Pasung, none of the articles mentioned Pasung or mental illness directly, but in Article 19 of this law, the government emphasised that the insurance premiums for those in need would be paid by the government. Indonesians whose income fell below the poverty line would be considered as low-income earners and would thereby be eligible for government assistance. The law itself did not regulate how the insurance premiums would be paid, and which categories of psychosocial disabilities would be included, as mentioned in the Law. The government's plan to subsidise coverage for low-income people with psychosocial problems was questionable given the fact that the majority of PIPs were low-income and uninsured (Dewi, Daulima & Wardani 2019).

4.3.4.7 Mental Health Act No. 18 0f 2014

Mental Health Act No. 18 of 2014 (MoH 2014) included several progressive ideas, such as focusing on ‘People with Mental Health Problems’ (Orang Dengan Masalah Kejiwaan), who were individuals at risk of developing a mental illness, and ‘People with Mental Illness’ (Orang Dengan Gangguan Jiwa), who were individuals who had been diagnosed with a mental illness (see Article 2b, Table 4), with specified treatment and care approaches. Despite the existence of the regulation for individuals with mental health issues, the policy was still not regarded by the community as the best option for them due to the persistence of Pasung and mental health problems.

Table 4-4: Chapters and Articles Relevant to Mental Health Act No. 18 of 2014

Chapter	Article
Chapter 1: General Terms	Article 2b Mental health treatment principles should be based on humanity. The "principle of humanity" means that the implementation of Mental Health Treatment for People with mental problems and mental illness is carried out humanely in accordance with human dignity. **For example, no restraints and so forth.**
Chapter V	Article 70, part 1 (1) People with mental illness (ODGJ) reserve the right to: a. Access mental health services b. Get mental health services in accordance with the pre-determined standard c. Have a guarantee for the availability of psycho-pharmaceutical drugs according to their needs d. Have the right to give consent for the medical action taken against them e. Obtain honest and complete information about their (people with mental health problems) mental health data, including actions and treatments they have, or will receive, from health workers with competence in the field of mental health **f. Get protection from every form of neglect, violence, exploitation, and discrimination** g. Have their social needs satisfied according to the level of mental illness h. Manage their own assets and/or those handed over to them
Chapter IX: Criminal Provisions	**Article 86** **Anyone who intentionally detains, neglects, abuses, and/or induces other people to carry out shackles, neglect, and/or violence against People with Mental Problems (ODMK) and People with mental illness (ODGJ), or other actions that violate the human rights of People with Mental Problems (ODMK) and People with mental illness (ODGJ), shall be punished in accordance with statutory provisions**

We have highlighted the detail within Article 86 (see Table 4.4 above) that explicitly states that perpetrators of Pasung may be subject to sanctions or punishments. Despite vague messages from this policy regarding what kind of criminal punishment would be implemented, the policy strongly suggests that perpetrators of Pasung are to be treated similarly to those who commit other criminal acts, despite most of them being members of the person's family or their close neighbours.

4.3.4.8 Law No. 19 of 2016 Concerning the Rights of Persons with Disabilities (CRPD)

The CRPD was ratified by Indonesia and incorporated into Law No. 19 of 2011 (MoSA 2011) concerning the Rights of Persons with Disabilities, which was then followed by Law No. 8 of 2016 (MoSA 2016) which replaced the previous law. Persons referred to as 'Persons with Disabilities' in this new law context, as mentioned in Articles 1 and 4, included those who had long-term physical, mental, intellectual, or sensory disabilities that hampered their full and effective involvement in society based on the principles of equality when confronted with numerous difficulties. The 2016 Act explains the rights of persons with disabilities as specified in Article 5, verse 1:

> Every person with disabilities must be free from torture or cruel, inhuman, degrading treatment of human dignity, free from exploitation, violence and arbitrary treatment, and has the right to respect for mental integrity and physically based on similarities with other people.

Another important point, as cited in Article 7, is that persons with disabilities have the right to be stigma-free, which encompasses freedom from harassment, humiliation, and negative labelling related to their disability condition. The enactment of the Law demonstrates the Government of Indonesia's commitment and seriousness in respecting, protecting, and fulfilling the rights of persons with disabilities, which are intended to promote their wellbeing, including the right to protection and social services in the context of independence, as well as in an emergency.

4.3.4.9 Ministerial Decree No. 36 of 2016 Healthy Indonesia Programme through Family Approach (Program Indonesia Sehat dengan Pendekatan Keluarga)

The Healthy Indonesia Programme through Family Approach (Program Indonesia Sehat dengan Pendekatan Keluarga (PIS-PK)) is a strategy implemented by Community Health Centres using a family approach (Puskesmas) (MoH 2016b). PIS-PK's priority areas, as mentioned in Article 2, were reducing maternal and infant mortality, and controlling the prevalence of stunting in children, infectious diseases, and non-communicable diseases, particularly hypertension, diabetes mellitus, and mental disorders. Primary Health Centres were to visit families in their coverage area as part of this programme to assess 12 health indicators in each family, as mentioned in Article 3, one of which was how family members with mental illnesses were treated. People suffering from mental illnesses (including Pasung cases) would then be identified and treated.

4.3.4.10 Stop Pasung Movement (Gerakan Stop Pemasungan/GSP)

GSP is presently led by the MoSA, which launched “Gerakan Stop Pemasungan” in 2017, in collaboration with the MoH at the national level. Different target dates have been set and revised as both Ministries battle with the immense task of achieving a Pasung-free Indonesia. The MoSA stated that Indonesia would be Pasung-free by the end of 2019, and then the MoH suggested that this would not be achieved until 2023 (MoSA 2017).

The transfer of the FPP from the MoH to the MoSA by the central government in 2017 changed the way the programme was implemented. While the MoH developed the FPP on a more institutional basis to care for those who had experienced Pasung, the MoSA established community-based pilot initiatives with a focus on social rehabilitation. The MoSA has implemented recovery-oriented practices in accordance with their 2013 Social Rehabilitation Programme Development Plan, which aims to enable people with mental illnesses who have been in Pasung, or have experienced homelessness, to return to their families as participating and productive citizens, while also providing accessible support services for people in their communities (MoSA 2017).

4.3.4.11 Ministerial Decree on Stop Pasung No. 54 of 2017

Over the past decade, there has been a profound effort in Indonesian mental health policy to shift mental health services to the community (MoH 2009a, 2017). Despite implementation being far from successful, the spirit of deinstitutionalising the system has been a key talking point among mental health service workers. Despite the changing role of the Ministry which led the FPP, the MoH enacted the new policy regarding Pasung via its Ministerial Decree No. 54 of 2017. This decree reinforced and elaborated upon the blueprint, emphasising the link between the establishment of a comprehensive mental health system and the eradication of Pasung in Indonesia.

This regulation depicts the Indonesian mental health service system, referencing other regulations such as the JKN (Law No. 40 of 2004 Concerning the National Health Insurance System) and the BPJS (Bureau of Public Health Services) (Law No. 24 of 2011 concerning the Social Security Administering Body) (MoLH 2011). Primary care facilities, such as Puskesmas (community health services), Sub Health Centres, the Indonesian Armed Forces, poly-clinics, and family doctors using out-patients with funds granted by the legal provisions, were the primary providers of care under this system. Severe cases needed to be sent to a district hospital, a private hospital, or a mental institution. Other treatment options included going straight to a public or psychiatric facility. Following treatment, the psychiatric patient needed to return to the community via a return referral to a primary health clinic where they would continue outpatient treatment. Even though it appeared to be a faultless system, many services such as housing and rehabilitation to reintegrate patients into society, as well as outreach programmes such as home visits by Puskesmas employees and cadres, were not fully covered by these insurance systems.

As part of the decentralisation process, the legislation also encouraged local governments to provide funds for treatment, as mentioned in Article 3. Although decentralisation has positive intentions in terms of equal distribution of mental health care, it also has detrimental consequences that have resulted in service fragmentation, which has been matched by rising fragmentation of management and funding. The burgeoning mental health system lacks a focal point for planning and responsibility to exert the type of stewardship historically undertaken by state mental health authorities. In Indonesia, health and disability insurance schemes for mental health treatment in the community have yet to commence. Another major concern is how community mental health services would be compensated under this plan.

4.3.4.12 Ministry of Health Ministerial Decree on Minimum Services Standard on Health No. 4 of 2019

As stated in Article 1 of this Ministerial Decree, the district government was responsible for providing appropriate care to all people suffering from mental illnesses. Furthermore, the district and province were required to implement the 12 standards of the Healthy Indonesia Programme through the Family Approach, as stated in Article 2, Point 3, of which mental health was one of the 12 indicators. Article 2, point 1 also allowed districts and provinces to include another indicator relevant to the needs of their district. Apart from this, as stated in Article 2, Point 3, the promotion of mental health was a priority situated within the larger field of health promotion, alongside mental illness prevention and treatment, and the rehabilitation of people with mental illnesses and disabilities. Community involvement had also been regarded as an important part of this law, where Article 2, point 6 stated that trained health cadres were to perform certain types of basic services outside of facility health services under the supervision of health personnel. The inclusion of the community was important to the continuation of the Pasung programme, because the community was where the cases had originally been identified (MoH 2019b).

4.3.4.13 West Java Provincial Regulation on Mental Health Service No. 5 of 2018

West Java Province was the first part of Indonesia to establish local regulations at the provincial level to govern mental health services throughout the province. There were 13 Chapters and 88 Articles in this Act (Pemerintah Provinsi Jawa Barat 2019) (see Table 4.5). The regional regulation was a derivative of the Mental Health Act No. 18 of 2014, which was enacted in response to specific conditions in the province. Many provisions in this regulation, such as the definition and management of Pasung, followed the Mental Health Act.

Table 4-5: Chapters and Articles Relevant to Pasung in West Java Provincial Regulation on Mental Health Service No. 5 of 2018

Chapter	Article
Chapter 1: General Terms	Article 1, verse 13 **Pasung, as described in this local legislation, might include different forms of mechanical or non-mechanical confinement that isolate individuals from the community, as well as other types of coercion, which include making it difficult for them to obtain health care**
Chapter 2: Mental Health Services	Article 4 Preventive, promotive, curative, and rehabilitative mental health services are provided in a comprehensive, integrated, and long-term manner Article 5 This provision serves as a model for all districts and cities in developing policies and implementing mental health services Article 10 **The mental health programme is carried out by reducing stigma, myths, discrimination, violations of human rights for People with Mental Problems (ODMK), who are individuals who are at risk of developing mental illness, and People with Mental illness (ODGJ), and treating them as part of the family and community**
Chapter V	Article 20.3 People with mental illnesses who endanger their own or others' safety, or who violate public order and security, are obligated to seek treatment and care in a health care facility. Security personnel might be ordered by health workers, and emergency treatment can be administered if needed Article 20.2 Consent for the hospitalisation of an aggressive patient might be acquired from the patient's spouse, parent, children, or other relative above the age of 17, or an authorised authority as defined by this legislation
Chapter VI: Organisation	**Article 72** **The provincial government and district/city governments manage street psychotics or psychotic homeless people and shackle victims through a rapid response team that includes at least elements of the regional apparatus that manage and control affairs in the fields of health, social, population, and civil records, manpower, and maintenance of public and community peace, non-government organisations, and other related elements**

Current data on the number of Pasung, many regions declared free from Pasung, are speculative. Every analysis needs to begin with a locally grounded case study because there is no reliable centralised data monitoring method for tracking Free Pasung Programme development. Hence, in

this policy analysis, we have also included the West Java local context to measure the implementation of the policy at the grassroots level.

Although West Java had many of the building blocks outlined in the 2017 national rule, such as some primary, secondary, tertiary, and outreach care, there were many gaps in the delivery of essential services. Civil society and other unconnected government activities covered some of these gaps; for example, the presence of community health advocates, despite the fact that some of them did not have the required mental health training and were only dealing with neonates, mothers, and the elderly in minor situations. The West Java health district stated that primary care mental health programmes were in operation, but in fact, the MoH contradicted this by stating that only 20% of these primary health care programmes provided mental health services. The most accessible primary care clinics, on the other hand, lacked mental health expertise; Puskesmas mental health nurses performed the best they could with limited resources and training, including limited medications and referral routes that were plagued by access concerns. Because of their remoteness, limited hours of operation, and the absence of emergency services, psychiatric and psychological clinics were inaccessible. A tertiary hospital was dispatched to the bulk of serious and emergency patients. Despite West Java being the first province to pass provincial mental health legislation, some of the provisions of the regulation could not be applied immediately as they required gubernatorial regulation (regulation at the provincial level) indicated in Articles 86 and 87. For example, it is still unclear how stakeholder cooperation or district-provincial cooperation worked.

Actors: During this time, the Ministry of Health did not act alone. Many other stakeholders were involved, including the Ministry of Law and Human Rights, which was in charge of regulating and enforcing human rights, the Ministry of Social Affairs, which was responsible for administering and enforcing disability rights, and the Ministry of Finance, which was in charge of funding the mental health services sector. Psychiatric hospitals, particularly those owned by the government, did not serve as the baseline for mental health care; rather, public hospitals were mandated to provide such care. Community health centres were also responsible for delivering primary care services, including early detection and treatment of acute conditions. The public was encouraged to get involved, whether through mental health groups, volunteering, or serving as drug compliance supervisors. With the support of mental health services and other institutions, the family, schools, the workplace, and the community took on this burden. While the family's responsibility to safeguard people with mental health issues remained, the person's autonomy to make medical decisions without being influenced by both their health care professional and their caregiver was fading.

Process: There have undoubtedly been some improvements in particular areas and with respect to specific challenges related to Pasung during this Third Era. Compared to the previous period,

mental health problems have received more government attention in terms of policy. Despite the fact that the budget has been shrinking, consumer organisations have emerged that now cover practically all mental health issues (Irmansyah et al. 2020; Maramis, Van Tuan & Minas 2011; Pols 2006; Pols & Wibisono 2017). The Indonesian Schizophrenia Support Community (KPSI/Komunitas Peduli Skizofrenia Indonesia) and Bipolar Care Indonesia (BCI) are two such organisations, among others, that address these specific illnesses. These organisations play a crucial role in raising public awareness about mental health issues. They also advocate for better mental health legislation and improvements in the mental health treatment system (Susanti et al. 2020).

The Indonesian government is now paying greater attention to mental health issues than it had previously, with many ministries being involved. Indonesia Bebas Pasung is a priority for the Ministry of Social Welfare. A special report on mental health issues was produced by the Ministry of Law and Human Rights, which urged that the government take the lead in reforming the mental health care system. Mental health issues in the workplace are receiving attention from the Ministry of Manpower, and the National Commission on Human Rights has launched an advocacy campaign to protect the rights of people with mental illnesses. All these events aided in the passage of several policies on Pasung, such as the FPP and the Mental Health Act of 2014. The context, content, actors, and process elements within the Third Era are summarised in Figure 4.3.

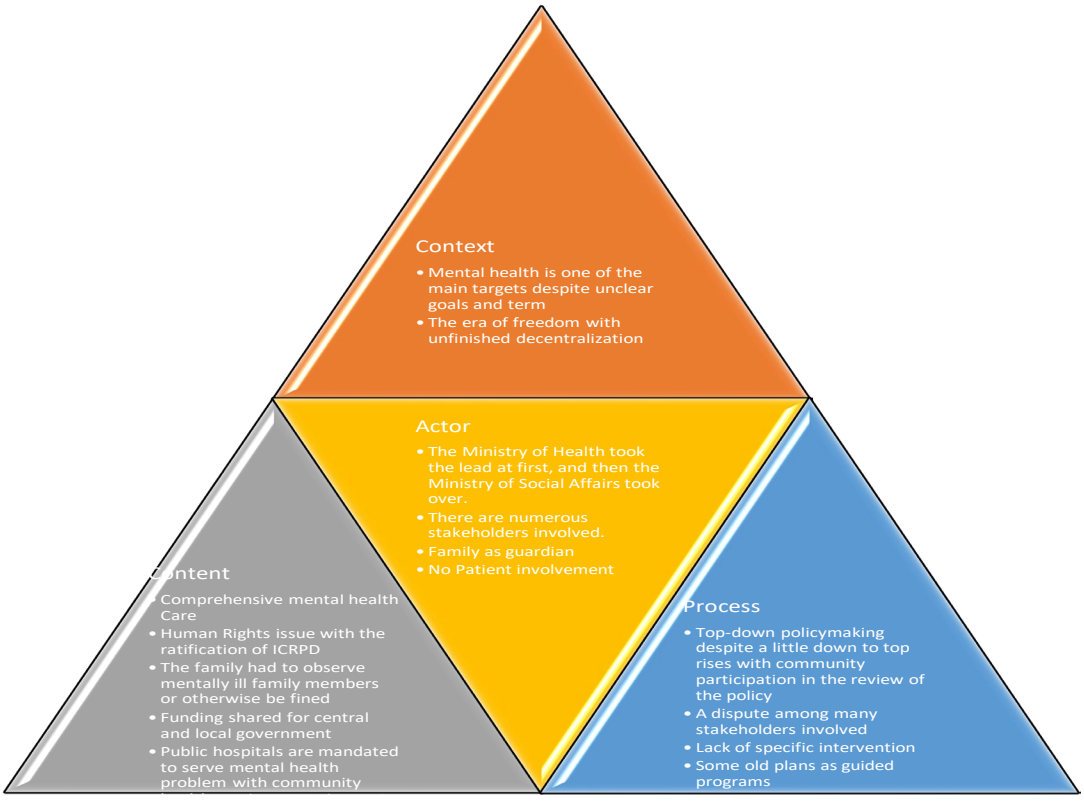


Figure 4-3: Health Policy Analysis on Pasung in the Third Era of Indonesia 1999-present

4.4 Discussion

The objective of this policy analysis has been to examine policies related to Pasung over time in Indonesia. The analysis has focused on four essential areas: the content of the policies, the people involved in policy change, the methods for designing and implementing change, and the context of the policies.

In Indonesia's First Era, neither Pasung nor mental health policies were implemented in the nation's mental health system. This was due to a number of causes, including war (Neelakantan 2013; Pauker 1980), the scarcity of human resources, and the revival of both endemic and epidemic diseases (Neelakantan 2013). Furthermore, the Penal Codes enacted a year after the proclamation of Indonesia in 1946 requiring the family to keep the person with mental illness at home or to accompany them all the time, introduced another layer of difficulty, as the family was obliged to take on these responsibilities. As a result, many people experiencing mental illness were neglected and denied medical treatment and imprisoned in their communities (Pols & Wibisono 2017).

The MoH reformed mental health treatment according to American standards during the second era, resulting in the construction of numerous transit homes, agricultural settlements, and a separate psychiatric institution, notably in Java (Pols 2006). However, the medicalisation of mental health issues tended to ignore the person's subjective experience of the condition in favour of delivering accessible mental health care within a complicated health system and biomedical paradigm (see Mental Health Act 1966, Article 1). Due to the country's inadequate health services, people in remote locations still had only limited access to care (Pols & Wibisono 2017; Porath 2008).

In 1977 (MoHA 1999), Pasung policy was first introduced into legislation in the form of a Ministerial Letter from the MoHA sent to all governors, urging them to stop using Pasung, and instead, to deliver mentally-ill people to a psychiatric hospital. This letter was in accordance with Article 6 of the Mental Health Act 3 of 1966 (MoLH 1966) which legislated that people with mental illnesses should be treated and medicated in a treatment facility. The increase in the number of people attending psychiatric institutions represented the local community’s greater participation in this method of treatment. However, this resulted in hospitals becoming overcrowded, prompting many families to keep their relatives at home. Significant human rights violations occurred as a result of this situation, with people with serious mental illnesses and people with psychosocial disabilities subject to Pasung, arbitrary and prolonged hospital detention, and involuntary treatment both in the community and in the hospitals (Pols & Wibisono 2017; Porath 2008; Setyonegoro 1978). Despite the introduction of a law in this period making it illegal to shackle a mentally-ill individual, the practice persisted.

In the Third Era, the Indonesian government has become increasingly aware of the need to address mental health issues. The Indonesian government has enacted health-related legislation, such as Health Law Number No. 36 of 2009, the FPP initiatives of 2010, and the Mental Health Act No. 18 of 2014 which dealt with mental health. Policies concentrating on disadvantage and social exclusion have come from a renewed resolve to address the links between poverty, unemployment, and mental illness during this period. For this issue, the government passed the Law on Indonesia Social Security Scheme No. 40 of 2004 and the Law on Social Security Agency No. 24 of 2011 which started the transition from voluntary to mandatory social schemes to support funding for health and mental health. This new insurance scheme enables people with mental illness to get treatment at mental hospitals or other health services. This new policy would directly affect the eradication of Pasung, as financial problems are one of the barriers to getting mental health services. Internationally, there was also a global policy shift from MDGs (2000-2015) to SDGs (2015-2030). In the MDGs, mental health was not specifically mentioned, but in the SDGs, there are some Articles (goals) that specifically mention mental health (Patel et al. 2018).

People with mental health problems who are neglected, homeless, and considered at high risk of harming themselves or others are obliged to get treatment and care in health care institutions in this era. In 2010, the MoH became the leader of the FPP, which had previously been overseen by the MoHA, three decades after the prohibition on Pasung was enacted. This was then followed by the enactment of The National Mental Health Act of 2014 (MoH 2014) which reaffirmed that any aggression against a person with a mental health condition, including Pasung, was deemed criminal, although the absent of law enforcement particularly to give punishment to those conducted Pasung created another barrier in eradication of Pasung practise This Act also served as a foundation for the creation of a comprehensive mental health system centred mostly on institutions.

Despite this progress, mental health difficulties have been inextricably tied to Indonesia's difficulty in implementing health programmes. Comprehensive mental health, which includes prevention, cure, promotion, early intervention, and rehabilitation cannot be implemented unless a government regulation is adopted under this legislation. In addition, the Mental Health Act of 2014 (MoH 2014) requires at least five government regulations, one presidential regulation, and three ministerial regulations to be properly implemented. These elements constitute a significant hurdle as developing the regulation is a time-consuming procedure that involves dealing with various parties' interests.

The MoH then issued two new policies to implement comprehensive mental health services. First, in 2016, the MoH introduced a new policy called “Healthy Indonesia Programme through Family Approach” (PIS-PK). Through this programme, Primary Health Centres would visit all families in their coverage area to assess 12 health indicators in each family, with one of the indicators being

how family members with mental illness were treated. People with mental illness (including Pasung cases) would then be identified and receive treatment. Secondly, MoH regulation No. 4 of 2019 on Minimum Services on Health, mandated that the district government should treat all people with mental illness appropriately. These two new policies are important tools to combat Pasung, even though their success has not yet been evaluated.

Furthermore, the FPP was conducted without any detailed instructions until the Health Ministerial Decree on Stop Pasung No. 54 of 2017 (MoH 2017), which was issued over seven years after the programme started. In my experience, the lack of detailed guidance causes health workers at the grassroots to feel perplexed about how to implement the FPP. Due to the large number of stakeholders involved, each actor has a different interpretation of how to manage Pasung depending on their organisation's interests. For example, a PIP who has a physical disease that should be treated in a general hospital before being admitted to a psychiatric institution frequently goes untreated and is left in Pasung because no stakeholder can holistically manage these comorbid conditions.

Collaboration in health care is a multifaceted process that brings together two or more people, sometimes from different professional disciplines, to work towards common goals and objectives (Fewster-Thuente & Velsor-Friedrich 2008; Reeves et al. 2017). Health care providers and patients alike benefit from interdisciplinary teamwork. The level of collaboration among providers can have a direct impact on patient outcomes (Godolphin 2009; Reeves et al. 2017). There are a number of reasons why this type of collaboration appears to be failing to eliminate Pasung. First and foremost are the job descriptions of all stakeholders. Another major element is that since the introduction of the FPP implementation in 2010, there has been no technical policy or instruction that has formalised the role of each stakeholder.

This situation is exacerbated by the incomplete decentralisation of health care policy-making and service delivery, particularly at the primary level. Ideally, as mandated by Ministerial Decree No. 4 of 2019, provinces and municipal governments develop their own plans and programmes to respond to specific local issues in accordance with national policy objectives, strategies, and priorities (Ayuningtyas et al. 2018; Rakmawati, Hinchcliff & Pardosi 2019). In practice, as in many developing countries, local governments struggle with unclear direction of change, as well as the dual dilemma of dealing with both finance problems (Rakmawati, Hinchcliff & Pardosi 2019) and pre-existing chronic problems that necessitate more resources (Patmisari 2014; Rakmawati, Hinchcliff & Pardosi 2019). It has been identified that an ongoing lack of awareness, low prioritisation, and lack of commitment by stakeholders are major impediments to the development of mental health services (Aspinall 2014b; Ayuningtyas et al. 2018; Maramis, Van Tuan & Minas 2011; Patmisari 2014; Rakmawati, Hinchcliff & Pardosi 2019).

It is also possible that policy-makers have overlooked international obligations and lessons learned from successful policy-making in comparable regional countries, resulting in disparities in target-setting, implementation mechanisms, and evaluation. A successful example is China, which implemented 686 programmes to scale up nationwide basic mental health services with the goal of improving access to evidence-based care and promoting human rights for people with severe mental illness. The programme ‘unlocked’ and provided continuous mental health care to people with severe mental disorders who were found in restraints and largely untreated in their family home (Guan et al. 2015). Of note is that the programme has developed an increasingly clear model of services that move mental health care out of the institution-based mental hospitals and into community settings, connecting provincial and district hospitals to primary-level health clinics that provide community outreach services. Rather than relying on older models for providing mental health services in primary care settings, which rely on training primary care doctors and nurses to recognise and respond to a subset of people suffering from mental illnesses who appear in their clinics, as has been implemented in Indonesia, the programme builds multifunctional teams and sends them into the community, which represents a greater commitment of resources. The programme also shifts its paradigm from medication only to a more comprehensive approach with rehabilitation and prevention as the core (Good & Good 2012; Guan et al. 2015).

Despite the Indonesian government claiming that the FPP has successfully reduced the number of Pasung cases from 18,880 in 2017 to 12,220 in 2018 (HRW 2018, 2020; MoH 2016a), repeated revisions of the programme (2010-2017 and 2019) have cast doubt on the actual number of people still in Pasung. In addition, in 2013, the Indonesian National Health Survey revealed that, of households identified as containing a person with mental ill-health, approximately 14.3% had someone in Pasung (MoH 2013). In a comparable survey conducted in 2018, the percentage of households with persons who were predicted to have a mental illness increased from 1.7 per mile in 2013 to 7 per mile in 2018, with 14% of households having someone in Pasung (MoH 2018) with the programme's amendment revealing that less than 9,000 people in Pasung were being treated (MoH 2016a).

The persistence of Pasung has prompted the central government to change the direction of the FPP which, at the national level, is now led jointly by the MoSA and the MoH. As both Ministries grapple with the enormity of achieving a Pasung-free Indonesia, they continue to set different deadlines. According to the MoSA, Indonesia will be Pasung-free by the end of 2019; however, according to the MoH, this will not be achieved until 2023. Aside from these differing deadlines, the MoH implemented the FPP on a more institutional basis to care for persons who had experienced Pasung, while the MoSA established community-based pilot programmes with an emphasis on social rehabilitation. The MoSA has implemented recovery-oriented practices in accordance with their 2013 Social Rehabilitation Programme Development Plan, which aimed to enable people with mental illnesses who had been incarcerated or experienced homelessness to return to their

families as participating and productive citizens, while also providing accessible support services for people in their communities (MoSA 2017; Stratford et al. 2014). The issue is that the infrastructure to undertake rehabilitation following community treatment is insufficient. In West Java, for example, there is only one such centre, which is 4-5 hours by road away from the psychiatric hospital.

Despite this discrepancy in targets, the MoH has stated that periodic provincial and community reporting on Pasung has begun, with mobile phone and social media technologies being used. At both the national and regional levels, cross-sectoral mental health teams meet on a regular basis to implement the FPP. Hundreds of Kader Jiwa (community mental health volunteers) and more than 700 general practitioners and primary health nurses have undergone mental health training and are currently working in the community. Also, 355 general practitioners and nurses from secondary-level health care have been trained. There has also been a rise in the number of provinces (10 provinces) which have allocated local funds for mental health and 20 provinces which have the FPP at the provincial level. Statistical totals derived from national surveys and projections, as well as data monitoring systems, might be inconsistent. Furthermore, because of the inclination for formally freed patients to be returned to Pasung once they are back in the community, incidents of Pasung continue to be documented in Pasung-free areas (MoH 2017).

A further issue is that, while the overall success in terms of human resource improvement is encouraging, policies and their operationalisation have lacked family involvement, even though almost every policy made includes the need for community engagement. Article 85, for example, allows communities to participate in mental health treatment by reporting any violence against persons with mental illness or if the person needs assistance. Apart from this commitment, what should a family do if an ill family member exhibits aggressive behaviour and the family's resources for treatment are limited? The family's perception of risk and safety from violence is crucial, as earlier research has demonstrated that aggressive behaviour and the family's incapacity to de-escalate it led to the use of Pasung (Buanasari, Daulima & Wardani 2018; Daulima 2018; Minas & Diatri 2008; Read, Adiibokah & Nyame 2009). As a result of caring for the person in Pasung, the family members faced stress and felt powerless, believing they had to shoulder the burden alone (Dewi, Daulima & Wardani 2019; Katuuk, Daulima & Wardani 2019; Reknoningsih, Daulima & Putri 2014). Pasung is frequently attributed to the family's failure to give adequate treatment as a result of the complex policy issues, with the expectation that the family understands how to manage people with mental illness and avoid Pasung (Irmansyah, Prasetyo & Minas 2009; Wulandari, Daulima & Wardani 2019). Furthermore, adequate policy implementation, including consumer and caregiver involvement in ongoing primary care support, has yet to take place, with little or no explanation as to how to operationalise this cooperation in the longer term. In addition to consumer and caregiver involvement, it has been determined that implementation should be aligned with improved coordination among all stakeholders, including health professionals, non-health

professionals such as those in social affairs, non-government organisations, and the public at large (Irmansyah et al. 2020; Ito, Setoya & Suzuki 2012). Overall, based on the policies identified, none of these policies give clear models for the Free Pasung Teams or guidance for safety interventions for the family who is in jeopardy when the person has relapse episodes (see Mental Health Act 1966 (MoLH 1966), Mental Health Act 2014 (MoH 2014), West Java Regional Legislation 2018 (Pemerintah Provinsi Jawa Barat 2019)).

This chapter has a number of limitations. The results cannot be extrapolated to other parts of Indonesia as West Java is a particularly well-resourced province in an area noted for its progressive mental health policies. A further limitation relates to the secondary nature of some of our data, as we did not expressly ask government officials for further details of existing policies and planned policy reforms. Our conclusions are therefore provisional, and more study is needed to corroborate our findings.

4.5 Conclusion

The effectiveness of policies targeted at releasing mentally-ill persons from Pasung was assessed in this chapter. The Mental Health Act of 2014, as well as other health regulations and the overall enhancement of mental health services, have helped to elevate mental health services, particularly Pasung, to a priority on the national health agenda. Unfortunately, more and better policies will not be enough to deliver mental health services to the entire population, especially at the community level where Pasung has tended to persist. Despite implementation efforts such as specific regulations and more operational programmes implemented by a few provincial governments in Indonesia, they are not evenly distributed and are more focused on curative and rehabilitative efforts with very minimal health prevention. To summarise, Indonesian Pasung health policies and strategies, particularly those in West Java province, lack the clarity and direction needed to implement existing evidence-based treatments ‘in place’ in the communities where they need to work directly with families to prevent the chronically high burden of Pasung. Failure to obtain continuing treatment and support, in particular at the community level, tends to contribute to despair among the actors involved in FPP. This, along with a perception of persons with mental illness as a threat to the safety and economic stability of the community, obstructs attempts to eradicate Pasung.

This chapter has provided a detailed examination of the existing cultural and policy context for understanding Pasung to set the scene for the current PhD research. The next chapter discusses the epistemological stance and research methodology, which entails social constructivism as the underpinning theory, and why the framework has been used to research Pasung.

5
EPISTEMOLOGICAL STANCE AND RESEARCH METHODOLOGY

5.1 Introduction

Previous chapters have provided a detailed examination of the existing cultural and policy context for understanding Pasung to set the scene for the current PhD research. Research methodologies that inform the research problem require a philosophical framework to provide a sophisticated understanding of the research question under investigation. Hence, this chapter details the research methodology, and its underlying theoretical epistemological stance to clearly describe and understand the practice of Pasung. This research used Interpretivism as the epistemological stance and Ethnography as the research methodology. The chapter is comprised of five main parts: 1) Interpretivism as the underpinning epistemological stance; 2) Ethnography as the research methodology; 3) Culture; 4) Reflexivity; and 5) Emic and etic perspectives. Each is discussed in turn with specific reference to the following research questions:

1. Why does Pasung continue to be practised in the Indonesian community?
2. What is the nature of Pasung as practised by families and communities in Indonesia?
3. How is Pasung perceived and experienced from the perspective of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers?
4. What are current understandings regarding the FPP's implementation, its effectiveness, and how it is practised?
5. How have Indonesia's policies on FPP and mental health influenced Indonesia's efforts to eliminate Pasung?
6. What are suggested methods and strategies to reduce Pasung across the multiple levels of the SEM?

5.2 Interpretivism as the Underpinning Epistemological Stance

5.2.1 Interpretivism and Positivism

Research is underpinned by a philosophical view about what constitutes valid enquiry and whether the research methodology is appropriate to answer the research inquiry (Grbich 2007). However, an explanation of the fundamentally different philosophies and the rigour with which they are applied in qualitative research is debatable (Atkinson & Hammersley 2007; Creswell 2018; Crossan 2003; Denzin & Lincoln 2011; Eriksson & Kovalainen 2015). Many scholars have different views on the categories, classification, and meaning of the research philosophy. The multiple and alternative views of philosophical thinking create particular questions for the researcher,

particularly the higher degree student at the beginning of their research journey (Mkansi & Acheampong 2012).

Despite its complexity, determining the research philosophy for a research project is paramount as this influences the study methodology and methods to be used. In simple terms, philosophy deals with how data should be gathered, analysed, and interpreted (Creswell & Poth 2016; Denzin & Lincoln 2011). This research used Interpretivism to understand the practice of Pasung based on the assumption that Pasung is a social reality that does not exist in isolation from its social context; rather, it is constructed by the experience of the actors involved and the cultural context (ontology). This view is supported by the fact that the interpretation of the data emerges from mutual cultural interaction among participants as its epistemology. The above assumption is backed by the theoretical lenses that the interpretive researcher sees the social reality as being immersed within the social setting where the culture lies (Creswell & Poth 2016; Denzin 2013). Hence, interpretivism is an appropriate paradigm for this research. I underline constructivism and interpretivism here as having a similar meaning as stated by a number of theorists (Charmaz 2006; Grbich 2007; Schwandt 2014) who claim that constructivism as an epistemological term is interchangeable with interpretivism. This stance posits that people's behaviour is complex, and a person may respond in different ways depending on their culture, content, and context. An examination of Pasung as a complex social and cultural issue appears to fit well within an interpretivist approach.

In contrast to interpretivism, positivist philosophical ideas propose that observation and reason are valid and reliable ways to understand human behaviour (Creswell 2018; Denzin & Lincoln 2011; Grbich 2007). In addition, this philosophical stance argues that valid information is based on experience and can be obtained by observation and testing phenomena. At an ontological level, positivists expect that reality is equitably given and is measurable by using tools that are independent and valid. In other words, information is objective and quantifiable (Flick 2013). Furthermore, positivists embrace logical methods and systematise the information process with statistics to provide precise parameters and their relationships. Positivism seeks to learn the truth through scientific inquiry and empirical observation (Denzin & Lincoln 2011; Grbich 2007).

Despite the dominance of positivism and the fact that much scientific practice has been produced from this paradigm, there has also been significant criticism. An alternate viewpoint contends that science is limited in its ability to address all of the issues affecting people(Taylor 2016). While positivism assumes that the world simply exists and is therefore separate from the will of the actor, an interpretivist epistemological worldview proposes that the actor plays a role in how their world is constructed (Crossan 2003; Denzin 1999; Grbich 2007). Since the 1970s, there has been a revival of interest in interpretivism, but with exacting methods to ensure the trustworthiness of interpretive

inferences, due to the inability of many positivist approaches to produce sufficient insight or new information about complex social problems (O'Reilly 2009a).

5.2.2 The implications of Interpretivism for Mental Health Treatment

The human sciences are riven by the conflict between positivistic and interpretive-phenomenological approaches (Bernard & Gravlee 2015). This conflict is reflected in medical research, including mental health research, which is primarily concerned with the positivist view informed by practical study of the field of health care delivery (Aho 2008; Rose, N 2007). The view that a biological process underlies all mental illness dominates psychiatric treatment approaches and remains a significant issue (Ahn, Proctor & Flanagan 2009; Bentall 2009; Lebowitz & Appelbaum 2019). This is supported by the fact that, often, only biological treatment is being implemented, and other therapies including those that attempt to support the person to manage behaviours, emotions, and their social circumstances are often ignored or used very little in practice. For example, Nesse (2017) argued that the advancement of behavioural theory has not fully impacted psychiatric treatment, which focuses on physical illness and tends to neglect behavioural and/or social conditions.

This focus on biomedical understandings of mental health has contributed to a disproportionate amount of mental health research being situated within a narrow scope that has been medicalised; that is, viewed predominantly through an ‘illness’ lens and requiring treatment by medical experts with a much lesser focus on the lived experience perspective (Rose, N 2007). Aho (2008) argued that, since the development of the pharmaceutical industry, there has been greater emphasis on the medicalisation of emotional disturbances as a mental illness which requires primarily psychiatric medication. Clark (2014) added that framing mental illness as a purely biological disease has led to the false perception that only medical treatment is effective in psychiatric treatment, but in the absence of any broader context in which the person is situated. As a result, the development of non-pharmacological therapies has been relatively limited (Ahn, Proctor & Flanagan 2009; Patel et al. 2018). Hence, the mental health practitioner has historically viewed the patient as a passive person, which means receiving but not being an active participant in their treatment and care (Ahn, Proctor & Flanagan 2009; Clark 2014).

Furthermore, Alderson (1998) has argued that many practitioners believe that practical research, understood to have a direct impact on patient clinical outcomes, is more useful than interpretivism, which has the potential to produce a more theoretical understanding of the underlying nature and causes of issues. The nature of how the current medical model of care is delivered serves to reinforce this view, in that the clinician often needs a quick assessment to determine the patient’s condition, to diagnose and deliver an intervention, and then move onto the care of other patients (Ahn, Proctor & Flanagan 2009; Bains 2005; Barbour et al. 2013; Guinart, Kane & Correll 2019). Clinical outcomes and fast responses to the needs of the PWMI are important. However, humans

are complex organisms, hence understanding the needs of someone with a mental illness is not as straightforward as diagnosing and treating mental illness in a biological way. Indeed, Lindsay and Norman (2013) have argued that a human is not a single organism, but a complex entity that cannot be separated from its function and social context.

Furthermore, Patel et al. (2018) identified an additional problem in the binary system of diagnosis for mental disorders, which enables diagnoses to be applied using somewhat straightforward clinical criteria. Yet this system is doubtful as a means to understanding mental disorders and their effective treatment in a holistic way and using psychosocial and other approaches, beyond medication, that may reduce the impact of mental disorders on a person's everyday life and experience. Rosenhan's experiment in 1973 (Fontaine 2013; Rosenhan 1973), in which people on the research team feigned mental illness symptomology to gain hospital admission and then acted normally once admitted, revealed that clinicians continued to see all of their behaviours (such as making notes and now claiming that they were well) through the lens of mental illness and labelled them as mentally-ill, despite them exhibiting no symptoms during their admission. Although Rosenhan's research has been heavily criticised, especially by the followers of biological theory, it illustrates that mental disorders are complex, diagnosis and treatment are potentially subjective, and that social and cultural research related to mental disorders is therefore very important (Fontaine 2013).

5.3 Biopsychosocial Perspectives and The Construction Of Pasung

As discussed above, mental health research situated within a medical model is underpinned by positivism which sees the world in terms of cause and effect and tries to prove this relationship. This view influences many mental health practitioners (Ahn, Proctor & Flanagan 2009; Aho 2008; Barbour et al. 2013). However, the rise of transcultural psychiatry and social theory in mental health research is situated within social constructivism, which believes there is no single cause or theory (Adler & Adler 2008; Guinart, Kane & Correll 2019).

> Psychiatry is arguably the medical specialty most sensitive to cultural influences. An individual's experience, expression, assessment, and regulation of feelings, thoughts, and behaviors are shaped by culture. Since mental health issues are particularly vulnerable to stigmatization, the expression of such issues and their evaluation by others can vary significantly. Culture creates a framework for the assessment of emotional, cognitive, and behavioral expressions and for the thresholds of disease and disorder ... (Guinart, Kane & Correll 2019, p. 2167).

From a constructivist perspective, social reality, the existence of the world, is constituted in and through human interpretation. This includes accepting that the 'truth' of social reality is not that which lies out there waiting to be revealed. Rather, it is the construction of social work by humans who experience and apprehend the world through subjective and interpretive activity (LeCompte

2002, 2010). Therefore, social reality is a matter of human perception, which humans use to construct and make sense of such experiences (Dodgson 2019).

Madison (2005) claimed that knowledge is not always factual or something present where a human can see it, but something that is perceived based on experience and as part of human learning. Consequently, the perceptual accounts of individuals and groups are in a dynamic state of change and instability, and thus, knowledge is not static. Individualised, socially and historically specific constructions describe and contribute to a rich, complex, and substantive picture of social reality and human interaction. Greifeneder, Bless and Fiedler (2017) define social reality as a product of thought or mind, which is perceived by a society that constructs culture and belief systems. Truths are actually multiple versions of social subjects' perceptions and understandings of their lived experiences of the world. Reality becomes an interpretation of various definitional options, as realities are dependent on how individuals and groups constitute the meanings of their own experiences of everyday reality. Eveland et al. (2008) added that social actors use signs, symbols, and social structures to make sense of their experiences. Interpretations of their life experiences are communicated in various modes of language (verbal, visual, and others).

As an individual who is socially, culturally, and clinically situated in a person's social life in Pasung, perceptual enactment of reality is grounded on particular lived experiences and understandings of the existence of Pasung itself. Hence, undertaking research on how the Indonesian community conducts Pasung, based on information obtained directly from participants through ethnographic research and presented using the participants' and researcher's perspectives, can develop an understanding of Pasung. As Flick (2002 p.2) claims, "… the periods of big narratives and theories is over: locally, temporally and situationally limited narratives are now required …". Given the fact that Pasung is experienced and perceived by a multitude of social beings engaging in it, a common reality can be constituted and symbolised in varying ways, manners, and modes. No definitive true or false judgement is to be imposed on these distinct conceptions of reality; each of them is seen as equally meaningful and constitutive of the complexity and plurality of human life and human interaction. Moreover, as the construction of the lived experiences of individuals and groups where Pasung exists is not fixed, but is instead impermanent, dynamic, and progressive, it is subject to the changing of specific social-historical or cultural contexts (Bentall 2009; Fontaine 2013). Having discussed and situated the thesis within an interpretivist epistemology, the next section details the ethnographic methodology adopted to examine the nature of Pasung.

5.4 Ethnography

5.4.1 Definition

Defining ethnography is somewhat troublesome as there are different angles and views in seeing and understanding this methodology (Atkinson & Hammersley 2007; Gobo 2008). As a social research method, the definition of ethnography has often overlapped with other methods such as

interpretive, case study, and fieldwork methods. Atkinson and Hammersley (2007) explained further that “there is no sharp distinction even between ethnography and the study of individual life histories …” (Atkinson & Hammersley 2007, p. 1). However, ethnography is often labelled as interpretivism as it aims to understand how humans act in their daily lives and in the context of culture (O'Reilly 2009a).

Ethnography is a qualitative design of inquiry to identify collective experience based on culture and social interaction within the community. Ethnography originated as a branch of anthropology and is used to describe, explain, and analyse a society or ethnic group (Atkinson & Hammersley 2007; Denzin & Lincoln 2011). As a method of inquiry often found in social research, ethnography focuses its activity on developing a detailed description of an aspect of ways of behaving and ways of thinking that have been enculturated into the person or community or culture being studied. The ways of behaving and ways of thinking are expressed, for example, in the form of writing, photographs, pictures, or films. As understood here, culture is everything related to society's behaviours, thoughts, and beliefs (Denzin & Lincoln 2011). What is described and observed can be in the form of language, livelihoods, technological systems, social organisation, arts, knowledge systems, language, and religion. To understand these cultural elements, the ethnographer usually stays with the people for a sufficient amount of time to interview, observe, and collect documents about the objects under study (Atkinson & Hammersley 2007). Data about these ways of behaving and ways of thinking are often collected using multimedia, for example, as field notes and images.

5.4.2 The Evolution of Ethnography

Before ethnography evolved into a dedicated methodology in its own right, it was historically seen as an addition to ‘ethnology’, which is the comparative study of Western and Non-western cultures (Atkinson & Hammersley 2007). In the late 19th century, the term ethnology was seen as insufficient, as many social anthropologists at the time began to use fieldwork in data mining. Fieldwork was conducted to gain primary data rather than just to inform theory. By conducting fieldwork, these early ethnographers revealed more informative and relevant data as they were immersed directly in the culture being observed. In addition, fieldwork also aimed to minimise the propensity of many theorists up to that time to impose their own beliefs and cultural biases on what they were observing, particularly as part of colonialism in which many people from across Europe settled in many lands with cultures that were different to their own (Atkinson & Hammersley 2007).

By the end of the 19th century, anthropologists such as Franz Boas began to recognise and argue that a combination of first- and second-hand data described the culture and beliefs in more comprehensive ways compared to a partial analysis based predominantly on theory and developed within a Western cultural lens (Atkinson & Hammersley 2007; LeCompte 2010). The framework for society's evolution and culture compiled by previous theorists was now seen as unrealistic, and not supported by real evidence. Boas was particularly concerned with the then-popular evolutionary

ideology that saw some races as more primitive, and Western culture as the most advanced. He introduced the idea of cultural relativism, arguing that all humans see and understand the world through the lens of their own culture (McGee & Warms 2013; Moore, JD 2009).

Furthermore, Bronislaw Malinowski shifted ethnographic understanding from only the emic to the emic and etic perspectives using the participants' view (Denzin 2000; Denzin & Lincoln 2011). From this perspective, participants became active subjects rather than passive objects. A discussion of the emic and etic positions is provided later in this chapter. Abu-Lughod (2000) echoed that participant observation creates an immersion vital to represent culture as harmonious rather than as alien. From this new thought, there emerged the view that an anthropologist must see for themself the group of people that is the object of study if they are to develop more reliable theories and knowledge about the cultural groups being researched. This was the origin of fieldwork in anthropology (Denzin & Lincoln 2011; Naidoo 2012). Since then, fieldwork has become the trademark of ethnography (Atkinson & Hammersley 2007).

As fieldwork became a critical element in ethnography, many researchers spent long periods in the setting to observe and immerse themselves in the observed community. This included fieldworkers such as Boas in North America, Alfred Haddon in Oceania, and Malinowski, who are regarded as the founders of modern anthropology (Denzin & Lincoln 2011; Helm 2001; McGee & Warms 2013; Moore, JD 2009). Both Boas and Malinowski believed that collecting data without fieldwork was fruitless (Helm 2001; Moore, JD 2009). The use of first-hand data in ethnography also aimed to increase the trustworthiness of the findings rather than trying to fully eradicate bias, which would be pointless. In other instances, proving this may include providing evidence that the researcher fully internalized the participants' experiences in order to accurately portray and interpret them. In other cases, this can include combining the findings of two or more investigators or data sources. Even though there was a shift from secondary to primary data, ethnography was still seen as subversive to a positivist concept. Positivists deemed that ethnography was an inaccurate method, arguing that it lacked rigour (Barbour, JD 2007; Coffey et al. 2004). In contrast, ethnographers have argued that the scientific approach fails to explore many phenomena beyond proving hypotheses (Atkinson & Hammersley 2007; Reeves, Kuper & Hodges 2008).

The ethnographic method illustrates the reality recorded in a community and systematically compiles a description of the community's culture (Helm 2001; LeCompte 2002). The main aim is to provide meaning for the culture under study. A more detailed discussion of the importance of culture within ethnography is provided in the next section of this chapter.

The strength of ethnography also lies in the use of more than one method of data collection (Reeves, Kuper & Hodges 2008); this flexibility allows for change as the research continues over time and produces a thick description for the ethnography. The term "thick description," which was first used by anthropological Clifford Geertz, describes how ethnographers interpret social

practices, symbols, meanings, and actions within a specific cultural group or society in a rich, contextualized, and detailed manner. Thick description explores the deeper levels of meaning and comprehension rather than merely restating the obvious (Geertz 1973b, 1988).The process involves the collection of data via field notes, journals, audiovisual material, and cultural artefacts, and the analysis of this data using codes and references (FitzGerald 2012; Flick 2013; Pink 2001; Silverman 2015). The study is then strengthened by triangulation and analysis, using such techniques as individual and group interviews and informal dialogue (Flick 2013; Silverman 2015).

This more thorough and broader shift brought ethnography into more fields and institutions such as psychiatry, nursing, social work, education, and more in the early 1960s (Creswell 2018; De Chesnay & Abrums 2015; DeVault 2006). For example, Erving Goffman's research, "Asylums: Essays on the Social Situation of Mental Patients and Other Inmates" is recognised as a critique of the biological model and a call for more humane treatment (Adlam et al. 2013). In the late 20th century, ethnography spread even further including to disciplines such as psychology and geography. The use of ethnography in broadening disciplines brought greater benefits as the methods began to be recognised as rigorous for understanding complex cultural situations. In contrast, the spread and broadening of application in many disciplines brought added consequences as ethnography was not well defined. This refers to many researchers having different philosophical orientations on ethnography and defining ethnography in varying ways (Atkinson & Hammersley 2007). Van Maanen (2011) added that the form of ethnography changes what is represented in the field and the methods largely depend on the quality of their application and how the results are interpreted. Therefore, deciding what type of ethnography will be used prior to conducting the research is essential (Atkinson & Hammersley 2007; Denzin & Lincoln 2011).

This study uses ethnography to examine social and cultural understandings of Pasung. This approach seeks to explain the participants' cultural situation based on information obtained directly from participants through participatory research and presented using a participant and researcher view, as described earlier in the chapter. This approach was taken in this PhD research, considering that PIPs depend on their families and community completely for their daily living needs. In addition, this method was chosen because Pasung is a largely hidden problem involving a stigmatised group. Therefore, it requires going directly to the source and setting to understand the circumstances in which Pasung exists. Lastly, the research involved exploring the practice of Pasung from the perspective of observers and participants (lived experiences, carers, communities, health professionals, non-health professionals, policy-makers and health system managers, and community health administrators) involved in freeing people from Pasung, including their customs and beliefs. Finally, direct feedback from those being studied could be sought on the conclusions and interpretations formed through the conduct of the research. Participant ethnography also involves the collection of data in multiple ways for triangulation over an extended

period of time with observation, in-depth interviews, examination of artifacts located within the research environment, and archival materials (De Chesnay & Abrums 2015; Garnett, Reynolds & Milton 2018; LeCompte 2010). This ability to triangulate the data from these multiple perspectives and processes was deemed essential for examining the complex and largely hidden issue of Pasung.

5.4.3 Culture

Ethnographic methods take an interpretivist position and have been systematically and continuously adapted in terms of philosophical arguments about how to understand social and cultural life (Creswell & Poth 2016; Denzin 2000; O'Reilly 2009a). Culture is an essential part of ethnography (Atkinson & Hammersley 2007; Turner 2000), and comes from the Sanskrit language buddhi (mind or intellect) which is defined as things related to the human mind and reason. In a narrow scope, culture is defined as a similar term for ethnicity (Muir-Cochrane, Barkway & Nizette 2018), but in a broader context, culture includes everything that humans can understand, including language, technology, religion, social organisation, and systems of knowledge. This knowledge is then used by people to depict experiences and construct meanings about social activities and behaviours, including rituals (Muir-Cochrane, Barkway & Nizette 2018; Spradley & McCurdy 2012). Culture has both explicit and implicit elements (tacit meanings). Geertz (1973a), for example, defined culture as a system of meanings and symbols arranged in a sense in which individuals perceive their world, express their perception, and make judgements. The symbols here are manifested in symbolic form in which people communicate, perpetuate, and develop knowledge (Geertz 1973a).

People live in a unique culture where they practice rituals and behaviours and pass these onto the next generation to preserve cultural identity (Leigh 2010b). Observing explicit cultural elements can be carried out relatively easily because participants reveal such cultural elements through their behaviours. This explicit culture is how people communicate, use language, dress and behave in specific social situations. Conversely, to understand the implicit or tacit culture, ethnographic research needs to be taken to construct meaning. This methodology deals with implicit and explicit cultural elements, which are created and understood by individuals, so data and meaning must be deduced carefully based on the participants' narrative and behaviour. Therefore, the ethnographer needs to be involved in the life of the community being studied by taking the role of participant-observer. Spradley (2016) emphasised that participation allows the researcher to directly experience activities, acquire a sense of how events unfold, and record their own interpretations.

While culture is a central part of ethnography (Atkinson & Hammersley 2007; Turner 2000), culture is also an essential part of mental health patient clinical assessment through observing patterns of behaviour including knowledge, habits, and social norms (Leigh 2010b; Patel et al. 2018). For example, in western culture, which is regarded as a major source of theories of mental illness,

individual autonomy is predominant. This means the responsibility for health care lies with the individual, whereby people may decide to enter the psychiatric hospital voluntarily without involving their family. Unlike in western culture, eastern culture (Indonesia for example) allows families and communities to make decisions about an individual's need to be hospitalised on the patient's behalf without their permission. In practice, this means the treatment decisions for a person, including PWMI, will be made by the family rather than by the person themself.

Furthermore, it is recognised that psychiatric symptoms are affected by the person's culture (Leigh 2010b; Zangeneh & Al-Krenawi 2019). This culture may include beliefs, practices, stigmas, and understandings among those involved (lived experiences, carers, the community, health professionals, non-health professionals, policy-makers and health system managers, and community health administrators). In the broader sphere, culture encompasses treatment, mental health resources, religion, the community, and family support. Health treatment including prevention and intervention is more effective if the culture is comprehensively understood (Pool & Geissler 2005). In this research, understanding the culture is important to understand the practice of Pasung. This includes the elaboration of Pasung as lived experience for PWMI, their families, and their communities. To be successful in undertaking this type of ethnographic research, the researcher must also acknowledge and reflect on the influence of their own culture and experiences which may impact how they understand what they are seeing in the field, and the meaning they make from the analysis of the research data. This need for reflexivity is discussed in the next section.

5.5 Reflexivity

Since the 1940s, there has been an increased emphasis in the research literature on studying the role of the ethnographer in the ethnographic process, with concepts such as reflection and reflexivity frequently becoming associated with ethnography (Davies 2012). Reflexivity is the process of becoming aware of oneself while conducting research, and it is a common and almost inescapable experience for ethnographers. Because the researcher is the principal research instrument, as he or she has access to the field, creates field relations, and performs and structures observations, such reflection is inherent in the process. Nonetheless, it is a common and disputed term in the social sciences, qualifying its claim to objective knowledge due to the way the researcher's personal attributes shape and influence the data gathered and, as a result, the information that emerges from it (Pels 2000).

Reflexivity generally refers to the examination of one's own beliefs, judgements, and practices during the research process and how these may influence the research. It requires openness and an acceptance that the researcher is part of the research (Finlay 2002a). Reflexivity is an iterative and reiterative process where the researcher reflects on their own beliefs, attitudes, and cultural influences as well as those that are being observed. Reflection and critical analysis are core to this

process especially in qualitative research, whereas it is regarded as a source of bias in quantitative research because of its subjectivity (Finlay 2002b; Gough 2016).

Reflexivity is a rigorous process in which:

> Researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and the universal (Berger 2015, p 220).

Practically, reflexivity is how the knowledge is produced, how to describe the experience, and how the researcher can relate the current knowledge to other knowledge that already exists. It is a continuous process undertaken by the researcher throughout the conduct of the research (Eriksson & Kovalainen 2015). Reflexivity is not merely a reflective action of the researcher about the intersection of participant and researcher, but also acts to enhance the credibility of the study findings. As ethnographic research is contextual, which means it takes place in a particular time and place, reflexivity should be clearly described (Dodgson 2019; Eriksson & Kovalainen 2015).

Creswell (2018) emphasised that ethnography presents the perspective of participants as a cultural community. Quimby (2006 p.180) described it as “the recording of a people’s way of life or aspects of their cultural reality”. Emphasis is placed on detecting and presenting participants’ perspectives and experiences. Although both Creswell and Quimby mention that the researcher’s views are de-emphasised, it does not mean they are not present. Subjectivity and reflexivity are unavoidable in ethnography and have become special characteristics in ethnography that differentiate this methodology from others.

As further articulated by Denzin and Lincoln (2011), in ethnography, the inquirer and what is under investigation are interactively linked; the researcher cannot conduct their enquiry and present their findings while suspending values, traditions, and assumptions from their daily and academic life. The researcher in this study is gendered, biographically situated, and professionally trained. Hence, the researcher inevitably brings an interpretive community to the inquiry, which encompasses particular historical research traditions and professional development. In other words, all these personal factors are incorporated into the research practice and contribute to the formation of a distinct point of view that the researcher takes when conducting their inquiry. The researcher’s individualised point of view, which is shaped by subjective factors, makes an objective observation almost impossible. Reflexivity is a way in which the researcher can lessen the divide between the emic and the etic (Oliphant & Bennett 2019), which will be discussed later in the chapter.

If, on the other hand, reflexivity is poorly practised or engaged in without critical thought, it turns the researcher's inherent voyeurism back on themselves, a narcissistic self-absorption that confuses

the object of study with the methodology (Hobbs & Wright 2006). Perhaps Hobbs and Wright (2006) were thinking of Geertz (1988, p 97) warnings about confessional writing by "the unbearably earnest" fieldworker. The use of obnoxious neologisms like ‘my story,' 'Me-search,' or 'I-witnessing,' which appears to be a gender-fluid trend, are inappropriate for academic research. Recognising that there is no 'view out of nowhere', and that the researcher is not the plot but the storyteller, is a difficult balance to strike.

In this study, for example, the researcher shared their values and interest in the research findings with their supervisors. I come from the Sundanese culture where the study was conducted. In the earlier stages of conducting the research, I therefore, made a number of assumptions about the data, given that I live and have grown up within that culture. For example, when I presented the early data, and the ideas and social context of the research in an early supervisory meeting, I mentioned that I had found very little information regarding the data. But my supervisor, who comes from a Western culture that is completely outside of the Sundanese culture, had a different shape and view of the data, asking many questions about what was observed in the video data and photos. This questioning enabled me to become more aware of the richness and nuances within the data that I had previously overlooked as part of my everyday cultural experience. Additionally, by responding to the supervisor’s questions, I was able to articulate and explain in greater detail the rich cultural context of Pasung and the environment in which it occurred, which I had hitherto taken for granted.

In summary, there is no denying that reflexivity, in the context described above, is an important aspect of ethnography. Reflexive elements can help researchers conduct more self-aware research, particularly when they are researching situations and groups in which they are involved and culturally embedded (Atkinson & Hammersley 2007; O'Reilly 2009b).

5.6 Emic and Etic

Emic and etic refer to research perspectives and strategies in observing a culture under study (Creswell 2018; Denzin 2000; Eriksson 2008). The emic is the information provided directly by the participants. Atkinson and Hammersley (2007) used the term “native point of view” which means the ethnographer observes the culture under study as an insider. This is often referred to as first-level concepts, which take the form of local language, thoughts, and ways of expression that are shared by the participants (Eriksson & Kovalainen 2015). The researcher's view is absent and no conceptual framework is used prior to the fieldwork or mining of the data (Quimby 2006).

Meanwhile, the etic refers to the researcher's interpretation of the participants' perspectives, which commonly uses an a priori theoretical framework (Atkinson & Hammersley 2007; Eriksson & Kovalainen 2015). These observations are often referred to as second-level concepts in the form of slang, idioms, and/or terminology developed by researchers to express the participants' similar

culture (Atkinson & Hammersley 2007). In an etic view, the researcher takes the position of a stranger or outsider (Atkinson & Hammersley 2007; Eriksson & Kovalainen 2015).

However, in practice, when writing the ethnography using emic or etic perspectives, it is not always balanced (Atkinson & Hammersley 2007). Watson-Gegeo (1988 p.1) argued that “ethnographic analysis is not exclusively emic. Rather, a carefully done emic analysis precedes and forms the basis for etic extensions that allow for cross-cultural or cross-setting comparisons”. Zhu and Bargiela-Chiappini (2013) saw emic and etic perspectives as being on a continuum rather than as opposed to each other. This means the analysis goes beyond the line of emic and etic as a process on a continuum.

The emic and the etic can occur at different stages during the research even though the researcher can clearly emphasise either using emic or etic (Atkinson & Hammersley 2007; Denzin & Lincoln 2011). For example, in this research, I conducted the study as an insider using emic data, given that I was part of the community mental health and research division staff who were involved in the Free Pasung Programme. The data were collected by the investigator himself (holding the camera and being present at the location). During the data collection, which was conducted during the years 2016-2019, the researcher stated the nature of their role to the participant to minimise any potential bias and to build trust. When interpreting the findings based on the participants’ views, this was reconstructed using the Socio-Ecological Model (SEM) as a framework.

I used both the emic and the etic for several reasons. Firstly, I used different types of data comprised of visual data, interviews, field notes, and medical records that cannot rely merely on the participants’ view, but instead, require the researcher's view. Secondly, Pasung is a hidden problem involving a stigmatised group, and therefore, requires both emic and etic perspectives to understand the circumstances in which Pasung exists.

This research involved an ethnographic study, informed by the theoretical lenses derived from a systematic review of the existing evidence, used as a predictive and explanatory tool. While the use of existing theory in ethnography is debatable, Cury and Bird (2016 p.201) explained that “pre-existing theory provides valuable assistance when transforming an insight about the world into an idea with explanatory and predictive potential”. In this study, the literature is presented in a different section (Chapter 3) as a systematic review, as suggested by Creswell (2018). The SEM has been used to underpin the study because of its suitability in understanding this pervasive issue at various social systems levels, and for exploring any intersections and influences across and between these levels (Kilanowski 2017).

5.7 Conclusion

This chapter introduced interpretivism as the underpinning epistemological stance for the thesis and discussed its most profound characteristics, defining this stance among other paradigms. This included the reasons for using it as a framework to research Pasung. Ethnography was then outlined as the methodological approach taken for this research as a result of the epistemological assumption that reality is constructed through interaction between the researcher and the researched, and shaped by individual experience. Hence, ethnography is an appropriate methodology to investigate practice of Pasung, considering the breadth of the problem in among limited resources in Indonesia. In the next chapter, I present other key aspects of the methods used, including interpretive ethnography, data mining, data analysis, and ethical considerations.

6
RESEARCH METHODS

This chapter outlines the research methods used to conduct the ethnography of Pasung practice in order to address the overall research questions posed in this thesis. The chapter comprises five sections. The first section provides a description of the ethnographic research methods where interpretive ethnography as a method is described in detail. The second section describes the location of, and the population involved in, the research. The third section details the three sources of data (photographs, videos, and in-depth interviews) in turn and in detail, the specific methods used to collect these data and the analysis performed with each data type as well as the plan for the triangulation of these data sources into an overall synthesis. The fourth section discusses the ethical considerations that arose as part of the conduct of the research, and how these were addressed. The final section covers the trustworthiness of the research, discussing the quality of the research and ways to reduce researcher bias. As described in Chapter 1, the term People with Mental Illness (PWMI) is used, referring to the commonly-used terms ‘patient’, ‘client’, or ‘consumer’, which are frequent terms used in the literature to refer to people who are experiencing or receiving care for mental illness. People in Pasung are referred to as PIP. The final section covers the trustworthiness of the research, discussing the quality of the research and ways to reduce researcher bias.

6.1 Interpretive Ethnography as a Method

This ethnographic research adds something specific to the study of meaning-making in Pasung: the ethnographer's access to the people's experiences in Pasung. Furthermore, ethnographers draw on their personal experiences. Because the experiences of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers are both the product of, and the reason for, their actions, ethnographers can better explain the practice of Pasung by comprehending these experiences. This chapter highlights the development of interpretive ethnography, discusses the application of ethnographic data in research, and introduces the concept of data mining.

As described earlier in Chapter 5, the choice of methods depends on how we maximise the advantages and minimise the disadvantages of each method and how we apply them to our research methodology (Atkinson & Hammersley 2007; Denzin & Lincoln 2011; Margolis & Zunjarwad 2018). This research employs interpretive ethnography rooted in interpretive philosophical thinking which poses that reality is socially constructed by the actor (Atkinson & Hammersley 2007; Creswell 2018). While traditional ethnography involves longitudinal and repeated observation in the research sites to observe and explore the culture, interpretive ethnography, in contrast, does not involve long periods of time staying within specific sites.

Moreover, it combines artefacts, pictures, videos, and digital traces to build and identify a detailed picture and understanding of the culture or cultural practices being researched (Atkinson & Hammersley 2007).

This research was conducted in a natural setting and attempted to capture the objects and interactions that occur naturally as part of the daily life of the participants and the communities in which Pasung exists. In interpretive ethnography, the researcher stands as a participant observer and not above or outside the context being observed (Atkinson & Hammersley 2007; Denzin 2013). The researcher engages in the activities, observes what is being expressed, and immerses themself within specific social contexts (Berger 2015; Denzin 2000). Data is derived from direct observation of behaviours, interviews, written opinions, and/or public documents (Shah 2017; Spradley 2016). In this research, photographs, videos, and interviews were collected as part of the participant observation and were examined in detail to understand the practice of Pasung in West Java.

Participant observation is a method commonly used in ethnographic research when collecting data, distinguishing ethnography from other methodologies (Atkinson & Hammersley 2007; Creswell & Poth 2016). In participant observation, the researcher is also a participant in the setting, gaining advantages as their position moves from one of being hidden, or being an ‘outsider’, into a clearer position within the cultural milieu (Spradley 2016). To one degree or another, participant observation is like living in two worlds, that of participation and that of research (Atkinson & Hammersley 2007). The challenge of participant observation is how to combine participation and observation, which enables the researcher to understand the culture as the insider while concurrently describing the culture to the outside (Eriksson & Kovalainen 2015; Spradley 2016).

The extent of participation depends on the culture being observed. In this study, participant observation was chosen, given that I was part of the Free Pasung Programme (FPP) team. The researcher explored the use of Pasung in the community setting, the experiences of those involved, the perceived reasons for its use, current interventions, and potential solutions. These methods were also chosen as the research was conducted in the naturalistic setting in which people lived and in which Pasung was practised, and where the ethnographer would gather information by participating actively and interacting with the participants in their own environment. In participant observation, the problem is formulated by starting with the individual experience as a point of entry, and then moving beyond this local problem, i.e., the family or concern, to explore and bring under scrutiny the social relations in which the experience is rooted (the community, the health system). This process was undertaken to enable exploration of the ‘social’ at the point of disjuncture between the actualities of those living in Pasung, and the way in which Pasung was managed either by the community or by health professionals. From the ‘point of entry’, which was the viewpoint of the people living with Pasung, the carer, and the community living nearby, the

researcher could examine how Pasung was perceived from the perspective of PWMD, family carers, mental health professionals, and community members. The research could then be broadened into how Pasung was managed in the community and what people understood about its management.

I conducted the research with a familiar cultural group – as an Indonesian researcher with a Sundanese background investigating Pasung within the Indonesian cultural context broadly and Sundanese more specifically. I was born and nurtured in the Sundanese culture where my study took place. Therefore, wherever I go, encountering Sundanese culture makes me feel ‘at home’. Also, the work I did from 2012 to 2019 when I joined the West Java community mental health team to assist those living with mental illness in the community became the basis of the research, involved in handling direct care provision to those in Pasung, and involved in the management and budgeting for the programme. I have more than 20 years of clinical experience working in the field of psychiatric nursing in a variety of settings, including emergency, in-patient, forensic, adult, child, adolescent, out-patient, and community settings. I highlighted the influence of viewing the practice of Pasung through clinical perspectives coupled with my Sundanese background, including the advantages and disadvantages, in Chapter 5 where I presented the research methodology. I also talked about how my PhD supervisors' discussions with me, who are not Sundanese but rather from Western cultural contexts, improved the study and allowed for more in-depth arguments and reflections. Hence, I needed to acknowledge my status as an insider rather than an outsider, to continually reflect on this stance and be mindful of how it might influence how I conducted the research and interpreted the findings.

6.2 Study Location

This research took place in West Java Province, in largely Sundanese culture which is the majority ethnic group in this province, as described in detail in Chapter 2. The study took place in multiple locations and at multiple levels, referring to administrative levels and health sector priorities (primary, secondary, tertiary, and community) throughout 11 cities across West Java. The reason for choosing West Java Province is that this province is the most highly populated in Indonesia and faces a range of complex mental health problems. Specifically, in West Java Province, 14% of PWMD are, or have been, subjected to Pasung one or more times, with 30% having been in Pasung in the past 3 months, in a context in which the existing primary and secondary mental health services are very limited. It is also the location where the PhD candidate works at a Psychiatric Hospital as the community research manager.

6.3 Data collection and analysis

Initially, I had intended to conduct this PhD research by collecting data prospectively in Indonesia using ethnography to directly observe and interview primary sources to obtain the data. However,

due to the COVID-19 pandemic, I was unable to return to Indonesia, and therefore, focused on using secondary data which I had already collected during my role with West Java Psychiatric Hospital (WJPH) and the Free Pasung Programme during 2016-2019. All existing data sets (videos, photographs, interviews, and field notes) had been gathered prior to the commencement of the PhD study by the investigator in West Java Province, Indonesia. Prior to the data collection, ethics approval was sought to obtain the data as part of the Chief Investigator's former role in the community mental health and research division. This was conducted to follow the ethical code of conduct in research involving human subjects in Pasung. The data has been kept in its original form, and no data has been modified, filtered (in the videos and photographs), or changed (see details in Section 6.4 of this chapter on Ethical Considerations below).

As mentioned earlier, this PhD research was conducted during the pandemic where gaining the primary data was limited. In December 2019, the world faced a global pandemic and international borders were closed (WHO 2020), not only in Australia where I was studying, but also in Indonesia where the research had initially taken place. Jakarta, West Java, and Central Java were the worst-affected provinces, accounting for more than half the total national cases (Indonesian COVID-19 Handling and National Economic Recovery Committee 2022). The resources available to combat the pandemic in Indonesia were quite poor, including human resources and health facilities, coupled with concerns about the low levels of health literacy of the population to comply with the restrictions imposed to combat the pandemic (Mahendradhata et al. 2021).

Despite the fact that the new normal was imposed in West Java in early September with the issuance of Ministerial Decree No. 47 of 2021, the programme was not fully operational, with many districts still restricted at Levels 2 and 3. Furthermore, the Indonesian border remained closed to international flights until March 2022 (MoHA 2021). With the issuance of Ministerial Decree No. 38 of 2022, West Java faced no restrictions at all, which allowed outreach programmes such as Pasung to be conducted (MoHA 2022). However, the study had only nine months left at this point, making completion extremely difficult. Hence, using the existing secondary data was the most viable option to address the questions during this difficult situation. As a result, the research was significantly changed to address the issues that arose during this challenging time. Furthermore, data collection and the ethics submission took longer than expected, delaying the entire research process. This ethnographic study used three approaches for acquiring, accessing, and generating data: interviews, observation with varying degrees of engagement, videography, photography, and field notes, which will be discussed further below.

6.3.1 Photo Analysis

6.3.1.1 Introduction

Visual images have never been used previously in Pasung research, but have been widely used in many other areas of research (Banks 2014; Flick 2013; Pink 2011a). The current research aims to

understand the practice of Pasung and how it is perceived from the perspective of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and health system managers. This research used ethnography with multiple types of data, including visual data. The collection of visual data in the form of videos and photographs was vital for exploring the practice of Pasung, as it is predominantly a hidden and stigmatised practice and is also experienced by people who may not be able to fully express their perspectives using other forms of communicating their experiences and circumstances (Asher et al. 2017; Irmansyah, Prasetyo & Minas 2009; Katuuk, Daulima & Wardani 2019).

Furthermore, Given (2008) added that visual representation plays a variety of roles in research and offers a holistic understanding of research participants. In Pasung, many participants in this research could not speak clearly in terms of expressing their experiences of Pasung. Some participants had become mute as a consequence of their experiences; therefore, visual methods were an important way to capture their experiences. Of note, however, none of the articles in the systematic review mentioned the inability to communicate as a feature of PIPs (Hidayat et al. 2020). One way to understand this practice in the community was therefore by undertaking ethnography using participatory and visual methods.

The photographs captured the practice of Pasung in a natural setting, and were taken to provide a different option that allowed the researcher to consider the social structures and circumstances in which PIPs live. I tried to capture the position of the participants in the practice of Pasung. For example, the photographs revealed that most PIPs were undernourished. This could have been a result of inadequate food or secondary infection from ‘living’ in dirty unhygienic places. Meanwhile, the textual data from the interviews and dialogues that occurred during the Free Pasung Programme team visit between the team and possible bystanders in the location often exposed a contrasting situation where families mentioned that the person had adequate nutrition and was bathed once a day. In this case, the visual data revealed something covert or hidden, that appeared to be at odds with what people said was going on, and this recognition underlines the importance of conducting a visual ethnography.

For the first aim, I intended to undertake prospective fieldwork to collect primary data, but then the COVID-19 pandemic hit the world and halted any ability to undertake travel to conduct further fieldwork. These circumstances pushed me to use secondary data collected earlier during the Free Pasung Programme conducted by the WJPH. Although this data was not intended for the thesis, but as an evaluation of the programme, it was a complete form of visual, audio, and documentary data. Secondly, this data was in unedited raw form and had not been used for any other purpose by other people, as I had personally collected it in my role as a member of the FPP team and research manager both for the WJPH and my PhD research. Thirdly, I received ethics clearance from the WJPH ethics committee to collect the data for the purposes of PhD research. In the

progress of the PhD research, in response to the constraints arising from the pandemic, this visual data became part of this ethnographic project. In this section, the production of visual images and their analysis will be described in detail.

6.3.1.2 Photography as Ethnographic Data

Photography and other visual data offer a different perspective from verbal data in qualitative research (Given 2008). There are many different views on how to deal with visual data. In this section, I refer to visual data as either a still image or photography, or a moving image or videography. They can exist as independent data that are completely separate and different from textual data, but sometimes can be a collaborative part of textual data gathering or as complementary to interview data (Banks 2014; Flick 2013; Given 2008).

More importantly, in ethnography, the contemporary use of media, pictures, and video provides a more nuanced understanding of social phenomena than just text alone. Some theorists argue that visual research stands as having its own methods, whereas Pink (2011a) and Given (2008) state that the use of all visual data should be stressed as an additional tool to gain an understanding of the overall ethnography (Given 2008; Pink 2011a). In other words, visual data is an objectified form of ethnographic knowledge. Hence, the visual ethnography position of this research is that the collection of visual images is used as an additional research tool as part of the data collection methods contributing to the overall ethnography.

Given that the visual data being analysed in this thesis were initially recorded for a different purpose, the question arises as to when a photograph or video is determined as ethnographic data. Pink (2001) suggested that the criteria for this are fluid; there is no fixed principle for a photograph, for example, to be called ethnographic data.

> … Any photograph may have ethnographic interest, significance or meanings at a particular time or for a specific reason. The meanings of photographs are arbitrary and subjective; they depend on who is looking. The same photographic image may have a variety of (perhaps conflicting) meanings invested in it at different stages of ethnographic research and representation, as it is viewed by different eyes and audiences in diverse temporal historical, spatial, and cultural contexts … (Pink 2001, p. 51).

Edwards and Morton (2009) argued that it is not a matter of images being called ethnographic data; rather, it is the researcher who instils meaning to determine the photograph as research data. Furthermore, the process of producing images as well as the experience of creating and analysing the data come together to be called ethnographic knowledge (Banks 2014; Pink 2011a). The use of visual data within ethnography preserves the interactions of the culture being studied. During analysis, this enables the researcher to view the content and analyse the meaning in its original enactment (Schwartz 1989). Pink also mentioned that the way in which photographs are presented, organised, and discussed serves as an analytical avenue without having to make a

possible intrusive request of having copies of the photos. According to Pink (2001), visual ethnography is not merely combining words used to describe the visual images (the narrative) to produce the desired result. Pairing narrative in textual form with photographs and video assists the researcher in documenting and symbolising the self-representations of the participants. Photography and videos also afford the researcher the ability to present a visual sequence of a particular chronology.

6.3.1.3 Researcher as Photographer

The use of photography, videos, or the combination of video and photographs with ethnography become the research tools of choice. There is a notion that this use of visual images for ethnographic representations may well replace other methods in many instances. However, while the advance of technology certainly has created a convenient mode for information access and storage, electronic techniques cannot completely replace other methods of conducting research (Pink 2001, 2006).

In this research, I used technology in the form of a smartphone and digital camera to produce images of PIPs and the community, including the activities of the FPP conducted by the WJPH. The reason for using the combination of two different types of visual technology tools was to provide ease and flexibility that could be matched to needs and environments as they presented themselves in the fieldwork. While the digital camera might produce sharper and better quality images than a smartphone, the latter delivered convenience in the field because it was lighter than the camera, and the battery lasted for longer before needing to be recharged. In addition, there was concern that using the digital camera might be too visible or intrusive and could become a distraction in practice. In practice, the decision to use one device over the other was based on what occurred in the field. For example, when there were enough people to provide care during the Free Pasung process with the PIP, I used a digital camera instead of a smartphone. In contrast, when a limited number of people were present during the Free Pasung process (usually when fewer members of the team were involved in visits to more distant geographically remote or mountain areas), I chose the smartphone for photo- and video-recording purposes.

There are two main ways to use photographs as research data in terms of how the photographer is positioned: either as the researcher standing separate from the action and observing the environment, or as a research participant being active in the environment while taking photographic images (Given 2008). In this research, the researcher acted as a photographer. Despite the flaws of not actively participating, the researcher as a photographer, as suggested by Given (2008), brings benefit as the researcher is then able to choose which sequence or moments need to be captured and observed in the events and activities occurring in front of them. This form of photography allows the researcher time and space to be reflexive while in the setting about what actions they were seeing involving bystanders and caregivers, and the researcher themselves.

From this, the researcher can then thoroughly examine the potential differences in actions and responses between participants based on the images being captured.

The use of various methods enabled the collection of relevant information across different angles and points of view. This contributed to generating a rich dataset and enabled a more detailed triangulation of the findings (Flick 2004; Patton 1999). Most photographs were taken concurrently with the interview process, as the FPP activity was mostly conducted in a single episode. The team went to the person's location, performed an examination, evacuated the person to the hospital, and the PIP returned to the community. Hence, all photographs were taken on the same visit as the interview and implementation of the FPP.

6.3.1.4 Analysing the Photographs

Analysing images is challenging. Silverman (2015) argued that there are difficulties in mixing observational data in the form of visual and audio data related to the complexity of analysing images and how to combine the methods with those already existing, such as interviews or text. In addition to this complexity, creating and analysing visual data itself is confusing as many methods exist for seeing and analysing photographic images. In addition, images can be interpreted in various ways by different researchers or viewers. Thus, there are many possibilities for understanding the images (Kress & Van Leeuwen 1996). More importantly, no single method has been found to be more appropriate than others for analysing visual data (Banks 2014).

Banks (2014) and Pink (2012) described many methods for analysing photographic data, and each discipline has developed its own ways of analysing this type of data. Banks (2014) supported their argument by referring to the work of Maxwell and Chmiel (2014) on discourse analysis, Hodgetts et al. (2008) on homelessness and social inclusion, Bateson and Mead (1942) on Balinese character, and the work on gender advertisement by Goffman (1979). Grbich (2007) echoed Banks' (2014) argument that emphasised flexibility as an important element in qualitative research, especially in ethnography.

Banks (2014) underlined the importance of describing the source of the image before analysing it, as "collected or created" and "found or made", which refers to the identity of the creator of the image. Similar arguments were made by Given (2008), who discussed the distinction between using participant-based representation and researcher-based representation for photography. Both Banks (2014) and Given (2008) emphasised that the source of the image here is important because this will influence how potentially different forms of analysis are then undertaken. Examples of participant-based representation or 'found' sources are photovoice and photo novella which capture the activity based on what participants felt or expressed. In contrast, examples of researcher-based representation or 'made' sources are photo analysis and photo-elicitation.

Different to the position argued by Banks (2014) and Given (2008), Emmison (2011) classified visual data into two categories: artefact (photography, movies, adverts, cartoons), and observing what people do in their daily lives. The former, photography as a cultural artefact, has been used for more than half a century (Marvasti 2004), with early examples being the research work by Bateson and Mead (1942) with Balinese photography, then Goffman (1979) with gender advertisement, and more recently by (Pink 2011a); Pink (2011b) with women and bullfighting. Most of these studies that used photographs as artefacts used content analysis as a single method, or combined content analysis using one or more other methods. Goffman (1979), for example, used semiotic and content analysis. The second category described by Emmison (2011) in which visual data is used as a tool in observation usually involves video data, for example, to examine an organisation's social interactions. The use of video to examine daily activities in natural settings will be discussed in a separate section on videography.

A third consideration in the analysis of visual data is the research strategies used. Silverman (2015) distinguished three different ways to process and analyse visual data: as quasi-experimental data; as a complement to other research data; and the visual data that stands in its own right as natural phenomena. The first two are conducted in an artificial setting in which the researcher could manipulate the conditions and the environment. The third one is visual data taken in natural settings where the researcher observes what the research participant does in their daily life. This PhD research on Pasung follows the third process: the research undertaken in a natural setting where I observed people's activities in Pasung and their environment and the management of Pasung through the FPP.

As mentioned above, there are many methods for analysing photography. Banks (2014) and Silverman (2015) suggested semiotic and content analysis as two main analysis methods for photography. Similar to Banks (2014), Grbich (2007) used content analysis to examine images, in addition to using three other types (historical, structural, and post-structural analysis) within the culture where the photographic images were taken. Instead of using typical content analysis, Grbich (2007) used ethnographic content analysis to describe the images and culture. Knoblauch and Tuma (2011a) used semiotic analysis, despite mostly using videography, Bateson and Mead (1942) used photo analysis, and (Pink 2011a) used content analysis. Pink added that visual ethnography is not a recipe that shows exactly what to do in research, but more like guidance for the researcher to develop methods suited to the observed culture. Other researchers used one or more methods of analysis; for example, Goffman (1979) used semiotic and content analysis. I used semiotic analysis and content analysis in this research, which I discuss in greater detail in Section 6.3.1.4 below. These analysis methods were also used in videography to analyse the video data collected for this study.

6.3.1.4.1 Semiotic Analysis

Semiotic analysis is the analysis of signs and symbols and their interpretation (Given 2008; Silverman 2015). Semiotic analysis looks deeper into cultural patterns as a response to textual, language, and visual data (Silverman 2015). As a research tool, semiotic analysis is relatively new, particularly in qualitative studies (Silverman 2015). Historically, this approach to thinking was founded by Zeno, a Greek philosopher, who was the first to analyse a sign's relationships. The Greeks observed natural signs such as smoke for the sign of fire or footprints for someone who was walking (Given 2008). However, during the 19th century, Pierce coined the term 'semiotic' (Hardy & Bryman 2004; Newton 1997). The Swiss linguist Saussure then applied semiotics to linguistics which he called semiology. Since then, semiotic analysis has been widely applied in other disciplines (Newton 1997).

As mentioned above, semiotic analysis involves the observation of signs and symbols. The definition of the word 'sign', according to Given (2008), is "anything [that] can stand for something" (p. 806). This does not mean that the researcher collects all signs; instead, it is the process of examining an object, how the object relates to other objects, and how these relationships assist our understanding of the researched object (Silverman 2015). Interpretation is then the determination of the meanings of signs and symbols through a complex process. Generally, a pre-existing theory is required to reveal the important aspects of the image, and thus, the interpretation (Danesi 2004, 2010).

There are two key components in the interpretive process to understand signs; the signifier and the signified. The first key component refers to physical signs, sounds, images, or letters conveying meaning in the form of a symbol, icon, or index. The latter is the personal interpretation of a signifier. The form of interpretation here could be denotative or as similar to what is written in the dictionary, connotative or explicit meaning, and myth or cultural metaphor (Bauer & Gaskell 2000; Danesi 2004). Myth is generally associated with fiction that includes gods or supernatural powers (Allen 2003); for example, if the community believes that mental illness is caused by Satan or black magic. The myth also has a general meaning of major fictional stories that have existed since ancient times (Allen 2003; Hardy & Bryman 2004). So, myth, while denoting what is fiction, also tends to refer to a story that seems to have a seemingly timeless and universal appeal and truth.

In this research, the semiotic analysis was undertaken as a series of four steps as described below.

1. I commenced by selecting the culture where I grouped the photographs from different people and regions. The key point in the first step was to align the images with the research questions that directed the research. Based on the questions, I chose which photograph was taken as data and eliminated those considered as not being linked to the questions or represented by another photograph.

2. Following the data identification, the next step was to sort the signs from the category or culture into: 1) icons, 2) symbols, and 3) index, and then into critical themes that allowed for categorisation of the signs.
3. Following this step, I analysed the themes arising from the collected signs by applying denotative, connotative, and mythical meanings to understand the practice of Pasung based on cultural trends, social rules, and particular meanings.
4. The final step was narrowing the themes to the key differentiators which allowed for a clear impression of the category or culture to be built. This was conducted by reporting of the semiotic analysis via visual and text summarisation of each key theme.

In brief, the four steps of semiotic analysis used in this research can be seen in Figure 6.1 below.

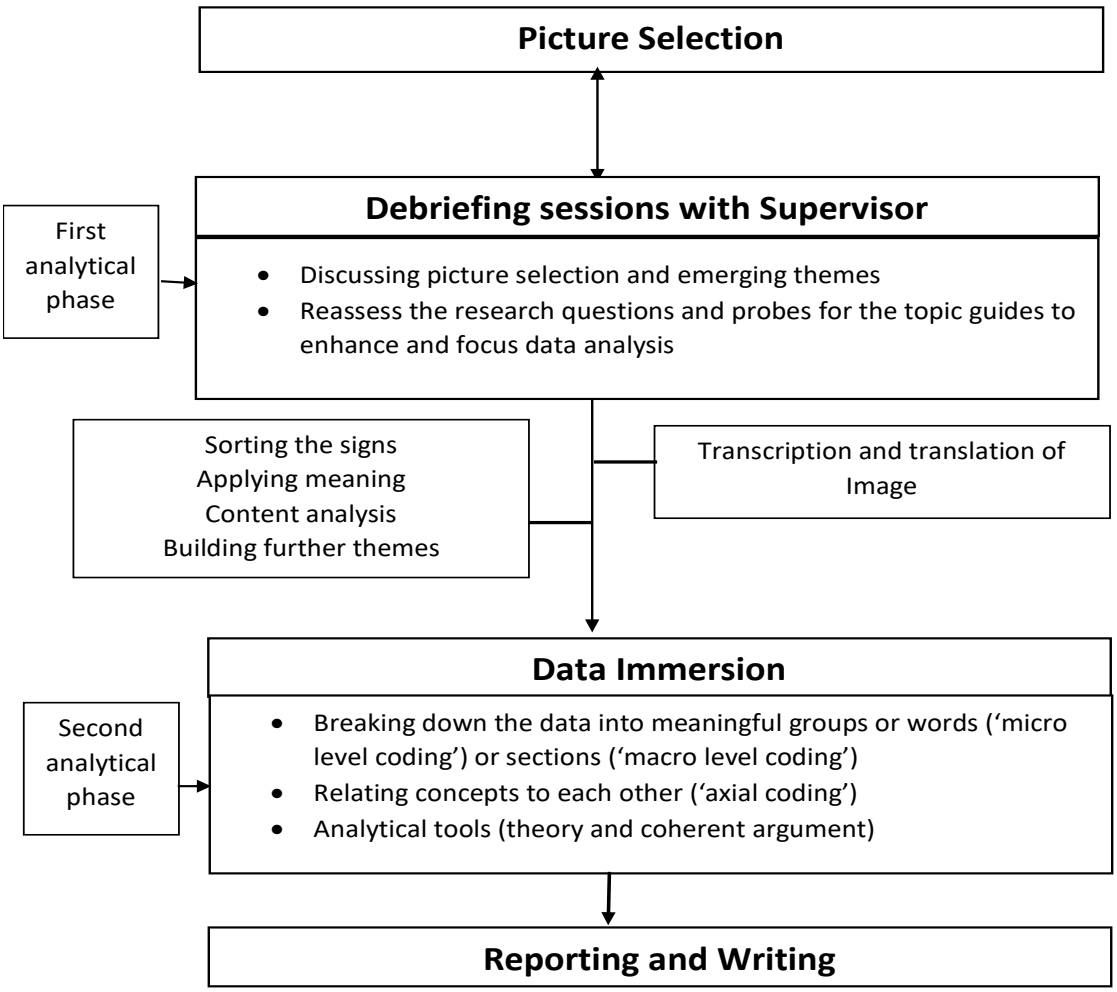


Figure 6-1: Photograph Analysis (Combining Semiotic and Content Analysis)

6.3.1.4.2 Ethnographic Content Analysis

Instead of using a typical content analysis that examines the presence, relationship, and meaning of key themes and concepts, this research used Ethnographic Content Analysis to unearth the cultural meaning of a still image. Ethnographic Content Analysis is defined as a type of analysis to identify signs in images and their meaning within the culture (Grbich 2007). Furthermore, Pink (2011a) echoed that investigating an image involves a focus not only on the content, but also on the image's historical process, contextual meaning, and cultural context presented in the image.

To understand the content and contextual meaning of the image, I followed Grbich's (2007) guidance, which suggested asking four questions: What is the image of? In what context was the image made?; What is the aim?; and, Is the image presenting the intended meaning? The next process was to link the content with the semiotic or sign, which was reviewed beforehand. In this step, I looked further at the interconnection of the signs with the related literature. I deconstructed and became familiar with the data by exploring the patterns that emerged from the photographs. This process was essential as it led to further analysis across the items. Understanding the signs also directed an antecedent or primary strategy for producing timelines, mind maps, and the initial consideration of argumentative and opposing views. Furthermore, the process also provided a robust introductory understanding of the evolving story of Pasung and the FPP which then led to the triangulation process.

Following the content analysis and the semiotic analysis, the next step was to identify themes, which involved coding, selecting, and checking the data for similarity, dissimilarity, and inconsistency. This phase involved coding either through inductive or deductive processes. Deductive themes were generated from the existing literature, i.e., Pasung. Meanwhile, inductive themes were produced through the semiotic and content analysis processes. These processes were continued by refining and selecting the codes that were combined into a more prominent theme, or separated into a small category. In this process, there was a possibility to refine the research aims and research questions, as all the patterns and relationships were being explored across all the emergent themes.

After the refining and selecting of codes was finalised, the themes were ranked, linked, and constructed. It was important to combine all themes into a conceptual map that described the overall key themes. The final step was interpretation and writing, which produced a theory and coherent argument for understanding why Pasung occurs. Here, theorisation informed by the literature and the interpreted visual data, was the main key point to understanding Pasung. This included considering how the developed theory was consistent with existing theory, or whether there was any new theory emerging from the interpretation and the detailed story drawn from examining the experience of an individual in Pasung.

6.3.2 Videography of Pasung Practice: Combining Content, Semiotic, and Sequential Analysis to Understand the Nature of Pasung

This section explores the use of videography to better understand the nature of Pasung. Videography is the combination of ethnography focused on natural social situations, the context of the video data taken, and video data analysis. Videography is based on an internationally recognised methodology that takes into account the data's audio visuality as well as its ethnographic collection and sequential analysis. Its subject matter can be broadly defined as communicative action in social situations, which in this study refers to the situation surrounding PIPs. While specific sampling and coding strategies account for the context, the detailed analysis is based on action sequences and non-social action. This sequential analysis and semiotic analysis are demonstrated by an illustrative case, which also demonstrates the importance of contextual knowledge. Through a videoing and unmodified method that creates a sense of conveying reality without analytical fragmentation, video records the everyday life experiences of PIPs and the implementation to free these people. This is frequently accomplished by emphasising tacit knowledge and embodied competence in order to produce a situation in which the camera operator as a witness, experiments and recognises the border between saying and doing and getting in touch with the experience itself beyond the sayable (Jewitt & Van Leeuwen 2001).

6.3.2.1 Introduction

The omnipresence of video has expanded the possibilities and influenced the way research data can be collected. In ethnography, for example, video is used to interpret and represent the culture (Knoblauch & Schnettler 2012; Pink 2006; Rose, G 2016). The video data in this research, containing the recorded activity of PIPs in the community as well as the FPP, provided the opportunity to interpret and represent the cultural and societal context in which Pasung occurs. Video allowed observation of the practice of Pasung, such as how the PIP behaves in their daily life, what family members do or do not do to support the person’s needs, and what role community members perform in the practice of Pasung. Video also enabled the recording and exploration of the implementation of the FPP, including what kind of implementation and what approaches were taken to reduce the practice of Pasung. Exploring the social and cultural background of the community in which Pasung exists allows the researcher to build a reflective understanding and critical appraisal of this practice.

Using the videos for the purpose of this PhD study required many issues to be considered. Firstly, the videos were taken during my employment as a mental health clinician in the Indonesian community. Hence, my recording of the videos did not follow any standard or predetermined recording process or method at the time. Secondly, the angles, the people, the situations, and the action sequences were recorded through the lens of my clinical background and my role as part of the FPP team. Therefore, the clinical lenses became a significant point in this research, and the meaning and interpretation of Pasung practice that I brought to this process were heavily

influenced by my role as a clinician. This argument is reflective of the fact that all video analysis is interpretive and cannot be value-free (Flick 2013; Knoblauch & Tuma 2011a; Pennington 2016).

While the video data were collected for the purpose of documenting the FPP process, and the content was recorded through a clinical lens, this did not diminish the value of the data for this project given that all data were constructed (Atkinson & Hammersley 2007; Banks 2014; Denzin & Lincoln 2011; Harper 2012). For example, many people believe that numerical data are more scientific than other forms of data, such as qualitative data; yet one could argue that categorising a person based on their age or based on their economic class is a form of construction in and of itself, and not free of cultural and social understandings.

As mentioned above, this research uses naturally occurring data that included video documents created by the researcher focused on the situation under study (i.e., Pasung), instead of producing it specifically for research. The act of collecting data in such cases is limited to record-keeping; for example, daily interactions or routines in the practice of Pasung. Knoblauch (2012) explained that there is no definitive formula for examining video data. Since the advent of research using videos as a primary source, there is now a wide variety of approaches to analysing video data (Flick 2013; Knoblauch et al. 2012; Knoblauch & Tuma 2011a; Rose, G 2016). This has led to extensive criticism of approaches taken by previous proponents of the visual method. For example, it raises the question of the nature of the conceptual theory for choosing different approaches in analysing the data and how to ensure validity and reliability (Alfonso, Kurti & Pink 2004; Pink 2006; Rose, G 2016).

With these above concerns in mind, the video data used in the current research were analysed using Interpretive Video Analysis (Knoblauch & Schnettler 2012; Knoblauch et al. 2012), in addition to sequential (Flick 2013; Knoblauch & Schnettler 2012), semiotic (Given 2008; Silverman 2015), and content analysis (Grbich 2007; Pink 2011a). These combined methods focus not only on categorising and interpreting data, but on the temporal structure of the data. Temporal structures are defined as time-patterned organisation used by humans to help them manage, understand, or coordinate their use of time. A good example of an explicit temporal structure is a deadline, which most people write on their personal calendar. Thus, the sequence of every movement or observed culture is analysed sequentially (Banks 2014; Given 2008; Grbich 2007; Knoblauch & Schnettler 2012; Knoblauch et al. 2012; Knoblauch & Tuma 2011a; Pink 2011a, 2012; Rose, G 2016). The justification for these chosen methods is detailed in the next section.

6.3.2.2 Videography and Video Analysis

6.3.2.2.1 Video and Its Various Types

Video technology has been used in many disciplines, including medicine, art, and the social sciences (FitzGerald 2012; Knoblauch 2012). Video itself is defined as a technology that enables someone to record, store, and review image and audio data (Flick 2013; Knoblauch et al. 2012).

Video can also be defined as qualitative data, similar to text, audio, and still images (Given 2008; Knoblauch et al. 2012; Pink 2012). There are benefits and problems with classifying videos as data. As videos have become ubiquitous, the visualisation of culture across many countries has grown significantly. Video has been used in many teaching processes and in communication more broadly, and is even remodelling our self-representations with the proliferation of social media such as Facebook and TikTok. However, the omnipresence of video generates a new set of possible ethical difficulties, such as the issue of how video analysis is conducted within the study setting (Banks 2014; Knoblauch & Schnettler 2012; Knoblauch et al. 2012), particularly when the data is highly sensitive, as in this thesis.

To gain insight into how video analysis is undertaken in the research reported here, the type of video will be explained prior to the detailed analysis. Given that there are many types of videos, the analysis was determined by the circumstances of the recording processes. There are two types that denote who records the video, i.e., the participant or the actor, and the researcher (Flick 2013; Knoblauch & Tuma 2011a). The former records what is called 'native' video, such as video diaries and video clips on social media platforms (Flick 2013; Pink 2007), while the latter has two types: observing situations and people in their natural settings and recording in experimental settings which are manipulated by the researcher (e.g., observing people or objects as part of experiments in laboratories). The videos used in the current research observed situations and people in their natural settings without intervention from the researcher. According to Denzin and Lincoln (2011), recording data in natural settings is important because it is central to making sense of, interpreting, or making meaning of the observed culture. The meaning of natural settings is referred to as the social situation or social action in natural settings. In other words, the existence of social action does not depend on the research design, but is realised by the actor under study (Knoblauch & Schnettler 2012; Knoblauch & Tuma 2011a, 2011b; Margolis & Zunjarwad 2018). For instance, this research recorded how family members treat someone with a mental illness in Pasung, or how the health care worker interacts, or deals, with someone in Pasung.

6.3.2.2.2 Standardised Video Analysis vs Interpretive Video Analysis

Photography and videography are closely intertwined, and their analysis shares a similarity in meaning-making throughout the analysis process. Pink (2006) affirms that "… [analysis] involves examining how different producers and viewers of images give subjective meanings to their content and form" (p. 95). While photography captures a moment in a single image, videography captures an event over a period of time. Given that the video is comprised of image sequences, the sequence of the moment captured in the video makes a difference in terms of how to analyse it (Banks 2014; Knoblauch & Tuma 2011a; Pink 2006).

In this research, I distinguished videography from video analysis to differentiate the video type in the collection and the type of analysis. Video analysis is the term used for the analysis of video

data or moving images (Knoblauch et al. 2012; Silverman 2015). Although the approaches in video analysis are very diverse, this study is limited to videography. The notion of videography highlights the fact that video is not only used as a technology to analyse audio-visual data provided by various media, such as film, television, or the Internet, but underlines the fact that audio-visual data has been recorded by researchers themselves in more or less naturalistic social situations (Knoblauch 2012; Knoblauch & Schnettler 2012).

Knoblauch et al. (2012) classify the methodological approach in video analysis into two categories: standardised analysis and interpretive analysis. The first type of video analysis is the most frequently used in many research disciplines. In standardised analysis, the video is cut into several segments and then coded according to initial coding derived from theory. Frequently, a theoretical assumption is constructed to be used for initial coding and follows a deductive process. For instance, the study of postural asymmetry by Philippi et al. (2006) used standardised video analysis based on recorded observations of infants to determine a deviation such as scoliosis. By contrast, interpretive video analysis emphasises the meaning constructed by the actors involved in the video. The researcher constructs the meaning of social actions and interaction among participants or actors or follows an inductive process (Knoblauch & Schnettler 2012 p.235). Although coding is also used in interpretive video analysis, it must be distinguished from standardised video analysis. The categories for coding audio-visual data in standardised video analysis are derived from theoretical assumptions. Furthermore, standardised video analysis does not explain the interpretations used to code individual data segments (Knoblauch, Tuma & Schnettler 2014).

6.3.2.2.3 Sequential Analysis

Sequentiality is the main source for interpreting social interactions in terms of their transience as represented in an audio-visual recording. Therefore, Sequential Analysis is the main methodological procedure applied to social interaction videos which comprise a series of social actions that are present in the video. Social action is the type of behaviour intended towards another individual. Social action is different from social behaviour, which is a one-way action conducted by a single person (Knoblauch et al. (2012 p.1); for example, how a patient scratches their back when seated. Social action needs two or more actors and comprises action intended towards other actors, irrespective of whether the other actor is a person, animal, or other entity (Flick 2013; Knoblauch & Schnettler 2012). For instance, in this research, a video shows a nurse bathing a patient, covering the patient's body with some fabric while the patient sat and was also washing their own body. However, also relevant to the current research, 'other' could be defined as non-persons (Argyle 2017), e.g., a patient talking to themselves could also be called social interaction.

Social action is inseparable from the interaction, which is the sequence of social actions between actors (Knoblauch et al. 2012, p. 654). Social action also contains interpretation and explanation. For example, the nurse covering the patient with the fabric can be understood to be respecting the patient's dignity and supporting the patient to feel secure and respected. Social action and interaction also have cause and effect. For example, by treating the patient carefully, the patient's affect remained stable, and he did not become aggressive, potentially understanding that he would get help. The nurse also likely felt safe as they did not perform potentially coercive or unethical care towards the patient.

There is some debate in the literature exploring social action in ethnographic research. For example, Goffman (1983) stressed that 'interaction order' meant a form of interaction wherein the actors share a common focal point of attention or 'focused interaction'. Interaction order is constituted by two or more actors (Goffman 1983); for instance, this research involved the Free Pasung Team freeing the PIP from Pasung while others from the community looked on. But this can also happen in a larger interaction such as in a meeting or a stage performance. For instance, in this research, meetings were held with the villagers to ensure whole of community involvement in decisions regarding Pasung. Whereas the interactive core in such situations may be produced by the interaction among those involved, such as through body gestures, the relationship between actors, actions, and external factors also plays an important part in the interaction (Goffman 1983).

By contrast, Garfinkel (1967) argued that there is no interaction order, and they question how someone can distinguish which social action will come first and what action will follow. Garfinkel (1967) further stressed that the actor's motive, power, and resistance influence how the action works. The actor also decides the next action and derives meaning from it. While this argument is important in the context of social action theory in ethnomethodology or focused ethnography, this thesis is conducted through the lens of interpretive ethnographic methodology, described by Denzin (2013 p.1).

> An ethnography that refuses abstraction and high theory. It is a way of being in the world that avoids jargon and huge chunks of data. Viewing culture as a complex process of improvisation, it seeks to understand how people enact and construct meaning in their daily life.

In this study, Sequential Analysis refers to ways of organising and analysing behavioural data in an effort to uncover sequential patterns or regularities in observed behaviour (Knoblauch et al. 2012; Knoblauch & Tuma 2011a). Thus, Sequential Analysis can provide basic descriptive information about the sequence of observed behaviour. At the same time, it can reduce the data to multiple theoretically targeted indexes of the sequential process which can then be used for further analysis using other suitable analytical techniques.

6.3.2.2.4 Ethnographic Content Analysis in Pasung video

In addition to social action and the actor, the context of where the video was taken should also be considered in the analysis. It should be noted that content analysis necessitates the collection of two minimum data sets, through which setting and context are being compared and contrasted (Knoblauch & Schnettler 2012; Knoblauch et al. 2012; Pink 2011a, 2012). For instance, this context could include consideration of who the decision-maker was for using Pasung, the political situation (including legislation, formal rules, and informal rules), the legal, cultural, and religious aspects of Pasung, gender, and mental health resources.

As stated above, the collection of video data demands a certain degree of ethnographic knowledge (Pink 2006). The videographer has to become familiar with the situation to such a degree as to be able to determine a relevant focus for recording the video (Knoblauch & Tuma 2011a; Pink 2011a, 2012). In addition, the videographer is required to gain knowledge about the contextual elements that are represented in the video, or that might escape the focus of the video camera, yet are indispensable to understanding what is going on. Thus, knowledge of the workings of the instruments used, the categories of actors, the structure of the space within the camera's focus or outside of it, as well as the events leading up to the recording, are required in order to be able to then interpret and later analyse the visual recordings (Harper 2012; Knoblauch & Tuma 2011a; Pink 2007). Hence, ethnographic content is fundamental to video analysis (see further detail in Section 6.3.1.4 on Photography Analysis).

6.3.2.2.5 Semiotic analysis in Pasung video

In addition to the sequence of the social action, the videos used for the current research also captured non-social visual aspects, including the material, the spatial, the buildings, furniture, instruments, etc., which cannot be analysed using sequential and ethnographic content. Thus, this research added semiotic analysis to the sequential and ethnographic content analyses. There are many contrasting systematic approaches to addressing these non-sequential elements. The two common approaches are Ethnomethodology and semiotic analysis. This research follows the process suggested by Goodwin (2000) which assumes that semiotics (the study of sign processes) can help the researcher to apprehend these visual elements. These elements are then taken as representations of visual signs. Based on semiotics, it is assumed that these signs are part of a more comprehensive sign system from which the meaning of these signs can be derived (Kress 2010). As such, speech appears to be embedded in several sign systems, such as graphic codes, gestures, and other environmental features (see further detail in Section 6.3.1.4 on Photo Analysis). Having described the concepts of interpretive, sequential, semiotic, and content analysis, the steps undertaken in the analysis are described next.

6.3.2.3 Analysis steps

As mentioned previously, there are no particular steps in analysing data within videography, and for each video, different types of analysis are possible (Flick 2013; Knoblauch et al. 2012; Knoblauch & Tuma 2011a; Rose, G 2016). In the current research, I administered several methods as a combination, to match the nature and needs of the video data. This research adopted the video analysis process from Knoblauch and Tuma (2011a), as the video was taken and constructed by the researcher. In this analysis, I kept the video in its original data form, with no manipulation or filtering, or any adding or subtracting of elements. However, to accomplish a specific representation of the recorded data, I chose and cut some of the video's frames. For example, video data was divided into a precise moment, look, specific action, and so on. In general, the steps for analysing the video data are shown in Figure 2:

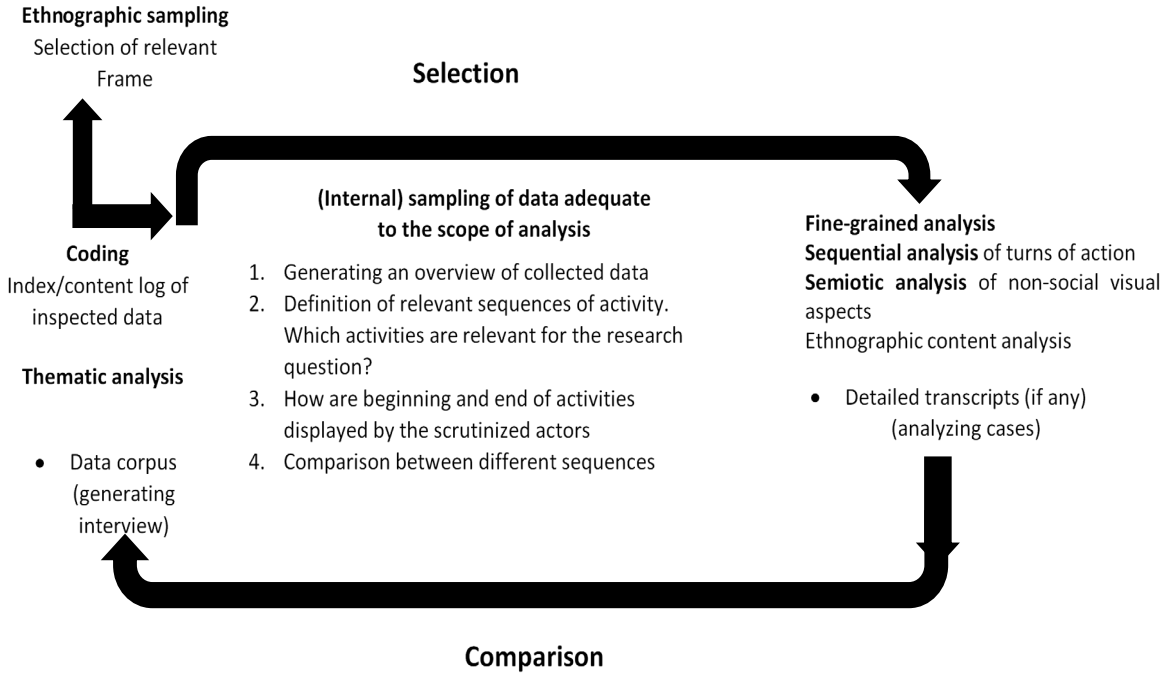


Figure 6-2: Video Analysis and Videography

Modified from (Flick 2013 p.445; Knoblauch, Tuma & Schnettler 2013)

Based on the figure above, there are three processes involved in the analysis: the input (internal and ethnographic sampling); the process of fine-grained analysis; and the output analysis. This is not a straightforward process of moving from left to right or vice versa; rather, it is a dynamic process with an intertwining and overlap between the steps.

6.3.2.3.1 Ethnographic Sampling

Silverman (2015) explained the process of ethnographic sampling with the metaphor of 'opening the woods.' As the videos were taken prior to the official commencement of the PhD thesis,

ethnographic sampling comprised selecting and observing the Pasung practices which had been conducted prior to the FPP activity, i.e., the video is of Free Pasung, but also captures the practice of Pasung itself. This phase is a critical point in understanding the videos in the ethnographic study as the relevant background of the culture needs to be acquired. In addition, this step is needed to capture the contextual elements of the videos. This research was conducted in West Java, which is majority Sundanese. The sampling was undertaken to represent contextual factors, including geographical areas (representing the nearest and the farthest from a psychiatric hospital), urban and rural areas, and type of Pasung. Given that the dataset contains 10 videos ranging in length from 5 to 31 minutes, we needed to choose which video and which frame from the video to use for ethnographic sampling. In this analysis, we chose 3 videos (detailed in Chapter 8) that presented a large number of relevant samples to answer the question posed in Chapter 1.

6.3.2.3.2 Internal Sampling

Internal sampling was conducted in four steps, including generating an overview of all the data and defining the sequences relevant to the research questions, which sequences were appropriate as a starting point, and which ones were appropriate as an ending.

Still Photo 6-1: the Interaction between the Free Pasung team and the PIP Inside the Hut

Following the process represented in Figure 6.2 above, internal sampling involved: 1. Generating an overview of the collected data; 2. Definition of relevant sequences of activity; 3. Exploring how the beginning and end of activities were displayed; and 4. Comparison between different sequences. Using the video from which Picture 8-2 above is taken, the first part of the analysis is as follows.

Data overview: The hut in which the man has been held is approximately 3 x 1.5 metres and 3.5 metres high with a pitched wood and tin roof. It is made of concrete. There are no windows, except for two small openings (15 cm square opaque glass bricks set into one wall approximately 3 metres up under the shaded roofline, and the one wooden door secured with a large chain, bolt, and padlock). There are three openings, the opaque glass bricks, the door, and a small rectangular opening of approximately 20cms x 10cms at the back of the hut for food and water. It is through this opening that food and water is passed to the man; it is the only source of light and free air to the inside of the hut. The man can reach through this opening with his hand and part of his forearm. Above this opening is a metal plaque nailed to the wall on one side and hanging lopsided with Arabic writing. The writing on it reads: “I ask forgiveness in God. We undeniably belong to God, and we shall return to Him." It is unusual to use these words to describe people who are still living, although it is not uncommon in areas where traditional beliefs have been entrenched that link the mentally-ill to the possession of a bad spirit. These words are used when a person suffers a disaster in life, when learning that a person has died, or when a person is placed there to ward off evil spirits.

Still Photo 6.1 above depicts the moment when the person inside the hut responded to the Free Pasung team as they tried to communicate with him. The numbers are described below:

1. The Arabic inscription says, "I beg pardon from God. We belong to God, and we will return to Him."
2. The rectangular hole through which food and water are inserted. Given that the doors are always locked, this tiny hole serves as ventilation.
3. The PIP raises his hand and asks for cigarettes. His hand looks dirty with long fingernails.
4. The personnel at the community health centre drew an image of the patient's hand.
5. The nurses attempted to communicate with the patient.
6. The outer building looked dirty covered with dust and moss.

The selected activity details are: The leader of the team from a psychiatric hospital, gave the order to the entire team. The team greeted, and communicated with, the person inside the hut. The man asked for a cigarette via the rectangular hole.

The activity began with the team exploring the hut, followed by the man waving his hands through a rectangular opening, and ended with the team leader commanding the team to begin evacuation.

Comparing and contrasting sequences. This entailed explaining the explicit and tacit shared background assumptions of various sorts of sequences. After defining and returning to the question, I will go into greater detail and seek to identify distinctions in Pasung practise in order to understand where the areas of divergence from this background are. We identify the level of interaction processes and then reconstruct their function in these processes to get a complete

picture of them. As a result, the real evidence is more like interactional than statistical data. For example, in these sequences, I picked the sequence that featured the social activity between the PIP and the team and why this happened, despite having been in Pasung for years. I compared the data with other PIPs who generally had difficulties in verbal communication, and then analysed the cause of this person having good communication contextually.

6.3.2.3.3 Analysis

Following the ethnographic sampling, coding, and internal sampling, fine-grained analysis was then commenced, with three different types of analysis. While the original approach developed by Knoblauch and others refers to the fine-grained step as sequential analysis (Knoblauch & Schnettler 2012; Knoblauch et al. 2012; Knoblauch & Tuma 2011a), the current research added semiotic and ethnographic content analysis, which then enabled the data to be thematically analysed. Indeed, sequential analysis is important to unveil social interaction, but there are also visual parts of the video that are not social actions. Thus, they needed to be analysed with different methods of analysis. To better understand the three analyses, the table below shows in detail how the three analyses were combined to reveal the nature of Pasung in relation to the video discussed above.

Table 6-1: The Comparison of Analysis

Ethnographic content analysis	Sequential analysis	Semiotic analysis
The picture depicted the hut which is approximately 1.5 metres by 3.5 metres with a pitched wood and tin roof. At the back of the hut, approximately 0.5 metres from ground level, was a small rectangular opening of approx. 20cms x 10cms. The door was locked and secured with chains that looked rusted, and was also secured with a padlock. As the context of this video was someone in seclusion and restraint in the community, I knew that inside the hut was a person. If there was no context, anyone could guess anything. As the ethnographic content analysis tried to uncover why and interpret not only 'what', as would be done in quantitative	As the action, the family and/ or community (which we know from the context and the video dialogue) placed chains, padlocks, and locked doors in front of the hut. As a form of social action, locking the doors meant keeping something inside the building, but also keeping those outside safe from whatever was inside, e.g., if we didn't know there was a person inside, we could assume it was, for example, an aggressive dog or other animal. However, because the 'something' inside is a person, it is intended to securely lock the person inside. The family/community do not	A non-social action was semiotically examined. The community installed the lock with the intention of securely locking the person inside. I needed first to consider the intended meaning of the social action and the non-social action. The example of non-social action based on the video dialogue was that the family did not intend to use it for a life sentence. They didn't want to kill or torture anyone by putting them inside a hut with a triple lock. That was not their intention. Then I can categorise it as a result of non-social action. Given that there was also an Arabic spell, I can associate it with

Ethnographic content analysis	Sequential analysis	Semiotic analysis
content analysis, the researcher questioned himself further, for example, why was it that they used a triple layer to lock someone there? It could serve for life or contain a very dangerous person.	want the individual to come out.	the devil, implying that someone inside is possessed by the devil or something evil.
The researcher then comes to the temporary conclusion that the family and/or community intended for the person inside the hut to never leave. There is a social stigma that the person engages in violent behaviour. However, this preliminary conclusion must be compared and contrasted with other results, such as the video transcript and the interview.		

6.3.2.3.4 Generating (Interpretation)

Interpretation is defined as how the researcher makes meaning from the research findings. In other words, it aims to make sense of the findings (Given 2008). In interpreting the videos, the sequence of social action and reflexivity were essential steps prior to the validation of the video interpretation (Flick 2013; Knoblauch & Schnettler 2012; Knoblauch & Tuma 2011a). In Figure 6.2 (see page 123), the data corpus (generating the interview) comes after the fine-grained analysis followed by the thematic analysis.

At this stage, I also considered video dialogue (if available) to support the findings. A selection of segments of video dialogue from the exchanges of those present in the above picture is provided below:

> From the outside, it appears that the condition is bad, and we may need a stretcher to transport this man to the ambulance.

Both the chains and the key had rusted.

> Is the family in possession of the key?

The team leader asks one of the family members while inspecting the rusted chains and the lock on the doors.

> No, we don’t have the key anymore. It's no longer there.

one of the family members responds.

The team leader, the female worker, and the social worker then move to the back of the hut.

> Oh my God, how could this happen? May God forgive all of our sins. Are you all right, sir?

The social worker asked the man inside with a surprised gaze while bending down.

> We're from the psychiatric institution, and we've come to get you out of here. You've been hospitalised there before, therefore you remember.

The social worker inquires more about the man. The team leader directs the team to begin moving. The female nurse bends down to call out to the man whose hand soon comes through the rectangular opening, fingers beckoning, as they talk and take photos. She greets the man and introduces herself.

> I am a nurse from the psychiatric hospital, how are you there?

Rather than answering the question asked, the man asks for a cigarette via the rectangular hole. The team continue to speak with the man inside the hut, whom his family refer to as Gunner. He does not respond to the questions and keeps asking for cigarettes. His hand makes the sign for smoking with two fingers, again and again.

6.3.2.3.5 Thematic Analysis

The next step was to create the coding comprised of a temporal sequence of events, a rough transcription of the activities, gestures and talk, reflections, and coding of sequences according to the research questions. No theoretical lenses were applied in the coding. Several questions were raised to assist in identifying the ideas and concepts, as suggested by (Given 2008). The final step was analysing all the cases and starting again with the first step as a cyclic process until data saturation had been reached. This was conducted to ensure the validity and reliability of the interpretation. During this repeated step, ethnographic knowledge was constructed, explained, and interpreted. This dynamic process is important to prevent a premature conclusion and to ensure that all processes have been thoroughly examined. More than one member of the research team was involved in the steps to improve rigour, strengthening the interpretive processes, especially their role in posing practical logistical questions about the actions in the video and cultural questions to the main researcher (e.g., Who is that person and what is their role? Who has seniority? What would be expected of this professional in Indonesia’s mental health system? Are there any gender issues relevant within this culture that we need to know about?).

6.3.3 Collecting and Analysing the Interview Data

In addition to photographs and videos, the research relied on in-depth interviews. Interviews are designed to learn how persons with whom the researcher is speaking make meaning of their lived experiences (Atkinson & Hammersley 2007; Denzin 1996; Denzin & Lincoln 2011). Interviews are designed to elicit rich, detailed, or 'thick' descriptions of events by encouraging participants to speak freely and comprehend the researcher's quest for understanding into a phenomenon that the participant has witnessed. Interviews with key informants are often part of an ethnographer's toolbox of data-collecting procedures (Atkinson & Hammersley 2007; Given 2008). These

interviews are very different from those used in survey research. They have been described as ‘conversations with a purpose’. Indeed, in the context of long-term anthropological fieldwork, differences between interviews and spontaneous discussions can be difficult to discern. In addition to such unplanned interactions, more formal interviews may be staged. Nevertheless, the tone and organisation of these interviews are characteristically conversational, and questions are not always asked in the same order or format as prescribed in the interview schedule (Atkinson & Hammersley 2007).

6.3.3.1 Participant Selection

The participants for the interviews ranged from PIPs, their families, community members, health professionals, non-health professionals, policy-makers, and health system managers. Choosing a sample size for this population, particularly for PIPs was difficult, given the sample size was small. It is true that the number of cases of Pasung is high, but finding PIPs who could speak or who fit the criteria was somewhat challenging. Atkinson and Hammersley (2007) argued that when the sample size is relatively small, decisions must be taken regarding where and when to observe, who to talk to and what questions to ask, and what to record and how. I also agree with Given (2008) that qualitative researchers should strive to make their methods as robust and defensible as possible, aiming for intersubjectivity in how and why design, sample, and analytical decisions are made (Denzin & Lincoln 2011). As well, an approximate sample size is required for planning, but the final sample size must be regularly assessed throughout the study process (Malterud, Siersma & Guassora 2016).

The Pasung participants were chosen from the FPP registry from a psychiatric hospital's overall register. The participant’s’ had no age restrictions or diagnoses that would exclude them. Exclusion criteria included having an intellectual disability or dementia in addition to being sentenced to psychiatric care, or being too confused to participate, as stated in the medical record. The FPP team contacted these individuals; in this case, their family or the carer, and invited them to participate in the FPP. Potential participants were contacted, and informed consent was obtained which was documented in the medical record. According to Indonesian law, the person who signed the consent form for Pasung participation had to be a family member or an authority figure.

Those who were not PIPs were recruited through purposive sampling (Denzin & Lincoln 2011; Given 2008). Purposive sampling was used to select participants in order to understand the nature and management of Pasung, including Free Pasung. Purposive sampling is the purposeful selection of informants depending on the attributes they possess in accordance with the study purpose (Creswell & Poth 2016; Denzin & Lincoln 2011). I made contact with potential participants as part of my role with the FPP which let people come to know me better through the implementation of the Programme. After a few weeks, I began more concentrated interaction and sought people’s consent to speak with me in my role as a researcher by asking some particular

research-related questions and if they could offer me their time to educate me more about specific issues. Most of those I called were delighted to respond to my inquiries. This group did not differ in age or sex from the PIP group. The details of those who participated in this research are presented in Chapter 9 (Interview Analysis).

6.3.3.2 Semi-Structured Interviews

The interviews were semi-structured, where the researcher provided an outline of the topics and issues to be covered. Semi-structured interviews entail the development of an interview guide that includes a pre-determined list of questions or issues to be addressed throughout the interview (Atkinson & Hammersley 2007). Semi-structured interviews were considered the optimal method for this study because they represent an ontological perspective concerned with people's knowledge, understandings, interpretations, experiences, and interactions (Given 2008). Although interviews are intended to focus on certain issues, there is no set range of responses to each question, thus it is essentially a two-way conversation between the interviewer and the interviewee (Denzin & Lincoln 2011; Given 2008; Gobo 2008). During the interview, the interview guide acts as a checklist, ensuring that the same essential information is acquired from each person. However, there is considerable flexibility.

Semi-structured interviews do not follow rigid rules and their execution is reliant on how the interviewee replies to the researcher's questions. Although there was a set of leading questions, the subject's response allows the researcher to submit more enhanced inquiries than those that were initially developed. This research used semi-structured in-depth interviews, as interviewees constantly say things that go outside the structure before the interview begins and after the recorder is switched off. Utterances that "spill beyond the structure" are frequently significant and, in some cases, crucial to interpreting the interviewee's answers (Denzin & Lincoln 2011 p.1000). Keeping this in mind, my interview drew on my empathy as a member of the clinical professions, a man, and a Sundanese, as well as my connection with the participants' daily lives. This strategy appeared to match the community extremely well. The interviewees, all of whom were older than me, enjoyed telling their stories and being heard. As a result, in each interview, I positioned myself as a listener and learner seeking fresh insight and familiarity, rather than as a formal interviewer with a series of questions. In addition to the participants being observed, I defined them as persons who shared their personal information, experiences, and thoughts with me through in-depth interviews.

The interviews with various stakeholders (the person, the family, health professionals, and community members) captured a range of views on Pasung practice and the FPP. Interviews were conducted with team members from across a range of services (the psychiatric hospital, community volunteers from the Bandung Area, primary health care staff from five cities representing the farthest and nearest to the hospital, nurses, general practitioners, social workers,

psychologists, psychiatrists, planners, and programmers) who were involved in the FPP. All interview respondents (representing several stakeholder groups) were asked about their views and experiences in relation to their understanding of what constituted and contributed to Pasung. Detailed information from all stakeholder groups was required so that a genuine attempt could be made to ascertain to what extent stakeholders shared the same meaning of Pasung, and agreement on how it could be reduced. Consumers and carers were also interviewed about their understandings and experiences of Pasung. This data enabled comparisons to be made across the groups. The data provided by all stakeholders via the methods employed in this study contributed to addressing this objective. It also contributed to the generation of a rich data set and enabled triangulation of the findings.

Language concerns were considered as they could interfere with the nature of the interviews (Marschan-Piekkari & Reis 2004). To allow for a more fluid conversation, the interviews were conducted in both Indonesian and Sundanese, a local language from West Java province. I am fluent in both languages. I took field notes during the data collection procedure to recall and capture the behaviours, activities, events, and other aspects of the interviews. In these notes, I recorded all my thoughts, ideas, questions, and worries as I interpreted the interviews, as indicated below.

6.3.3.3 Collecting and Analysing Field Notes Data

Field notes are defined as notes written by the researcher during the fieldwork to record the activities, behaviours, events, and other culturally related features of an observation (Atkinson & Hammersley 2007; Schwandt 2014). Field notes are aimed to be read as evidence by the researcher to understand the culture or phenomenon under study. The field notes may constitute the primary data collected for a research study or as complementary to other research data collection (Given 2008; Schwandt 2014). In this study, field notes constituted complementary data.

In field notes, researchers record descriptive information such as place, person, and time as well as reflexive information including data, personal ideas, and details of the research process (Given 2008; Schwandt 2014). Denzin and Lincoln (2011) further add that field notes are a “twin process” in qualitative research together with the narrative. Thus, field notes are a unique process and are written more like a personal journal of the researcher. The researcher kept extensive field notes related to interactions with stakeholders as well as any actions, interventions, or advocacy that eventuated during the management of Pasung as part of the FPP activities. These field notes captured a written record of what I saw, heard, and experienced in the field, as well as my reflections, subjective feelings, and thoughts about what I observed. The field notes were produced while I was in the field or as soon as possible after I had left the field. The field notes contained two main parts, namely descriptive and reflexive information. As part of the descriptive information, I presented factual data about: 1) the setting, both the physical and social environment; 2) time and

date; 3) interactions (what type, the pattern and the frequency of the interactions); 4) what kind of actions were undertaken by the participants; 5) communications (verbal and non-verbal); 6) the behaviour of participants (including conflict resolution, decision-making, or collaboration between the participants); 7) who the participants were and their roles; 8) the description of Pasung from the participants' perspectives, including any quotes or comments related to Pasung and its management; and 9) the reactions occurring while observing. In the reflexive information, I recorded ideas and suggestions about Pasung and Free Pasung. This included any questions that arose during the observations and any unanswered questions from analysing the data.

6.3.3.4 Thematic Analysis

The material gathered from the interviews was turned into data systematically using theoretical thematic analysis (Braun & Clarke 2006) informed by the Socio-Ecological Model (SEM). Thematic analysis is a method in qualitative research for examining data to identify similar themes or patterns that occur repeatedly within the data (Flick 2013). This method can be identified by coding inductively from raw qualitative data (interview transcripts, video recordings, etc.), or deductively (theory-driven) based on theories and results of previous research (Boyatzis 1998). Interviews are recorded and transcribed wherever possible. The level of detail that goes into interview transcription varies depending on the analytical goals. The interviews were largely analysed for content as evidence and actual experiences, thus broad transcription sufficed. In general terms, if the ethnographer wishes to pay more specific and comprehensive attention to the venue of the conversation, the environment and setting in which the exchanges take place, as well as the content, more detailed transcription may be required, but this was not the case in this study. There are six common steps of analysis (Braun & Clarke 2006) for interview data. Although this framework appears to provide a step-by-step guide to thematic data analysis, the actual data analysis process for this study was not linear, as these steps were interconnected and frequently performed concurrently, as detailed below.

1. Familiarising oneself with the data

The researcher translated the interviews from Sundanese to Indonesian and then into English, keeping the sentence structure and irregular forms of terminology, as is the norm in everyday speech. To ensure the accuracy of the translation, the transcripts were double-checked and then analysed by the supervisors. My supervisors and I began by reading through all the English transcripts and taking notes on our first impressions. Irregular terms, colloquial language, and abbreviations in the transcripts were retranslated. In certain instances, quotes were modified to conform to English grammar (past tense). Any additions to the quotes were in square brackets and were based on the context of the entire interview.

2. Generating the code

The process of identifying a thematic framework occurred concurrently with the indexing (coding) of the data or interview transcripts. NVivo was used to complete the data coding process. To promote rigour, the researchers were immersed in the data set and participated in the analysis. Furthermore, the researchers participated in an active reflexive process to assess their influence on the interpretive process, which is recognised as crucial for increasing the quality and rigour of qualitative research (Denzin & Lincoln 2011; Finlay 2002b).

The researcher began this coding phase by undertaking open coding, in which all aspects, ideas, or themes identified from each interview transcript and which fit the conceptual frameworks or that emerged from the data, were coded into free nodes. Both my supervisors and I coded all the transcripts independently, and a meeting was held every two weeks to discuss any points of difference, reach agreement about how to proceed, and make minor changes to the coding scheme. Once a consensus had been reached, I indexed all the transcripts using the final developed coding scheme, but I also added additional codes as needed to the data. In this step, I transcribed the data set, and read and re-read the transcription, creating initial ideas and attention to detail of latent or explicit content. A social constructivist philosophy underpinned the importance of active reflexivity throughout the analysis, in which any knowledge or findings identified through data collection and analysis were informed by the active participation of not only the participant, but also the researcher in generating the data, as informed by both sets of lived experiences.

This procedure resulted in the collection of a lengthy list of codes, with each node or code being examined. The researcher then used a closed coding process to group together codes that were similar or redundant into a group of codes as a hierarchy of nodes (parent nodes, children nodes, grandchildren nodes, and so on). In other words, similar or redundant codes were grouped together under the same theme (and sub-theme) derived from the SEM frameworks used in this study. During this stage, the data codes were used to inform the creation of new themes, or themes that fell outside of the conceptual frameworks. Both sets of conceptual framework-derived themes served as the foundation for the thematic framework.

3. Theming

Codes were collated into themes. Thematic analysis, which is guided by both theoretical assumptions and research questions, is a versatile data analysis method (Braun & Clarke 2006). In this study, data analysis took place in two ways: a deductive top-down theory-driven method and an inductive bottom-up data-driven one. A deductive approach meant that the form of analysis was limited to preconceived frames, which included the SEM, whereas an inductive approach meant that the themes identified were strongly linked to the data, implying that the coding process occurred without attempting to fit the data into a pre-existing model or framework. Fereday and Muir-Cochrane (2006) used NVivo to describe a six-step procedure for this hybrid approach. The

steps were as follows: creating a coding manual, testing the code's reliability, summarising the data and identifying the initial themes, using a template for the codes and additional coding, connecting the codes and identifying themes, and corroborating and legitimising the coded themes.

4. Reviewing themes

The themes were checked against the codes to see the relationship and how it worked with the entire data set. This phase began with the development of a list of potential themes and ended with the refinement of those themes. During this phase, it became clear that certain candidate themes were not true themes (for example, if there was insufficient evidence to support them or the data was too general), while others were merged (e.g., two apparently separate themes might form one theme). Other themes were divided into sub-themes. Patton's dual criteria for evaluating categories (internal homogeneity and external heterogeneity) are highly relevant in this context (Patton 1999, 2002). Data within themes should be meaningfully coherent, with obvious and detectable divisions between them. A thematic map was then created.

5. Defining and naming themes

In this step, I refined each theme and the overall story, undertook an ongoing analysis, and generated a clear definition and defined names for each theme. Throughout this phase, I kept each theme's connection to the research question and the entire data set, while maintaining the simultaneous nature of the evolving integrated analysis. As the identification and evolution of the concepts progressed, I also examined the link between the categories. At this point, I defined and refined the themes given in the study, as well as assessed the data linked to the themes. By 'define and refine,' I mean defining the 'essence' of what each theme was about (as well as the themes as a whole), and determining what part of the data each theme captured. By the end of this phase, I had a firm understanding of what my themes were and were not. One test of this was to see whether I could convey the scope and content of each subject in a few phrases. If not, the topic needed to be further refined.

6. Reporting

After a complete set of themes had been created from the full analysis, the final analysis was undertaken. The selection of vivid, concise, coherent, logical, non-repetitive, and engaging accounts of the stories the data told through compelling extract examples, the final analysis of the selected extracts was conducted, tying the analysis back to the research question and the literature, leading to the production of the analysis report.

6.4 Ethical Considerations

Ethics approval was sought and granted by the WJPH Ethics Committee when the lead researcher was an employee of the hospital. In the Indonesian ethics system, shared data, including patient data, can be used for other research purposes or by the institution for evaluation with the

permission of the Director. However, data must not reveal or disclose the identity of the person or the family. The WJPH ethics approval included consent for the current research project. All data were collected prior to the commencement of the PhD study by the lead investigator in West Java Province, Indonesia. Prior to data collection, ethics approval was sought as part of my former role in the community mental health and research division for the WJPH, and with the understanding that it would be used for my PhD research. The visual data was collected and kept in its original form. As this data was identifiable, I used pseudonyms for each participant, de-identified the names of locations and organisations, and any potentially identifying features of the visual data (such as people's faces) were blurred to ensure anonymity.

Furthermore, ethics approval for this PhD research, including the use of data collected in my role in WJPH, was granted by the Social and Behavioural Research Ethics Committee, Flinders University (SBREC) and from the West Java Psychiatric Hospital Research Ethics Committee (16/Diklit/01/2018). The letter of permission was received from the Director of West Java Psychiatric Hospital for the further use of this data for the current PhD research.

In the data collection process, as a mental health worker and a member of the community health department at the WJPH, I played a role in the management of the FPP including budgeting, planning, and evaluating the programme. As an insider, I had important knowledge and the necessary sensitivity and experience in caring for a PIP; also, some staff participants were my professional colleagues. However, I ensured that I followed the ethical practice standards and regulations established for all staff of the WJPH and the community as a whole, and respected the privacy of all participants, who could elect not to be involved in the research without adverse impact on their standing in their established roles in the services. The data (videos, photographs, interviews, and field notes) were used only for academic purposes and not for commercial purposes. All the data gathered is part of the WJPH Free Pasung and the results of the research will therefore be shared with the WJPH for evaluation purposes. In addition, to ensure objectivity, I explicitly stated to the participants at the time that I had a role as a researcher and also as a community manager with WJPH. Also, I was not involved in the direct care of PIPs and stood as an observer only.

All participants who participated in the FPP had been informed of the steps required as part of their participation in the programme. Even though the programme was mandatory as part of the government initiative to reduce seclusion and restraint in the community, participation was voluntary. Consent was given prior to the data collection and stored in the person's medical records. For those who did not want to participate, they (or their family member where the person was unable) needed to sign a dedicated Programme form stating that they were unwilling to participate.

For the interview data, the participants provided written or verbal consent to be involved in the study. The lead researcher is an experienced psychiatric nurse who, along with medical and other staff present at visits to PIPs, determined whether the person was able to provide informed consent. Due to levels of incapacity, confusion, and psychosis of many PIPs, their consent was not possible. Alternatively, and in lieu of this, the family or community member providing basic needs to the person provided consent for video and photo footage of the Free Pasung process to be undertaken.

For the already collected video and photo data, seeking written consent from all participants was not possible or appropriate given the context (especially for the PIP, and in some settings where large numbers of family and community members were present to observe the visit by the FPP team). Verbal consent was obtained from the range of people in the videos where possible. Written consent was not possible given the nature of the visit to the sites. Given the context, I sought a waiver of consent from the Flinders University ethics committee to use the secondary data, as it was also impossible to identify, locate, or access all the people in the videos due to their dispersal, circumstances, and because of the COVID-19 pandemic (the researcher has been located in Australia since commencing his PhD in mid-2019 and travel back to Indonesia was not possible at this time).

Family members of the PIP provided consent for the FPP team to visit and film, and this consent was documented in the person's WJPH medical record prior to the visit, as described above. They were assured that no identifiable information would be used by the researcher, and that any use of images would likewise have people's faces and any identifying aspects blurred out for the purposes of reporting the results. All interview data were de-identified as part of the reporting. In this research, all data is held in de-identifiable form only on the password-protected Flinders University R drive. This includes a number for each participant which is matched to each numbered video (no identifiable details of names or actual addresses are recorded). General de-identified demographic information only is recorded, e.g., age, gender, location type, ethnicity, caregiver situation, Pasung history, diagnoses, and general social history and health, if known.

6.5 Trustworthiness

Trustworthiness refers to the procedures that researchers take throughout the study process to ensure that their efforts are purposeful, transparent, and ethical. (Lincoln, Y & Guba 1985) define four criteria for determining the trustworthiness of interpretive research: credibility, transferability, dependability, and confirmability. Credibility implies that the research findings can be relied on. This principle is applied in this study because the research findings have been validated using field notes, interviews, photographs, videos, and/or transcripts. A systematic, step-by-step presentation of the data, combined with a concurrent literature review, ensures that the findings can be extended to other similar groups and future research or transferability. The process of the

research, including the choice of methods, must be clearly presented in detail to fulfil the requirements of dependability, while the interpretation of data needs to be supported by a detailed description of the process of data collection, data analysis, and interpretation of the data, and supported by detailed reflection, which leads to confirmability (Denzin & Lincoln 2011).

In this research, a reflective strategy was used to emphasise that I, as a researcher, am not only a neutral observer, but also an integral part of the knowledge generation process. Reflexivity is the assessment of one's own attitudes, opinions, and practises during the research process and how they may have influenced the research. It necessitates openness and acknowledgement that the researcher is a participant in the investigation (Finlay 2002a). Reflexivity is an iterative and reiterative process in which the researcher considers their own views, attitudes, and cultural influences, as well as those being observed. Reflection and critical analysis are essential components of this process, particularly in qualitative research, which is seen as biased when compared to quantitative research due to its subjectivity (Finlay 2002b; Gough 2016).

As indicated in Chapters 1 and 5, I am both an insider and an outsider in this study. While the 'insider' role heavily influences the study of information or evidence in the field, the process of extracting evidence from the findings to develop new insights is predisposed by the 'outsider' position. Combining these roles enables the researcher to deploy their discoveries for both academic and practical usefulness, notably for knowledge development. Working closely with my supervisors during the analysis stage also ensured that I could evaluate the data as an outsider. Thus, by introducing this level of trustworthiness, the researcher's personal biases and peculiarities were avoided as much as possible. As dealing with all threats to validity is clearly difficult, the key focus in developing rigour is not to eradicate all such concerns, but to understand how a specific researcher's values and background are used and how these influence the conduct and results of the research.

In summary, Chapter 6 has presented the methods, including the use of ethnography, through which the researcher examined the social and cultural understandings of Pasung. This approach seeks to explain the participants' cultural situation based on information obtained directly from the participants through participatory research, and has been presented using a participant and researcher view. In Chapter 7, I present the findings of the photo analysis, examining photographs of PIPs and their community in order to attain detailed insight into the meanings derived from photographs of Pasung.

7
THE PRACTICE OF TRADITIONAL SECLUSION AND RESTRAINT (PASUNG) IN THE SUNDANESE COMMUNITY – RESULTS OF THE PHOTO ANALYSIS

7.1 Introduction

In this chapter, I present the findings of a photo analysis related to the practice of Pasung. A photo analysis has not previously been used in a similar study on Pasung in Indonesia, which was conducted in a non-institutional setting, and this finding added a significant contribution to knowledge on Pasung specifically, and mental illness in general. To do this, I first provide brief context on the results of the photo analysis to foreground this step in my research. This includes the influence of my Sundanese cultural background and my mental health professional experience on my motivation to undertake this study. This is followed by a brief revisit of the process of analysis that was used. I then provide the findings of the photo analysis as a series of themes, drawn from 135 of the 1,760 photographs of PIPs, and the Free Pasung Programme (FPP) team's activities in the communities where Pasung was practised. Of note, the description of the themes was accompanied and supported by several photographs of circumstances that may be distressing to the reader.

7.2 Methods

In order to obtain detailed insight into the meanings derived from photographs of Pasung, this study employed a two-tier analysis consisting of semiotic and content analysis. This blended method was particularly effective for providing the descriptions and meanings of the photographs (Goffman 1979; Grbich 2007; Pink 2011a). Before determining which elements were the most relevant for the photo analysis, the critical question was whether photographs were an effective means of representing Pasung as practice. Despite the fact that a discussion of using visual data is crucial for comprehending this practice due to the stigma around Pasung, our systematic review discovered no articles that justified or invalidated this sort of visual analysis to discuss Pasung practice (Hidayat et al. 2020).

To begin, the photographs were viewed or 'read' several times, to enable the researcher to become more closely acquainted with the entire dataset. Detailed notes were also taken to highlight important points and aspects of the photographs. Of the available photographs, 135 were purposively selected for further analysis based on their representation of the diversity of Pasung characteristics, including geographical area, gender, age, family condition, the type of Pasung, and photographs that the analysis team agreed conveyed content, context, and meaning related to the research questions. Context, content, and meaning are important in determining the sample as not all visual methods can be used in all contexts (Banks 2018). In practice, decisions are best made

after researchers have assessed whether specific visual procedures will be appropriate or ethical in a relevant research context, allowing them to account for their relationships with informants as well as their experience and knowledge of local visual cultures (Pink 2011a). Following this, semiotics was used to analyse the photographs (Jewitt & Van Leeuwen 2001). First, we looked at the content to explore perspective, focus, tone, setting, and themes. The symbolic meaning was then deciphered by reviewing the images that were referenced in the photograph (Emmison 2011).

As a result of this photograph selection, and the associated discussion within the analysis team, I became even more aware of my personal biases and idiosyncrasies. Through discussion with my supervisors about my views and interest in the research findings, a process used to reduce bias and develop robust methods in both data selection and analysis, I realised I had made a number of assumptions regarding the data in the early stages of doing the research, because I live and have grown up in the Sundanese culture. When I presented the early data, my thoughts, and the social context of the research at a supervisory meeting, for example, I mentioned that I had discovered very little information in the data. My point of view was described based on my clinical lenses and cultural understanding at that time, but my supervisors then provided another perspective as an outsider. As a consequence, this prompted me to think more deeply about the photographs and the process of analysis.

An interpretive description of the storylines contained within the photographs was then undertaken. I wrote down the narrative inferred from the photographs using primary notes, which was conducted concurrently with the data collection. Similar content was combined into a series of central themes in the second phase of the analysis process, which was then further condensed into higher-level hierarchical themes. These were then abstracted into the overarching central issue of ‘No room for escape’. These themes were then discussed, examined, and evaluated in this phase, and the results are shown below. The photographs shown in the findings section have been blurred to protect the identity of those who contributed to the study and appear in the photographs.

7.3 Results

This photo analysis was a large part of the ethnography study for this thesis, to understand the practice of Pasung. For this photo analysis, we described all aspects of both content (content analysis) and meaning (semiotic analysis), as noted above.

Figure 7-1: Themes around Pasung Based on Socio-Ecological Model Perspective

The findings highlighted one overall theme: 'No room for escape', implying that coercive restriction occurred over time for PIPs, sometimes for the remainder of their lives. The finding above suggests that Pasung was perpetuated via four interconnected levels of the SEM: 1. Individual; 2. Interpersonal; 3. Community; and 4. Policy (see Figure 7-1). Prolonged Pasung was exacerbated by physical and mental illnesses that developed or worsened on an individual basis. Poverty and an ageing caregiver at the interpersonal level compounded the situation by making the caregiver unavailable owing to their inability to provide sufficient care and support due to physical deterioration, time constraints, and poverty. Thirdly, by stigmatising the PIP as aggressive and violent, the community played an important role in the use of Pasung. Access to mental health services was hampered by an unfavourable physical environment, which led to more forcible confinement and constraint. The politics surrounding Pasung then played a part in the practice's lengthy existence, with certain community members and politicians using it as a commodity to potentially enhance their own local standing or political agenda. Pasung practice continued while the rest of the community went on with their lives as usual. These four aspects have informed the following themes derived from the analysis.

7.3.1 Individual Factors Related to Pasung

Individual factors describe physical and mental illnesses that make it difficult/impossible for a PIP to leave Pasung (i.e., people are placed in Pasung due to mental illness which is then exacerbated by Pasung with the added issue of the development of physical illness and incapacity relating to Pasung). The nature of Pasung, which typically uses one or more combinations of physical

constraints contributed to the theme of ‘No room for escape’. The isolation or separation from the community where the Pasung was initiated made the PIP vulnerable to becoming severely physically and mentally-ill, or deteriorating, as some PIPs demonstrated a lack of communication and withdrawal. Gender and age also played a key role, as Pasung may be applied at a very early age and also over a lengthy period of time without any gender difference, as seen by examples of a young lady being in Pasung for years. The detail of the individual level that contributed to ‘No room for escape’ is described below.

7.3.1.1 Types of Pasung

The findings revealed that Pasung can take several different forms. Despite its many variations, Pasung is characterised by the use of one or more mechanical devices to restrict a person's movement unwillingly, whether by family members or the community. Another common type of Pasung discovered was a combination of seclusion and restriction, with these two types rarely appearing separately. As a result, there is little chance of the PIP getting away from Pasung. The following is a description of various types of Pasung identified in the photo analysis.

1. The Wooden Log

The typical form of Pasung is using wooden logs, which is the original traditional form of Pasung, with most people referring to Pasung as this type where a wooden log is attached to the person’s lower leg in a traditional manner like a stock. There are two different types of wooden logs. The most common is the permanent long log attached to the basement or permanent cement (depicted in the left-hand photograph). This type of wooden log cannot be lifted and is attached permanently to the wall or floor. The second type is non-permanent, and consists of merely a wooden log tied to the PIP's leg, which they may raise or move despite being unable to walk.

Photograph 7-1: The Different Forms of Wooden Stock Used in Pasung

The size of the wooden stocks varied greatly, but most were large and solid which was debilitating to the person's capacity for movement. Frequently, the stock was combined with other mechanical tools such as chains (shown in the middle photograph in Photograph 7.1). It was common to have the person fixed to a wooden log in an open hut or in a small room. In many cases, the FPP team had to carry the person and the stock intact to the hospital for removal using specific heavy equipment or cutting tools because, in many cases, the keys for unlocking the stocks were missing, or the lock was so corroded that the keys no longer worked.

When I looked closer at the man pictured in the middle of photograph 7.1, his stocks seemed relatively new given the fresh colour of the wood. However, the other two pictures indicated that the woodwork had been installed some years previously, as the wood had already perished, and the colour had darkened. I found many of the stocks were made from salvaged wood cut down from nearby trees. Some were still in their original form, while others had been sawn like those in the two outer pictures above. All appeared to have been purpose-built for Pasung by someone with knowledge of carpentry, given the shape and construction of the wooden stocks, the precise measurement of the holes to fit the person's ankles, and the choice of timber that was not easy to break.

2. Chaining

Photograph 7-2: The Type of Chains Used in Pasung

Chaining is another common form of Pasung. It could be that chains are available from the local market and that the family, or the community, did not need to build a hut or special room for Pasung, thus reducing the cost they would otherwise have incurred from building a dedicated hut or structure. Many chaining types are permanent. In the left-hand picture above (7.2) is a man in his mid-40s in Pasung in a farming area with chains attached to his right ankle. There were a lot of native plants and vegetables around the hut where he was chained. It was a short walk (approximately seven minutes) from the neighbourhood. These iron chains were welded to a concrete block on the floor. The chains were approximately 1.5 metres long, so this man could move around. There was a squatting pan toilet placed near the corner. Again, this whole structure was well made and designed for long-term Pasung use, for ease of cleaning and maintenance, and so that the man was unable to escape.

Unsanitary conditions are a common scenario accompanying PIPs, like the man in the picture on the right above, where they were forced to sleep, eat, and defecate in the same small space. Many were subject to physical and emotional abuse, as well as being ridiculed by children. Some had a padlock attached to them, but most of the keys were missing or, if present, the locks were not working any longer due to their poor condition and weather damage.

3. Small Hut

Photograph 7-3: A Mini-House in The Middle of a Fishpond Used for Pasung

Photograph 7.3 depicts a man who had been put in a small hut in the middle of a fishpond. The family, with the support of the community, built this hut. It almost resembled a house with walls and an elaborate roof, but without access in or out. The hut was completely exiled from the surrounding area by the water that physically blocked the hut's occupant from accessing his neighbourhood. The yellow arrow shows the 6-8 feet width of water that acted as a barrier. It appeared to act as a moat because it had a similar purpose as a defence mechanism. The builder or architect of the building might have wanted something that could prevent this person from coming out permanently. The family and the community seemed afraid of this person; hence, they exiled the person in this way.

I could still see the bottom of the pond, so the water was not very deep. I could even see little fish around the area. However, because this photograph was taken during the dry season, the pond may become inundated during the wet season. As a result, it would be more difficult for the person 'living' in the hut to depart, as he would have to swim in the event that he was able to break free of the hut itself, which was reinforced with wood to prevent it from being opened. The water acted as a sewage system in addition to acting as a barrier. The effluent from this hut occupant would flow straight into the pond, where some contaminants (as well as maybe mosquitoes and other insects)

would be eaten by the fish, which would then in turn be eaten (by the person or the family). As a result, it was created to be ecologically friendly, to blend in with the natural flow of life in the environment. At the same time, the caregiver was liberated of the responsibility of providing toileting and bathing assistance to the PIP.

This hut was also intended to serve as a ‘home’ for this unfortunate person. Given the lack of access to the outside world, it is unknown how the family met the man's basic requirements, such as food. Because there was no running or piped water in the hut, it is unknown how this man showered and toileted himself, or perhaps he never had access to amenities other than the pond. Did the caregiver give the man water in a bottle or feed him with a long stick through the hole at the front of the hut? As he was undressed when the FPP team discovered him, it was also unclear whether he had been given any clothing or where it had gone.

Photograph 7-4: A Remote Small Hut Used for Pasung

Some huts used for Pasung were also built on land close to the neighbourhood (7.4 left-hand photograph), while some were exiled in the jungle or in more remote farming areas (7.4 right-hand photograph). These huts were usually small in size so there was only enough space to fit one person. While these two huts were built in different geographical areas, both were constructed in farming areas. The farm hut was traditionally a primitive residence used as a temporary shelter for the farmer during their long hours of work and sometimes to preserve or store a crop. Although built close to the community, people might not notice that the hut had switched its function to

become a place of confinement for Pasung. In addition, the fence served as a barrier, so it was difficult to access. When a fence is in place, it serves to indicate to others that the land is owned by someone, and they are not permitted to enter without permission.

4. Open Shelter

Some PIPs were less fortunate and were confined in very basic shelters that did not have solid walls or structures that would protect them from the weather and the natural elements.

Photograph 7-5: Open Shelters Used in Pasung

The shelters in Photograph 7.5 may have been previously constructed huts that had been ruined by weather and a shortage of maintenance. It is conceivable, though, that they had been constructed without any walls. Apparently, all the persons in these photographs were unclothed when the FPP team first saw them, with the man in the third photograph dressed in batik (traditional Indonesian clothing) supplied by the team after they had arrived.

There are two plastic bags hanging on the wooden post in the top-left photograph (see blue arrow). These contained one day's worth of food. The family sent three bags of food to this man in the morning and left them for him to consume whenever he wanted. The bags' contents only consisted of rice, tofu, and salted fish with no fruit or vegetables. Most of the time, the person did not have an option of what sort of food, or how much, he ate. He appeared to be quite thin, and a lack of

nutritious food may have been one of the contributing causes. However, his family may have been unable to offer enough nourishment due to their financial constraints. This is prevalent among lower-income families in West Java, who are normally able to consume only one meal each day.

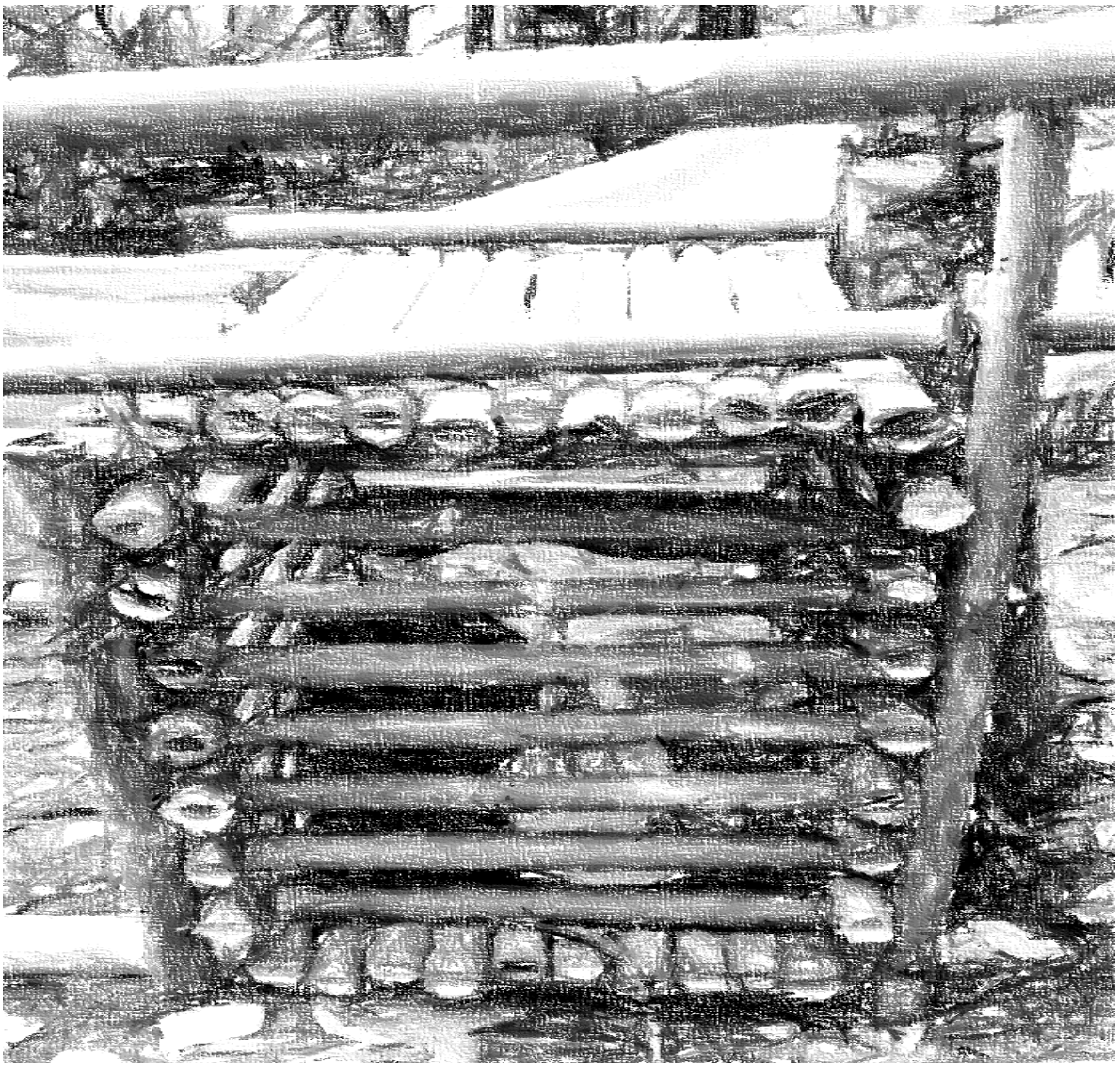
5. Humans in Cages

Several PIPs were living in a cage in an environment with highly fluctuating temperatures due to their location, exposure to the weather, and a lack of bedding or other coverings. Their activity was severely limited to sitting for many hours, a few moments of squatting, and no room for standing. Exposure to such an environment relentlessly 24/7 usually led to contractures in the knee joints (noted in the later theme on physical condition).

Photograph 7-6: Grimacing Eye through The Hole Inside The Human Cage Used in Pasung

At first glance, I did not notice there was someone in the wooden cage depicted in Photograph 7.6. I have seen many similar cages like this in my village; however, they were used for cattle and there were definitely no humans inside them. The cage in the photograph was made from raw timber which looked like it had been cut directly from the trees and then placed in this way to form a cage. It seems that the family had help from someone to make this cage; it was unlikely to be the work of one person due to its size and detailed construction. Constructing it would have required the builders to calculate and measure it thoroughly, to ensure it would fit a person inside. They inserted many big nails into the timber to establish a solid structure. From outside appearance, it appeared that the cage was relatively new. But looking at the man's face inside, grimacing in pain, I could

see that his head was pushed against the top of the cage; it must have been very uncomfortable and painful. He also sat and lay on the hardwood floor, with the sharp side of the wood all around him that would have added to his discomfort.



Photograph 7-7: A Man Inside a Bamboo Cage with Long Chains

The photograph above (7.7) depicts another cage; this time made from bamboo. This type of cage was a familiar scene in this district given that most of the houses had cattle and the main income was from farming. This cage was placed in an agricultural area similar to where they breed livestock. Banana trees surrounded the cage; thus, from a distance, it was difficult to see that there was a man inside. This material is available almost everywhere in rural areas of West Java and is the easiest and cheapest component available for building. I was not surprised that this material was used as a place for Pasung. How the bamboo was assembled, layer by layer, to make it a sturdy building showed me that it was made strong for this specific purpose. And again, the manner of its construction emphasised that it was made by someone who knew how to work with

these materials, which means the family was not necessarily the only ones who built it; instead, perhaps the community in some way facilitated the practice by providing the resources.

Sitting and lying in the bamboo cage was perhaps more comfortable than in the one made from raw wooden blocks as I can see this man inside could lie down to sleep. I was not making any judgement or presumption that this type of cage was any better than other types; however, I made interpretations based on what was presented in the picture. Neither the picture nor my interpretations are meant to discount the level of pain and suffering experienced by any individuals in Pasung in such cages.

6. Segregation/Social Isolation

Photograph 7-8: **A Small Room Used to Isolate PWMI in Pasung**

Isolation or solitary confinement was also a very common form of Pasung used by families. Although many families and/or communities referred to this segregation as a non-Pasung act, instead viewing it as just locking the person in at home, this did fit the definition of Pasung established for this study, because the person was unable to leave their enclosure. In the right-hand-side picture above (Photograph 7.8), the mosaic form which the structure took symbolises that the place was built on purpose. It might have been built in this way as camouflage so that no-one would notice the presence of the man inside the mosaic. It appears that it was also built to last given that the construction was very solid and sturdy. Most of these types of isolation places are

quite small, roughly 1-2 square metres in size. Some are bigger with toilets. In this place, PIPs often have very limited ventilation or access to fresh air and natural light. Meals are usually provided on a plastic plate or in a plastic bag passed through a small hole. The person does not leave the enclosure.

7. Cell Like Prison

Photograph 7-9: A Cell-like Prison Inside a House Used in Pasung

Some people are imprisoned within the house in a cell. Both males in the photographs above (7.9) are locked within a cell inside a house. It looks like a prison cell where offenders are held. The bars on the entryway of these cells appear to have replaced the previous standard doors. Both cells, however, cannot be accessed as the bars are fixed to the wall and there is no visible handle or method to unlock them. It is comparable to the fixed-to-the-wall window security bar. The bars are constructed of heavy steel and are arranged in vertical and horizontal lines, making it difficult for someone to escape. Commonly, the cell has no windows, as shown in these photographs. If it has a window, it is usually a very small crater-like one, like the triangular one in the second photograph. A meal could be inserted through the spaces between the bars. A toilet is mostly available inside these types of enclosures, although some did not even have a toilet. Generally, their condition was filthy and dark.

8. Linen Restraint

The young man in Photograph 7.10 was restrained using fabric. This form of restraint is also never called Pasung in West Java. It is very similar to the restraint process used for highly agitated patients by staff of the psychiatric hospital, and this form of restraint can last for days. Unfortunately, according to information provided to the FPP team, the young man in Photograph 7.10 had never been unchained; the fabric had remained in place for many years, and the family rarely changed the fabric when it got dirty.

Photograph 7-10: A Teenager Restrained Using Linen on His Bed

The photograph (7.10) suggests that the family intended to place this young man on the bed for long periods given they had placed the rubber sheet over the mattress to prevent it from getting wet and to minimise their efforts to clean up after the young man. Urination was unavoidable and it seemed that the family were well prepared for dealing with it and making the situation perhaps less stressful for them as they did not have to clean or remove the mattress. What interests me was the rosary on the bed next to him (the yellow one). In Sundanese culture, and some other cultures in Indonesia, this is commonly used for prayer and/or treatment performed to release bad spirits.

7.3.1.2 Materials Used for Pasung and Room Conditions

The majority of the resources used for Pasung comprised robust materials that could withstand a variety of elements to ensure their purpose was met. We observed that most people in the rural regions used locally acquired wood and bamboo, and that the shelters were separated from the

home. Meanwhile, most shelters in metropolitan areas were placed within, or relatively adjacent to, the house. The use of chaining and cells, or a combination of the two, was widespread in the urban regions.

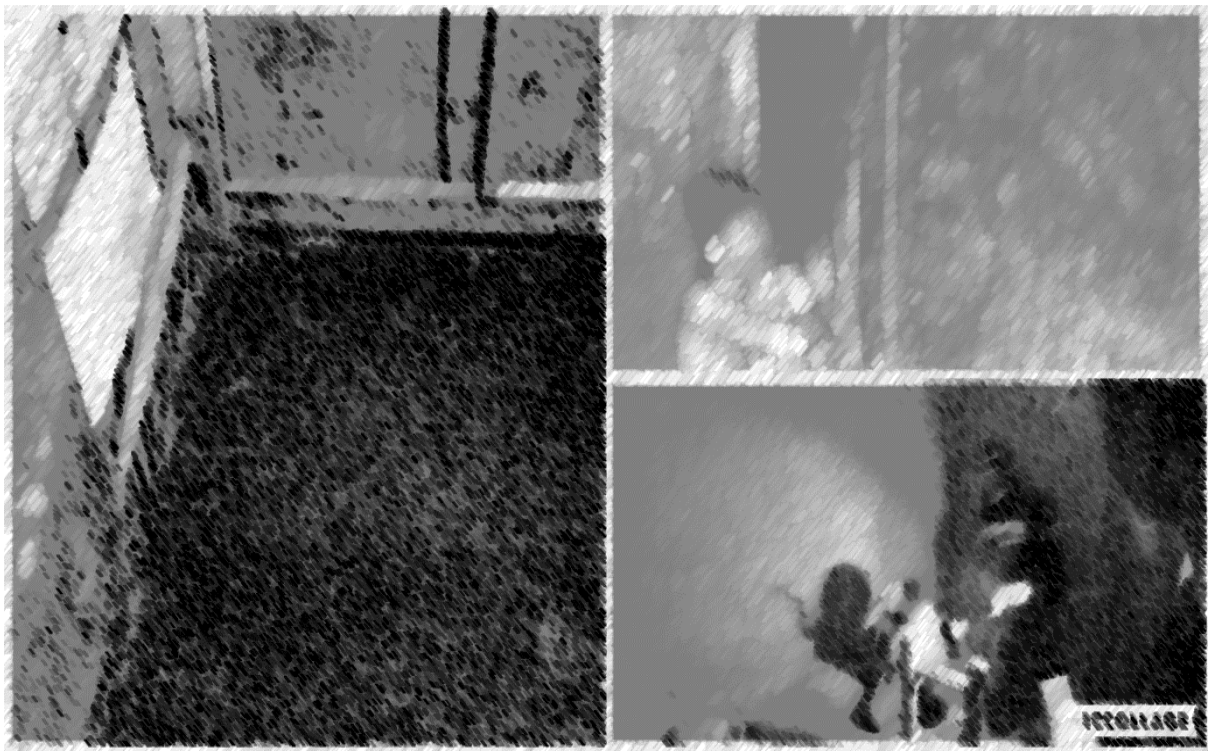
As previously mentioned (see Photograph 7.11, and later in this chapter when stigma is discussed), the perception that a mentally-ill person was dangerous, evil, possessed, and/or violent led to the use of different material dimensions in order to prevent the PIP from leaving their place of confinement. The location and type of buildings in which Pasung happened, combined with the type of mechanical devices and isolation from others, showed that they were designed to be a place that could not be escaped from (as detailed in the themes later in this chapter). In addition, the structures were built to last, as seen by the solid construction and layered materials used to isolate the PIP, indicating that the location would be used as a long-term shelter for the individual. The locations used for Pasung were mostly filthy and dark.

Photograph 7-11: A Woman Shackled in a Confined Space

The building in Photograph 7.11 was used to isolate a woman who was deemed by her family to be aggressive. Like many structures used for Pasung, it was perhaps built to last for many years given that it had a solid structure. The size of the nails suggests that it was constructed to ensure no escape. The walls consisted of two layers of wooden blocks in addition to wooden logs attached to the person's legs. It was a dark, filthy environment designed to keep the person there for years. I

cannot imagine living without light, no communication with people nearby, and no activities at all. The woman even had to sleep while sitting upright. If we looked at this structure from a distance or just passed by, we may not recognise that someone was living there. Most passers-by would likely think it was a temporary hut for the local farmer. This highlights that this individual was hidden in Pasung by her family, and helps to explain why Pasung is frequently overlooked.

The people confined to these types of structures were mostly naked (like many other PIPs shown in the separate themes), and this also applied to the woman in Photograph(s) 7.11, whose family gave her the dress after the FPP team arrived. I believe this woman felt so embarrassed when we opened the barrier as she was lying naked, attempting but unable to cover herself, particularly because all of us were men. So, we let her family get her dressed and waited before we proceeded. Although women's and men's personal concerns have grown more comparable than in the past, nudity in my society still has strongly gendered overtones, particularly in the religious communities in West Java in which many women live. Female nudity and the need for privacy are more important concerns for women than they are for males.



Photograph 7-12: Darkness in the Rooms Used for Pasung

The typical situation, as seen in Photograph 7.12, was that the PIP was kept in dark conditions, even in daylight when these photographs were taken. This can be seen as a metaphor for ‘No room for escape’, as it limits escape through visual input/the ability to escape from the mind. The first photograph depicts a separate chamber built of wood in a home in a city setting. It was completely dark, with no windows to allow natural light in, and doors that were always shut. We

could not see the floor at all. The Free Pasung team had to enter the building in the third photograph (in the right-hand corner) with a flashlight to make sure no-one was inside.

Photograph 7-13: Built-in toilet

Another example of apparent efficiency in the design of places used for Pasung is how some Pasung locations had built-in toilets, as illustrated in Photograph 7.13 (although many do not). The PIP was placed directly on top of the toilet hole. As a consequence, whether urinating or defecating, the effluent would go directly into the tiny creek or a small bucket that was generally built beneath the structure.

Photograph 7-14: The Cattle and The Place of Pasung in Pouring Rain

Many of the places used for Pasung were hidden, and it was difficult to notice there was a person living inside. For example, in Photograph 7.14, the little cage used for Pasung emphasised that the location was designed with care, was properly measured and nicely positioned, and that it was hidden. From the outside, no-one would ever have guessed there was someone living there, as it was a typical scene that observers would assume was a cattle and chicken enclosure.

Photograph 7-15: A Man Naked in Squalid Conditions

The photograph above (7.15) depicts the squalid conditions in a room used for Pasung. This man was lying down on the floor, a small part of which was carpeted. Rubbish and spoiled food were everywhere. It looked like it came from several discarded food wrappers. The family gave this person wrapped food instead of giving it in a dish, and the wrappers were left to pile up as no-one cleaned up the room. This indicates that the family had little intention to care for this person and perhaps will let him die in this place. The wrapped food also suggested that the family had limited time for support or treatment, or had other responsibilities such as work, which led to the condition of the PIP being neglected.

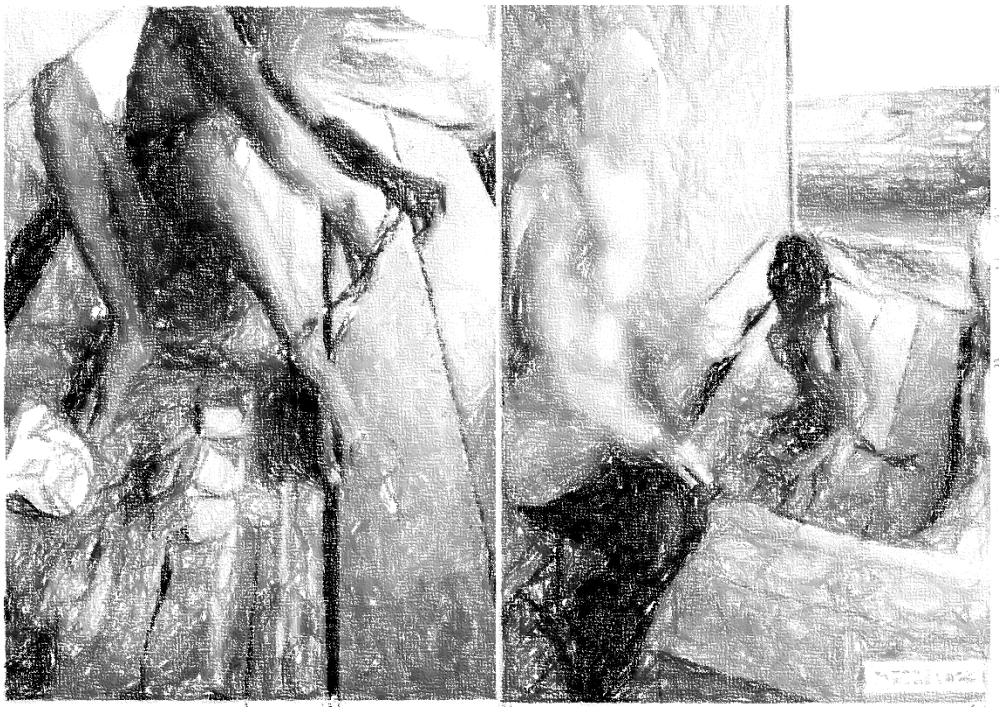
7.3.1.3 Gender and Age

The photo analysis revealed no gender or age differences in how families used Pasung, and which types of Pasung were chosen by them. The young girl in Photograph 7.16 is an example of how the use and type of Pasung do not prefer one gender over another, nor do they differentiate based

on age. She lived in a district around 3-4 hours from the provincial capital that could be described as a rural area given it was located in the heart of the region. However, access to local health facilities was relatively close. The family mentioned that she was possessed by an old spirit. She was verbally aggressive and rarely slept at night. Her lower legs were placed through holes in the large wooden block that was made from raw trees. The colour of the log was a little dark, indicating that it had not been freshly cut and had likely been applied for this purpose for years. The wooden log was attached to the wall and was tied at the end with wire and locked in place with nails. This meant she would never have been able to escape. Throughout the day and night, she sat and laid down on hard surfaces. It might have been similar to, or even worse than, someone who was bedridden. When we freed her, she did not have enough strength to get up, and her hand grabbed me weakly. She was completely inoffensive. I am curious as to what choice or rationale led to the decision to put such a hefty log on this small young girl for such a long time.

Photograph 7-16: Gender and Pasung

The type of Pasung made no difference in terms of age. The photograph below (7.17) shows how chains were placed on a 9-year-old child who was laughing and playing with his younger sister when we arrived.



Photograph 7-17: Age and Pasung

This child in Photograph 7.17 had reportedly been chained for 11 months. He was chained in the backyard of his house. The report said the child was hyperactive, sometimes displaying tantrums, playing with sharp tools like knives, and also displaying “juvenile delinquency” behaviours. From his posture, I did not think this child showed harm towards anybody; playing boisterously and running can be perceived as a normal thing for children to do. Perhaps the family had another reason for using Pasung with their young son.

The place used to confine him was made from a mattress. The family and/or the community cut the middle of the mattress out and modified it with five planks of wood put in somehow to replace the bed springs and padding. At the end of the right-hand side, a chain was inserted into the plank. He could only move around the plank as the chain was under a metre long. They measured the length of the chain so he could not go outside of the boundary of the mattress. It seemed well thought out by the person who developed and designed it for the purpose of effectively restricting and containing the child’s movements, leaving ‘No room for escape’.

He looked skinny and short for a typical boy of his age. He ate directly from the wooden floor without a dish. The family gave him food and placed it on the floor which looked dirty. When asked about this, the family said the child liked eating this way and had been doing so since he was a toddler, when he ate frequently without a dish. On the right-hand side was his sister (right-hand

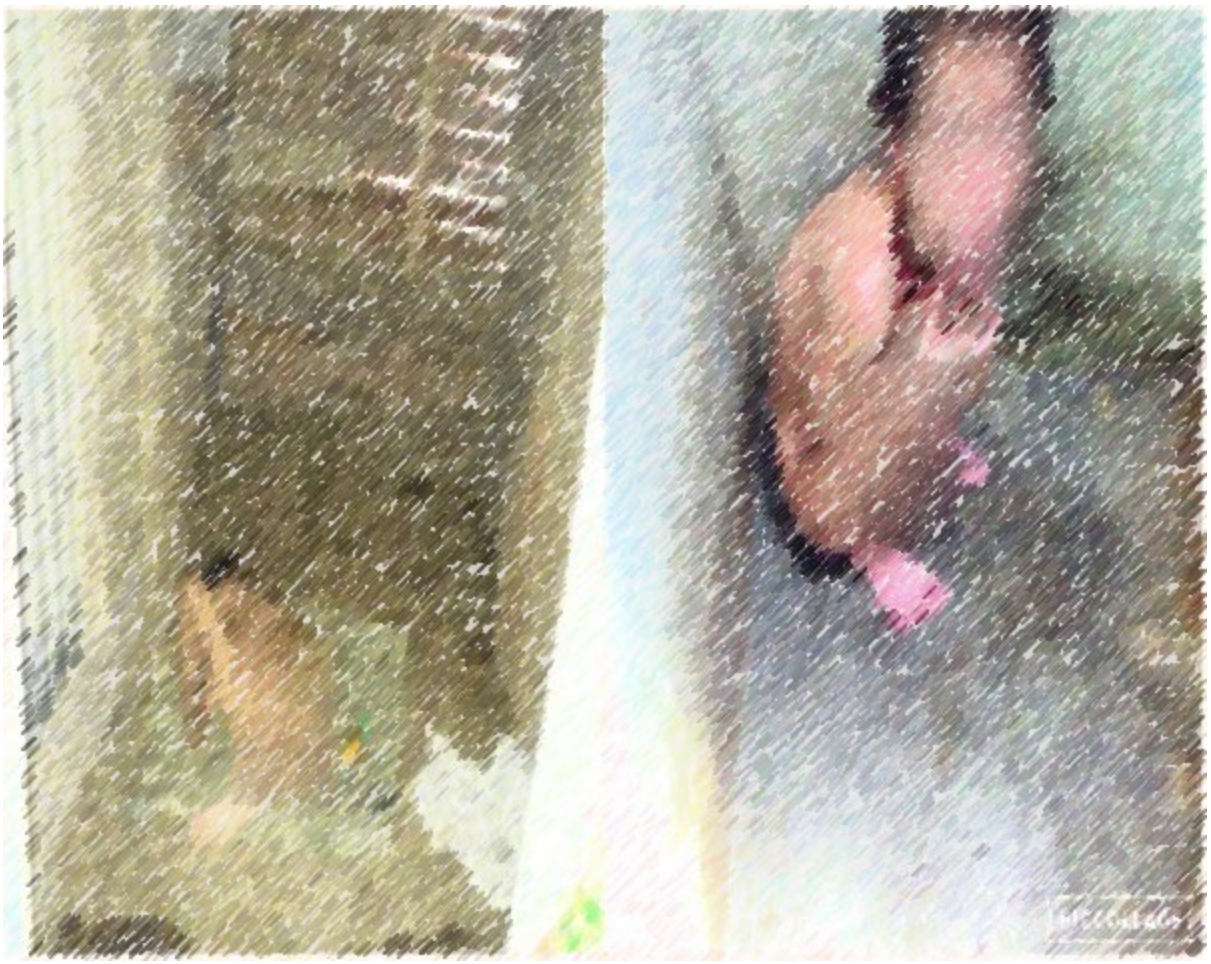
side of the photograph with the pink dress). I wondered what she thought seeing her sibling in chains. She kept talking to her brother while we were there. She sang a song that sounded like a traditional song. It was noon and I wondered why she had not left for school, instead sitting around with her brother. Her brother was smiling while he ate, and he appeared to enjoy his snack while his sister sang to him.

7.3.1.4 Physical Illness and Pasung

The photographs below depict the issue of physical illness as an impact of prolonged Pasung.

1. Emaciated

Many PIPs were malnourished due to a lack of nutrition, and the adverse impacts on their physical health were significant. There were many reasons why the person would become emaciated. It could be the family were unable to provide sufficient food for them due to time commitments or the economic burden, or some other reason such as infectious or chronic diseases. We found that some suffered from chronic diarrhoea and many had tuberculosis.



Photograph 7-18: Malnourished Conditions of Life in Pasung

In Photograph 7.18 above, both women in Pasung appear to have lost their cutaneous skin layer and also lost significant muscle throughout their bodies. Their upper and lower bodies look skeletal. Their faces are very thin, their skin has many blemishes and sores, their eye sockets are sunken, and they appear to look helpless. The woman on the left did not have the energy to even get up. Near her back was a tiny bottle of mineral water (150 ml) for her to drink. Her appearance was pale, so she was probably dehydrated. She lay on the ground, which was covered by a torn and soil-stained floor mat. The shattered wood let in a glimmer of light. Urine was strewn throughout the room (note the dark areas on the soil). The second woman did not fare much better. She had both arms wrapped over her torso and appeared to be trembling. Next to her leg was a plastic glass (approximately 200 to 250 ml). She might have been dehydrated in a similar way.

2. Ageing and Death in Confinement

Photograph 7-19: Ageing and Death Whilst in Pasung

Photograph 7.19 shows a man in his late 40s who has been chained for over 10 years. Throughout his life, he had been placed in Pasung on multiple occasions. He had ascites (fluid collection in cavities inside the abdomen), enlargement of the liver, and elevated blood pressure when we tried to remove him (180mmHg). As psychiatric hospitals do not have facilities to treat mentally-ill patients with a physical illness, this man was referred to a general hospital. However, he was initially rejected by several secondary hospitals, as most local hospitals did not have a facility for persons with mental illness, especially for in-hospital care. He received some therapy at a tertiary

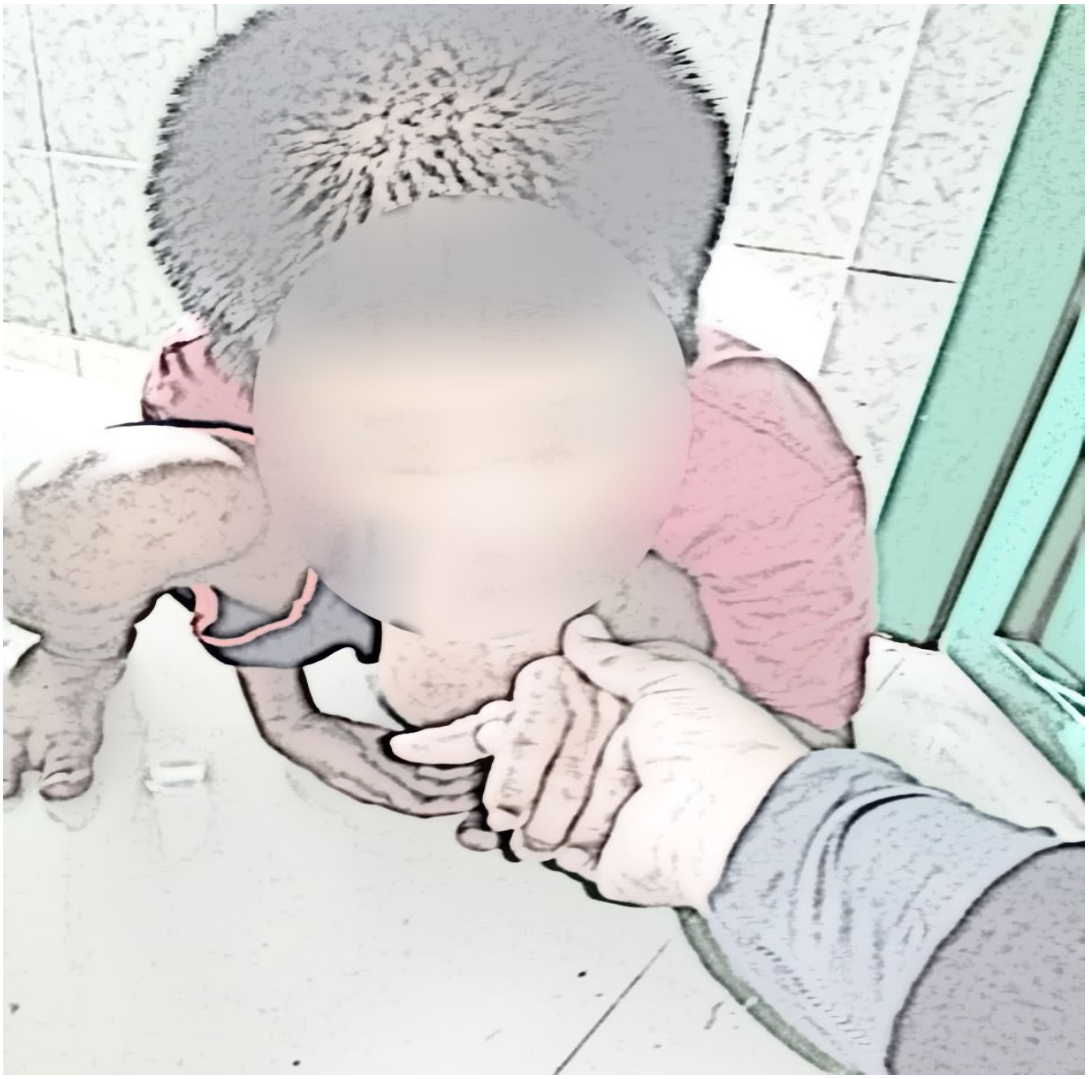
mental facility, but he died soon after his release from the hospital in the hut where he was imprisoned.

3. Other Common Physical Illnesses During and After Confinement

People who have experienced being confined in Pasung can experience significant physical health problems during their confinement and the impacts can be long-lasting or can lead to permanent physical damage and disability.

Photograph 7-20: Physical Health Problems and Pasung

The man in Photograph 7.20 looked non-aggressively towards the medical doctor who was assessing his physical health and evaluating his legs. He could not stand on his own. His legs were bound with ratan, and he had several lacerations on both legs, as well as significant contractures and rashes. When the doctor touched his leg, he grimaced, indicating that it was painful.



Photograph 7-21: Contractures are Common

Photograph 7.21 shows the contracture on the knee joint of this woman which limited her motion. Being in a wooden log for more than 5 years made her knees stiff. Possibly, these joint contractures had been caused by prolonged immobilisation due to Pasung, which limited the passive range of motion of her joints. She will likely need long-term rehabilitation to regain the use of her legs.

7.3.1.5 Physical Condition and Pasung

Nudity has cultural, physical, and mental implications for PIPs. Nudity was also frequently evident in the photo analysis where most of the PIPs that we rescued were stripped. Many cultures have a taboo against exposing sex organs, or to be more specific, the sex organs of grown-up men and women, as well as boys and girls once they reach a particular age. The taboo extends considerably further in Sundanese society than it does in Western societies. There are unique and very harsh restrictions for and regarding women, in addition to the ordinary strictures (which apply to both men and women). It is deemed indecent or immodest for women to exhibit their hair, legs, or their faces outside of the home.

Photograph 7-22: Nakedness and Pasung

A man sleeping naked on a hard floor is presented in Photograph 7-22. The place was filthy. Urine was splattered all over the floor (see blue arrow). He slept in a foetal position with his body and head curled and his limbs drawn, possibly indicating that he felt cold. It could also be a visual indicator that he was experiencing distress, fear, or emotional withdrawal. Many pictures were drawn on the wall by this man. The picture interested me as it also appeared in another photograph. To me, the picture on the left side looks like an evil spirit with a face and scary eyes.

In my cultural understanding as a Sundanese, clothing and nudity are both considered essential in human life from a cultural perspective. The fact that humans are born without clothing is viewed as a sign of sinlessness. However, adult nudity is regarded as unnatural, as though virtue were the distinguishing feature between man and animal. As humans use clothing to express their social identities, someone who is undressed could be associated with a negative state, such as losing their sanity. Nudity, on the one hand, connotes sexual closeness and pleasure. On the other hand, it objectifies feelings of guilt and fear about one's body.

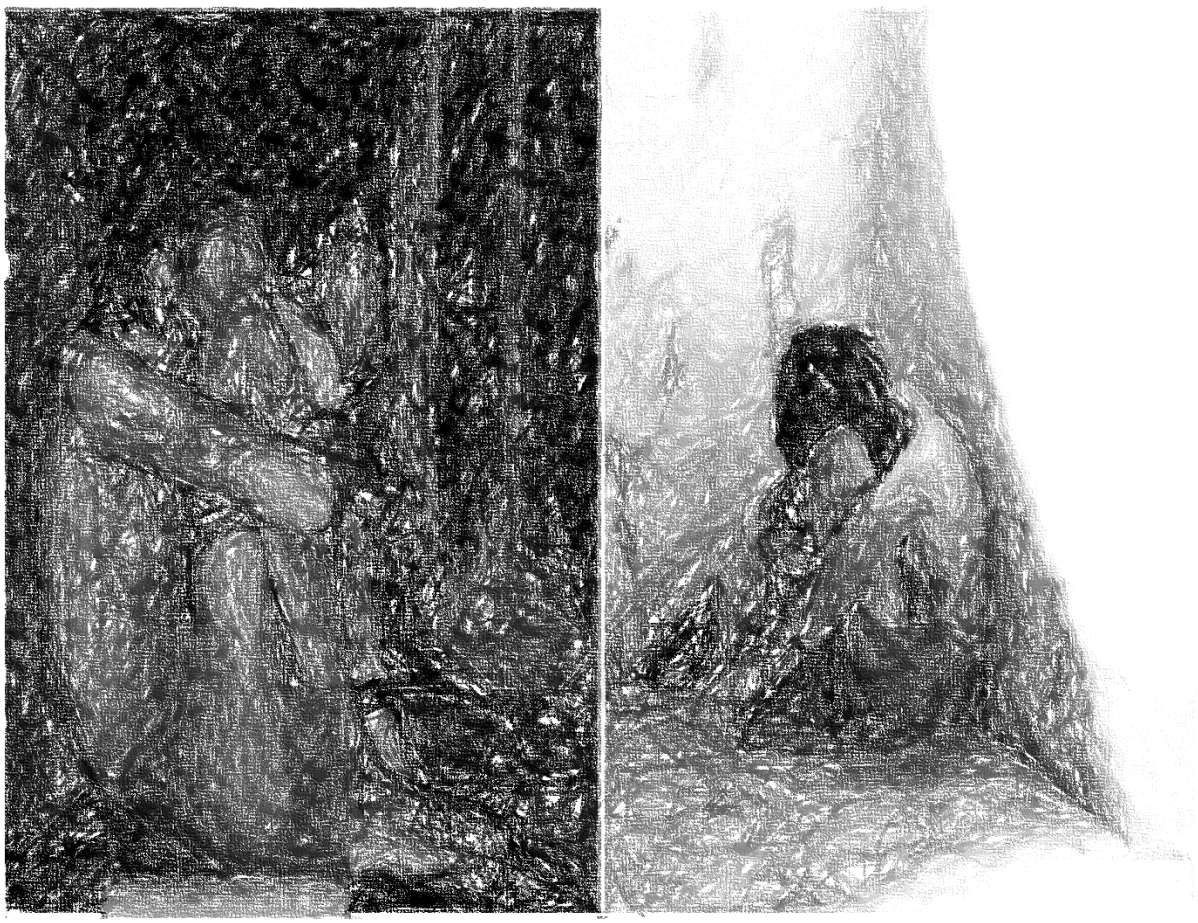
Nudity also has physical effects which may impact the protection like their clothes used to. This PIP may be exposed to cold or hot temperatures (as shown in the photograph). Inside the hut, the body was in direct contact with hard materials such as the floor, wooden logs, and other materials. Mentally, nudity is an embarrassment for PIPs as nudity is considered a moral contradiction. Nudity can also cause physiological sensations that elicit more unpleasant emotions. A person may feel

exposed to aesthetic evaluations of their physique when they are unclothed. Scars, body rolls, hair, varicose veins, and other bodily traits that had previously been hidden by clothing were now visible, as presented in Photographs 7.22 and 7.23. Not only does appearance matter, but when a person is nude, for example, awkward posture and clumsy actions may become more apparent, making him or her feel sexually problematic. As a result, PIPs can be affected by many somatic illnesses, objects of humiliation owing to their nudity, and be unable to leave the cycle of Pasung, leaving ‘No room for escape’.

7.3.1.6 Psychological Condition and Pasung

Many PIPs have negative psychological impacts as a result of Pasung or continuous Pasung. Some displayed disinterest in people, while others were unable to interact properly. However, there were cases where the PIP still displayed good reactions in terms of responding to what they were asked and directed to do. Other psychological symptoms included irritational anger, light sensitivity, deterioration, and talking to themself. The photographs below depict the issue of psychological distress as an impact of prolonged Pasung.

1. **Foetal position**



Photograph 7-23: A Young Man and A Young Woman Curved Their Back and Bowed Their Heads while Chaining in Their Isolation Room

In Photograph 7.23, the man and woman are in their late twenties and have obviously positioned themselves in a foetal position with lengthy chains linked to their legs. This position is most commonly seen in those who have had severe psychological or physical trauma and is a visual indicator of the experience of stress, fear, or emotional withdrawal, and is also seen in those who have felt severely cold as a result of being exposed to cold air. The weather was pleasant outside, but it was damp and dreary in the room. The wall was covered with mould and mildew. Even when we tried to interact with the man on the right as we entered the room of the abandoned house, he remained in this stance. He appeared to be in another realm and did not respond to our greeting. Similarly, the woman remained in this posture until the female nurses arrived to wash her. White lesions were found everywhere on her body (probably fungus).

2. Losing eye contact

A further indicator of the psychological state found in the photo analysis was that some of the PIPs did not make any eye contact when the FPP team approached them.

Photograph 7-24: Lack of eye contact

Photograph 7.24 depicts that both men seemed uncomfortable making eye contact or had lost confidence in doing so. Many PIPs who had lack of eye contact also appeared to have poor communication skills; several appeared mute and used gestures, non-verbal communication, and/or used only very minimal sounds during the process of freeing them from Pasung. It may be that they were in pain, or had not communicated with people for a long time; however, lack of eye contact is also a sign of trauma, in this case, the trauma of Pasung.

3. Bewildered in Pasung

For many, living in stocks had become a normal part of life, basically, their world. Once the stocks were off, I observed that many looked bewildered and confused, and some also appeared to have lost their ability to speak. They might not have understood what was happening to them. My sense of this situation is that, at some stage of their solitary confinement or segregation, they became either mentally-ill, or a pre-existing mental illness had worsened as a consequence of segregation. The initial confinement, the ongoing confinement, and potentially freeing them from Pasung, may be experienced by the PIP as traumatic events.

Photograph 7-25: Bewildered in Pasung

They may also have felt threatened by the presence of strangers, as seemed to be the case for the man in Photograph 7.25 above, who stepped back and looked bewildered when the team came in. Not a single word came from his mouth. He stared with blank eyes and with no expression as if he was not interested in the presence of other people. With his two hands, he covered his genital

area, indicating that he was aware of the social norms regarding hiding nudity. It was an unusual situation, as some PIPs were not entirely conscious that they were nude.

4. Disinterest and withdrawal

Photograph 7-26: Fear of strangers

Another female, shown in Photograph 7.26, had been chained and confined at home for more than three years. She ran and climbed up a tree after the FPP crew removed her chains. She screamed fiercely and would not allow anyone to touch her. We tried to persuade her to come down, but she refused until one of her relatives calmed her down and assisted her. Given her lack of interaction with others for so long, she appeared to have issues with trust. She may have attempted to call for assistance, but as no-one responded, she came to fear and hate others.

Photograph 7-27: Disinterested and Withdrawn

The man in Photograph 7.27 also had no interest in communicating with the team. He sat half-naked and looked at the wall where he had smeared faeces during his confinement. Clothing was scattered around the room. He drew the faces of people with tears dropping from their eyes showing grief. He drew lines that looked like a tally to me (see blue arrow). Did he count how many days he had lived there? I touched the pictures. It looked like they were made from a mixture of materials. But an unpleasant smell suggested that he probably drew these pictures using clay from the chipped pieces that had fallen from the ceiling and mixed it up with something like dried excreta mixed with soil from the damaged floor.

Photograph 7-28: Avoiding

This man in Photograph 7.28 turned his back when the door was opened. It could be that he was angry or did not want people to see his facial expression. It could have been an expression of disbelieving in people any more after spending nearly a decade in Pasung. In my culture, when someone does this, it means you are not here for me, and he does not need our presence there. Physically, it could be a sign of photophobia, a condition in which the person avoids bright light, especially when someone has been living for a long period in darkness.

5. Anger

Photograph 7-29: Anger

The woman in Photograph 7.29 exemplifies another reaction that was commonly displayed by PIPs when they were being freed. She refused her family member's hand when it was offered to help her to stand up. She just stared at her family member's hand and did not even shake it. She was probably upset with, or untrusting towards, her family for their action of putting her in Pasung.

6. Reaching out for help

Not all PIPs, however, acted in the ways described above. Some, like the man in Photograph 7.30 below, was waving his hand when the team was talking outside this hut. He was calling for help or might have been asking for food. I can see the soft drink bottle below the hole and also the small creek to drain the waste from his enclosure.

Photograph 7-30: Reaching out for help

7. Freedom

The man in Photograph 7.31 looked very happy when the chains were released. He held the back of his family member tightly as if he was a child who wanted protection. As seen in the photograph, he appreciated his freedom as he was no longer confined by locks, barriers, or walls. While in Pasung, his family was always watching over him, even while he was sleeping. He had no choice over whom he spent his time with, what he ate, or where he travelled as he had no personal space. There was a feeling of fear and distrust in the environment. It may have been difficult to discover love or even a pleasant human touch. He had lost contact with his family and friends. While the man was gaining his freedom, the others around him, especially one of his relatives, smiled as they observed what was happening. His smile felt incongruous to me, given the terrible circumstances in which someone's independence had been taken away due to his condition.

Photograph 7-31: Freedom

8. This is My Home and Life Continues as Normal

Photograph 7.32 shows a woman who had good communication skills. Her gestures showed me that she frequently spoke to her family or someone else from the community. She showed that she was not afraid of our arrival, and spoke with a clear voice stating her name, but she could not remember how long she had been there. She told me that the place was “her home”.

Photograph 7-32: This is my home

The place which she called home where she was confined was made from bamboo. The place looked dark, with mould and mildew everywhere. The bamboo was rotten and there was space in between the slats, so someone outside could see what she was doing, so she had no privacy. The spaces between the bamboo slats also let the wind come in. The smell of cattle mixed with mould was very strong. I imagine it would have been very cold inside there at night or when the temperature dropped. I saw no blanket or jacket there, so she relied on the sarong which covered her head. Rubbish was scattered on the floor.

Photograph 7-33: The Man in Long Chains Sitting in Front of His House Watching a Worker

In another urban area, a man with a long chain was sitting in front of his house. A construction worker laboured while the man in chains sought him out from a distance. The worker must have been alerted that someone was in chains, yet he seemed unaffected by the presence of this individual. This man was another PIP who could communicate verbally. Despite some unrelated answers, he was able to answer and reply to some of the questions asked. Some PIPs were emotionally disturbed as a result of extended solitary confinement, and others were in poor physical condition. This man, on the other hand, had a high muscular density and appeared neat, implying that he showered and had adequate nutrition.

To summarise, at the individual level, the nature of Pasung entails varying degrees of material resources that either improve Pasung practice or are harmful to the health of PIPs. This type of Pasung might be related to the availability of space and materials, and could take any form which

differed according to the geographical area. However, the intent was the same; each type was designed for ‘No room for escape’. As a result, PIPs were dealing with physical and other psychological problems. PIPs needed to deal with both Pasung and the symptoms that occurred as a result of either a past illness that caused them to be in Pasung or the excesses created by Pasung. Some PIPs, for example, were unable to walk firmly, while others were unable to walk at all. As a result, people became demoralised and lost hope of escaping Pasung, or became depressed as a result of the uncertainty and maybe impending death.

7.3.2 Interpersonal Factors Related to Pasung

Interpersonal factors describe individual relationships between PIPs and their community, spouse/partner, and family, and in particular, the connection between a person's behaviour and the family’s perceptions of risk. The findings demonstrate that the family felt there were no effective, accessible alternatives to constraint and isolation. Two inter-related concepts impacted the decision to use Pasung. Poverty restricted access to mental health services, which encouraged restriction and isolation. Second, an elderly family and an absent caregiver drove the community and family to isolate and restrain the PIP. When a family's demands for caring and functioning collided, they were frequently forced to choose between shackles and/or vagrancy. Pasung then was a more viable option, as vagrancy might have resulted in a fine or complaints from neighbours.

1. Poverty

The photographs demonstrated that poverty, either in the family or in the patient, was a common factor in many cases of Pasung.

Photograph 7-34: The Carer and Poverty

In Photograph 7.34, an elderly woman dressed in a red outfit sat patiently as the evacuation took place. She sat watching with her hand on her son's leg. She was the mother of a PIP. During the whole process, she was silent. With so many visitors coming to her house and so many eyes on her ailing son, she appeared confused. I could see that she was perplexed. While everyone on the scene may have blamed her for restricting her child, she may have had few alternatives for seeking and receiving help for him. She was a single mother who had raised her unwell son alone. She was the breadwinner (the main source of income) for her family, while also doing household chores. She worked daily in the farming area rice fields as a casual worker and was paid a mere IDR30-50 thousand per day (AU$3-5). She left her son unsupervised during the day. She may have feared that her son would wander or behave aggressively towards their neighbours. Furthermore, she might not have been able to de-escalate her son’s aggressive behaviour due to her age and physical condition, or she might not have known how to deal with it. In addition, the area in which they lived was a suburb about 15 minutes by car from the nearest community health centre and under an hour drive to the local general hospital. It was even further to get to the nearest psychiatric hospital which was 4-5 hours’ drive away.

2. Ageing family

Many Pasung caregivers were also absent, and some, if they existed, were elderly. Most of these elderly caregivers were mothers.

Photograph 7-35: The Nurse Visiting the Family in The Community

Several families had psychotropic medications provided to them by the community nurse to give to their family members with mental illnesses in Pasung. Note in Photograph 7.35 that the nurse took care to package and label the medications in an effort to facilitate the family administering the medications to the person after she had left. The family depicted in Photograph 7.35 continued to keep their family member in Pasung, despite receiving regular visits from the community nurse who provided them with medications to give to the person. My experience of being involved in the FPP team is that many of these medications never reached the person, either because they refused to take them, or the family were unable to manage the medications. This raises a number of questions about the family's and the person's level of mental health literacy, their beliefs about medications, their trust in health professionals, and the challenges they may have faced in administering the medications as scheduled.

Photograph 7-36: Pasung, Poverty and Ageing Family

Several families, as pictured in Photographs 7.35 and 7.36 were ageing, with some of them unable to read. My knowledge of these communities informs me that some PIPs came from extremely poor family circumstances where even elderly family members had to leave the house to work on farms or to do other jobs during the day to fulfil their basic needs, such as acquiring food; taking the PWMI to a health care provider for medication or tending to their needs at home may have been perceived as a lesser priority.

Photograph 7-37: A Family Member Caring for The Person's Basic Needs

In Photograph 7.37, a family member can be seen spoon-feeding a chained man. What is unclear here is: How often does the family have time to provide nutrition? How much is mental illness a focus for the family? Who within families takes on the primary role of tending to the PIP and what influences this? Do family members have different perceptions of the problem, and do they have conflicts about the solutions? Do families experience feelings of helplessness, frustration, loss, guilt, and compassion fatigue in this role?

Photograph 7-38: Food and Water are Scarce for PIP

Another photograph, as seen above, shows that the family has a limited amount of time to provide adequate food and drink. Pasung was designed to be efficient, so the family did not have to go to the PIP every time. The family constructed the structure with food and water insertion without having to open the hut. While some PIPs still had access to food during their confinement, some others found it hard to even get water. The photograph above depicts a bottle used by the person inside the hut for a drink. The bottle looked dirty. The family only came once a day to deliver food and water. He might have felt thirsty and this was why he inserted the bottle through the hole to ask for water.

3. Between Shackles vs Being Vagrant

Photograph 7-39: Interpersonal Exchange between Family Member and PIP

In Photograph 7.39 above, the young man in Pasung had spent 5 years in stocks. The man on the left is his brother; they appear to be engaged in close conversation and a cigarette is exchanged as part of their interaction. The man in this photograph was crying when he visited his little brother. I stood still seeing this man shed tears as he was one of the family members who had confined his brother.

To summarise, at an interpersonal level, the photo analysis prompted me to consider that these families felt there were no effective, accessible alternatives to constraint and isolation. Poverty, in

addition to ageing families and absent caregivers restricted access to mental health services, which encouraged restriction and isolation. Family responses to mental illness may be located along a continuum between rejection and coping, with the furthest extremes ranging from vagrancy (abandonment by the family) at one end, to home chaining at the other. Within the lifetime of the person's mental health condition, families may shift from restraint to rejection or resignation.

7.3.3 Community Factors Related to Pasung

The community plays an important role either in promoting PIP treatment or generating negative effects on the overall impact of PIPs. This photo analysis identified a lack of accessible alternatives to restriction and seclusion, showing that community members believed these practices had no effective, accessible alternatives. This view is influenced by two interconnected themes. First, an unfavourable physical environment contributes to aggression, restraint, and use of isolation, which is linked to geographical location and access. Second, public stigma influences the use of prolonged Pasung as stereotypes and prejudice about the mentally-ill as violent and dangerous led to isolation and discrimination.

1. Remoteness, proximity, and unfavourable physical environment

Analysis of the photographs showed that spatial location, either in urban or rural areas, played an important role in shaping environmental risks for Pasung practice. The landscape of the West Java province, with many mountains, steep terrain, forests, rivers, and agricultural land, created both opportunities to isolate PIPs as well as difficulties for the team in conducting the FPP (see Photograph 7.40).

Photograph 7-40: **Inaccessibility in Rural Locations**

While some PIPs were confined in the neighbourhood within homes or structures that were near others, many of them were exiled in the woods without access to people, naked, and not well fed. The man pictured above (Photograph 7.40) was naked prior to the FPP team's arrival on the scene, at which point they provided him with these clothes. He was chained to a bamboo tree and had been there for more than 5 years. The bamboo wood where he lived was located 20-25 minutes walking time from the nearest community. He looked dirty, and his condition suggests that he probably had not bathed for years except when it rained. He had long, matted and dirty hair before the team cut it off. As shown in Photograph 7.40, the topography of West Java province, with its many mountains, steep terrain, forests, rivers, and agricultural areas, made administering the FPP more challenging for the team. Some parts of rural West Java were even inaccessible to vehicles or other modes of transportation. To reach individuals like the man in Photograph 7.40, the FPP team needed to go on foot or by motorcycle.

However, in West Java, photographs revealed that Pasung was not only found in rural areas; it was also found in many places in urban areas located close to health service access. The four pictures below in Photograph 7.41 are an example of Pasung in one of the big cities in West Java which ranks as the third most populous city in the world.

Photograph 7-41: **Pasung in Urban Locations**

The photograph depicted the narrow street which separates the house and the neighbourhood. I assume it was troublesome for people to hide someone in such a dense district. Perhaps everyone would know if someone was ill, or something had happened to their neighbour. When the FPP team opened the door, there would be someone else's door right next to it. But, in fact, most people present told the FPP team that they did not know anyone in Pasung. This poses a number of questions: Was the family hiding this from their neighbours? Was society somehow different, perhaps more individualistic, in the city?

Photograph 7-42: **Urban Pasung Can Be Overlooked**

The woman in Photograph 7.42 above was in her 30s and was in Pasung in an urban location that was only seven minutes away by car from the local psychiatric hospital and under ten minutes walk to the nearest community health centre. Her circumstances suggest that remoteness of location and inaccessibility of health services were not the main reasons for this woman being confined by the family in a separate hut. It looked like a 'multi-purpose' hut, as there was a water well, cattle, cattle food storage, and a family graveyard co-located with the hut. Surprisingly, it was missed

even by the local health authorities including the psychiatric hospital until the news of this woman's situation appeared in the newspaper headline one day before the FPP evacuation process. That is, it was in plain sight but overlooked by the community.

2. Public Stigma

Mental illness stigma appears to be largely accepted by the public at large in West Java. Photographs demonstrate some of this stigma, which was even communicated implicitly. For instance, the sentence "berbahaya in Bahasa" means dangerous in the shelter used for Pasung.

Photograph 7-43: Stigma (Living Here Dangerous Person)

The words written on the front wall of this concrete enclosure (Photograph 7.43) provided passers-by with the name of the person, the date and year the hut was built (8-10-2007), and the warning sign, "beware dangerous place, do not give any dangerous tools", indicating a strong stigma around PWMI in West Java. The fact that the majority of individuals were aware of these stereotypes, at least for the passers-by, did not mean they agreed with them. But the photograph where this man was exiled was far from the community as shown above, and people avoiding being close to them suggested that the community appeared to agree with this stereotype.

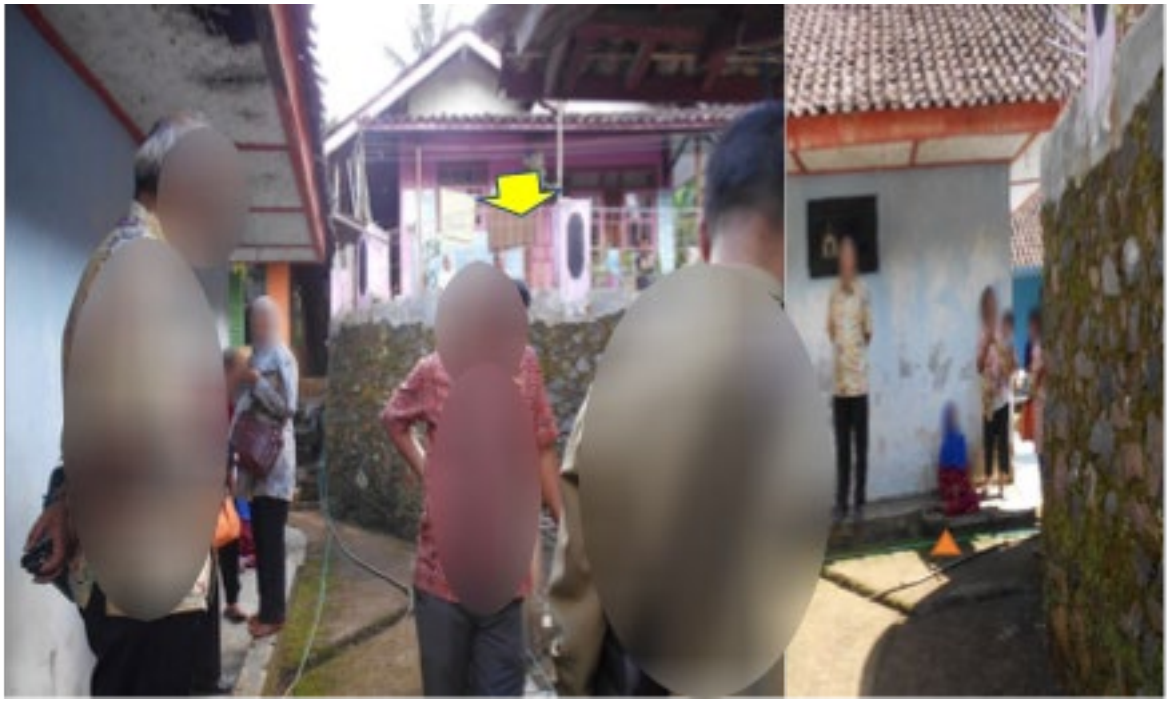
Photograph 7-44: **The Man Is Half-Naked and Confined Using The Wooden Log, With a Combination of Chains on Both Hands and Legs**

These negative stereotypes led to social distancing and/or the community physically distancing. For example, I found one man, as shown above, who was over 40 who had been confined for many years. The wooden log seemed to be designed for a long period, given that it was mixed with chains (see the right corner) both on hands and legs. The chains were already rusted, and the colour of the wooden log looked dark and worn which showed it had been used for years. The photograph showed that the person might not be released either for eating or fulfilling basic toileting or hygiene needs.

Arguably, the community could say they did not know and were not involved in this situation which created such inhumane treatment to this ill man. However, when I looked closer at the wall next to the wooden log, there was a large mark and damage to the structure. It appears that this person had been trying to escape by breaking the log. He probably also made noises to show his existence to others in his environment, as he also screamed a lot when I arrived. The extent of this damage to the wall (the force of contact) and the apparent weight of the wooden stocks and chains suggests that this person had used significant force to try to gain his freedom despite the cost of injury to his legs. Although the heavy wooden log was likely to need at least two people to lift it, this person appears to have managed to lift it with both of his legs, as if he had adapted to the weight. In addition, the blue arrow indicates a small window about half a metre in height and a metre in width. This suggests that any noise from his screams or banging the wooden log onto the wall

would have been heard by people outside. However, even with the noise from the wooden log, none of the neighbours came to help this man. This condition, in fact, might have reinforced the stereotype of PWMI as dangerous, leading to the community physically avoiding him.

The photographs in 7.45 below show that the house where a man was confined was in a crowded area where other houses were separated only by a narrow street. On the left-hand picture (yellow arrows) some neighbours also became passive bystanders. They were mostly watching from a distance, the activity of freeing the person from Pasung. I did not know the content of their conversations, but they looked curious about what was happening. The photograph reinforced how the community behaves towards PWMI in Pasung. Instead of offering help, they tended to pick up idiosyncrasies to try to guess what the story was about. Some of these women were also talking to their children while seeing the person being freed from Pasung, but it was unclear what they were saying. Frequently, when the Free Pasung Team came to treat the PIP, some people, mostly children, wondered what was happening. None of us or the community explained to this young generation what had really happened and what they should do if seeing this type of traumatic scene. Mental illness appeared to be seen as entertainment by these young people.

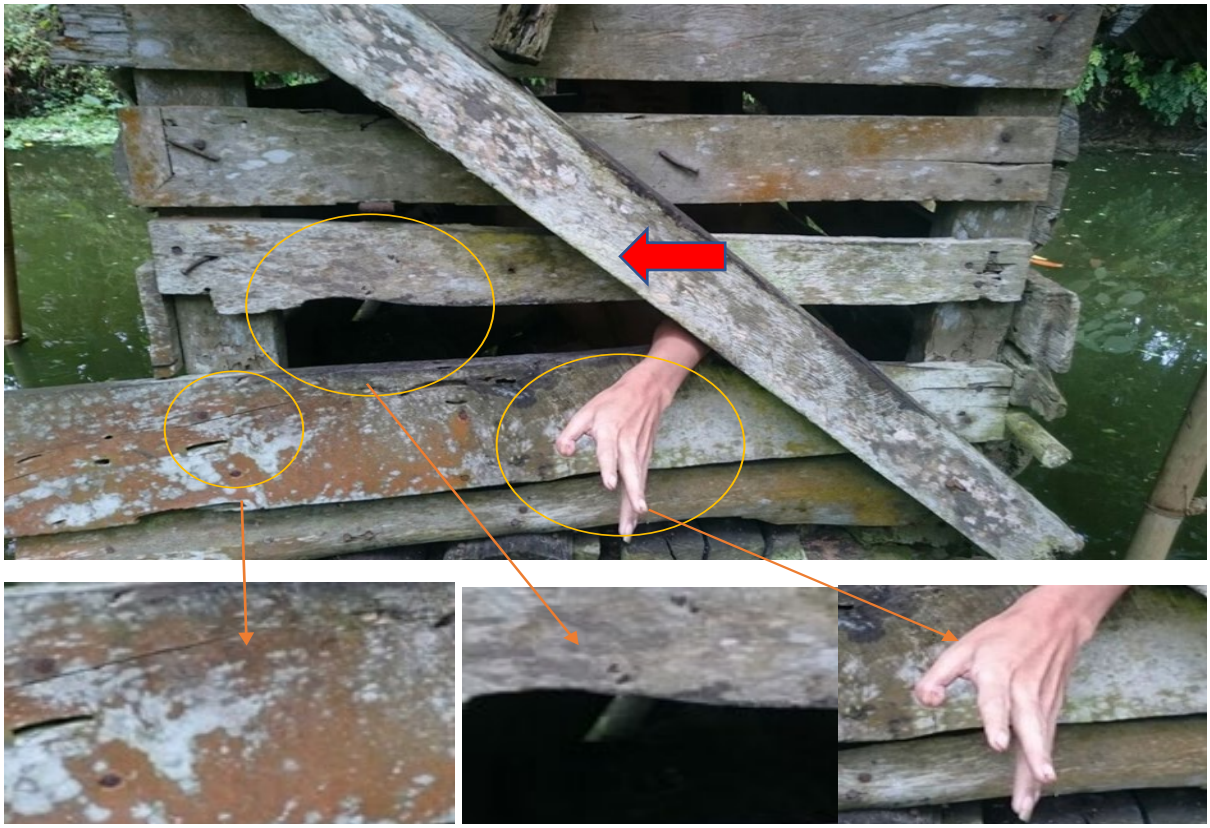


Photograph 7-45: **The House and The Neighbour**

The significant impact of stigmatisation also motivated certain members of the community to join in the creation of a shelter for a mentally-ill person; for example, the man who had been put in a small hut in the middle of a fishpond (Photograph 7.46). The family, with the support of the community, built this hut; it almost resembled a house with walls and an elaborate roof, but without access in or out. The hut was completely exiled from the surrounding area by the water that physically blocked the hut's occupant from his neighbourhood. The yellow arrow shows the 6-8 feet width of water

acted as a barrier to prevent this person from coming out permanently; in other words, to protect others in the surroundings from the resident of the hut. Meanwhile, in the above photograph (7.45), everyday life continued around the PIP. Perhaps people were unaware of the person or were fearful.

In rural areas, the isolation of PIPs was severe. A person could be put in a hut that was completely separated from the neighbourhood.



Photograph 7-46:**The Man Isolated in the Small Hut Waving His Hand**

This hut also aimed to be a 'home' for this unfortunate man. When I looked at the hut for the first time, I misinterpreted it as a toilet. In many villages, particularly in the West Java countryside, toilets built in the middle of a fishpond or creek made from bamboo or in a semi-permanent form are frequently found. But when the person's hand began waving from the peephole, I realised there was a man inside the hut. The shelter was about three feet tall and was therefore not even high enough for the man to stand upright. He must have been kneeling or sitting for the duration of his confinement in the hut.

The diagonally positioned wooden cross (see red arrow) was intended to keep the doors from being opened from the inside. However, it could also have been a warning to others that someone or something thought to be harmful was present in the area. It could also have worked as a medium to repel evil spirits or someone possessed by the devil in Sundanese culture, such as in

my village. As a result, anyone walking through, or passing by, the hut should avoid upsetting or confronting it.

Photograph 7-47:**The Man Isolated in Hut Deep In The Woods Under The Glass Roof, so He Has Constant Light Both from the Sun and the Moon**

Apart from the spiritual symbol associated with evil depicted above, another individual was placed in a cottage far in the woods with access only foot. We had to navigate through rough terrain and dense vegetation. The cottage where this man lived was a 4 by 3 metre structure with plastered walls and a cement floor. The roof was tiled with a glass roof in one place, allowing the sun and moonlight to directly illuminate this man's body. The family believes this was done to free their child from a malevolent spirit. Putting him deep in the woods would help him calm down as he would be able to reflect on his angry behaviour and lessen the chance of violence in the neighbourhood. Belief in demonic possession, or the belief that persons suffering from mental diseases were possessed by demons, spirits, devils, or ghosts, or had been subjected to a spell, was common in Sundanese cultures and beliefs. Spiritual healers, chaplains, dukuns (shamans), and paranormal healers were among the traditional and alternative healers, often known as ‘able’ people, who were commonly sought out by patients, their families, and community members for therapy. Traditional healers, on the other hand, were usually physically or mentally abusive towards their patients throughout the treatment process in attempting to exorcise the devil, Satan, or demons from the person's body, which may include isolation and confinement in some cases.

I know this view is also very strong in my village. It is one where psychiatric symptoms are viewed through a supernatural lens or as punishment from the gods. But does this view affect how people decide to place their family members in Pasung instead of seeking out other kinds of therapy like spiritual or traditional healers? Or is it that the family and/or community hold stigmatised views towards people with mental illness which involve negatively stereotyping them as aggressive, violent, and dangerous, and which then positioned PWMI as social outcasts?

To summarise, the community factors indicate a wide range of beliefs about aggressive behaviour in relation to mental illness. Some of these misconceptions and beliefs had an influence on mental and physical health, while others caused negative stigma. Many people who suffered from Pasung also had to deal with both problems. Furthermore, the lack of accessible alternatives to Pasung, showed that community members believed these practices had no effective, accessible alternatives which resulted in lengthy Pasung and ‘No room for escape’.

7.3.4 Policy Context of Pasung

While the Free Pasung intervention tried to minimise the use of Pasung, as well as the risk of harm and death to the individual, some people acted differently and had other goals. The media representations of exposed nakedness and identity, the utilisation of other forms of seclusion and restraint by health practitioners, and the loss of family and individual privacy all strengthened this viewpoint. Another issue was how the FPP programme became a commodity for political campaigns. These reflected the policy context of Pasung identified in the photographs.

1. An ethical dilemma

Photograph 7-48: **The Free Pasung Team Intervention**

There were ethical dilemmas around Pasung, as seen in Photograph 7.48 above. In the scene depicted in the left-hand photograph, the FPP team were taking care of the PIP; they cut his hair, bathed him, dried him with a towel, and gave him suitable clothes to wear. It took more than 30 minutes to do these tasks. It looked easy to do, but making the person who was isolated for years trust us was troublesome. Therapeutic communication needs to be taken both to the family, the PIP, and the community. Likewise, in the right-hand photograph, the FPP team were checking the person's medical condition. However, the question arises when undertaking such interventions, should we bathe them naked in front of everyone else, particularly when it might be that a person of a different sex to the PIP provides the treatment? With so many people around, what does the PIP feel about it? Would they feel shame? While the health worker or other government and non-government agency provide treatment for someone in Pasung to reduce possible significant injury or death to the PIP, there is a possible threat of losing privacy for the patient as they are being the object of the treatment (e.g., people naked and many people are watching).

Photograph 7-49: **The Team Put Fabric Restraint on This Man**

Photograph 7.49 depicts the team putting clothes on the PIP, releasing the wooden log from his legs, and restraining him again although he was not aggressive. If they were released from Pasung to be restrained in another form, did the PIP feel free or did this make no difference to them at all? If the hospital or health worker did similar things to Pasung, why should they be released from Pasung?

Photograph 7-50: **Reporting on Pasung for the media**

A further ethical issue relates to the role of the media in Free Pasung. Photograph 7.50 depicts a reporter who took a picture of a PIP. While the media play an important role in disseminating information and increasing the awareness of the community to cease Pasung, they created problems concerning confidentiality. Many photographs of PIPs and their families can be found in the media without facial blurring and anonymisation of their names.

2. The politics of Pasung – Who benefits?

While most people provided care for the person as part of the process of freeing them from Pasung, the presence of some people was perceived to have a different purpose. In the picture on the left in Photograph 7.51 below, the politician stands upright next to the family member (and the PIP who is interestingly still behind bars) and poses for the camera. Perhaps they need to be seen to be taking action to address Pasung to win the favour of voters in their community.

Photograph 7-51: **The politics of Pasung – Who benefits?**

Although it appears they are not interacting directly with the PIP, in the picture on the right in Photograph 7.51, the bureaucrat is again posing for the camera, where the PIP appears to be cowering from them. This raises a number of questions: Is the bureaucrat using Pasung for their own political purposes? Is the social volunteer doing something similar for fundraising, and are other officials such as health administrators similarly benefitting from this focus? Are these approaches to the problem helping the PIP?

Photograph 7-52: **Media Portrayal of Collaboration and Action to Address Pasung**

Free Pasung involves many people from many sectors ranging from local government, volunteer organisations, community health centres, social affairs, public health offices, and psychiatric hospital staff, and each has a different priority and target informing and driving their involvement. Photograph 7.52 above exemplifies how the FPP team prepare to undertake the intervention to free a person from Pasung. We hold a meeting before the implementation process and this stage can take even longer than the process of freeing the person. The negotiations required are very demanding to ensure buy-in and cooperation from every stakeholder involved and moving each of them towards a focus on a similar goal. There are 16 people in the above photograph, each ensuring their presence in the process of freeing one individual. It appears to be a very ‘official’ affair.

Photograph 7-53: The FPP Team

Before the evacuation, the FPP team met in a huddle. The huddle was convened to address the evacuation procedure, transfer to the hospital, post-hospital care, and ongoing therapy. There were several stakeholders, each with their own interests and objectives, which made communication and management difficult. Despite the fact that these stakeholders had the same goal, they were interdependent and came from varied backgrounds. Free Pasung necessitates a lengthy negotiation procedure. This disconnect has an impact on how various health and non-health professionals in West Java manage and deliver care to the mentally-ill in Pasung.

3. Family Life, Pasung and Less Community Involvement

The process of freeing a person is undertaken as a team; it involves planning together, communicating, and negotiating. Sometimes, we do not involve the family. In Photograph 7.54 below, while we were busy planning, the family were also sitting watching from a distance, looking somewhat confused and silent. This situation can occur, particularly when the family are absent or are ageing.

Photograph 7-54: **The Family Look On**

The above photograph showed how the family (the older couple) were left out of the meeting which raises a number of questions: Should the family be more involved and how should that look? What is the role of the PIP in decisions about how Free Pasung should occur? What does the team consider when deciding if and how to involve the family or the person? What factors influence how the various stakeholders work together and negotiate decisions?

To summarise, the policy-related findings reveal that the intervention to free someone from Pasung involves many stakeholders and people. It is a long, complicated process because of the range of

bargaining positions between the stakeholders involved. Although the attention of media and politicians brings some benefits in term of FPP as a priority to be solved, this situation however brings a negative influence on how the FPP becomes a commodity for political campaigns rather than for the eradication of Pasung which has resulted in ‘No room for escape’. Although health care providers and patients can be seen interacting during the FPP implementation, consumer involvement is not visible as the family is left in limbo while the team continues to communicate, negotiate, and plan together. The family was just sitting there, looking perplexed and silent as they watched from afar. Equally, the PIP’s role, beyond being the object of the activity, was unclear.

7.4 Summary and Concluding Statement

Pasung continues to exist through four interconnected levels of the SEM: Individual; Interpersonal; Community; and Policy. At the individual level, the nature of Pasung entails varying degrees of material resources that either improve the practice of Pasung or are harmful to the health of PIPs. This type of Pasung might be related to the availability of space and materials and could take any form which differs according to the geographical area. However, the intent is the same; each type is designed for ‘No room for escape’. As a result, the PIP is dealing with physical and other psychological problems.

On the other hand, families often felt there were no effective, accessible alternatives to Pasung. Poverty in addition to elderly families and an absent caregiver restricted access to mental health services, which encouraged restriction and isolation. Family responses to mental illness may be located along a continuum between rejection and coping, with the furthest extremes ranging from vagrancy (abandonment by the family) at one end, to home chaining at the other. Within the lifetime of the person’s mental health condition, families may shift from restraint to rejection or resignation. Pasung practises strained the relationship by causing physical clashes between families and PIPs, as well as preventing social and emotional engagement. Families provide comfort and, conversely, coercion.

Stigma towards mentally-ill PIPs appears to be insidious, characterised by stereotypes, prejudice, and discrimination. Furthermore, the lack of accessible alternatives to Pasung, shows that community members believe these practices have no effective, accessible alternatives. The policy context hampered the already problematic FPP, which appears to be a lengthy and complicated process due to the range of bargaining positions among the stakeholders involved. This disconnect affects how various health and non-health professionals in Indonesia manage and deliver effective care to the PIP, resulting in ‘No room for escape’.

8
MULTIPLE BARRIERS TO HEALTH ACCESS FOR PERSONS IN PASUNG: VIDEO ANALYSIS

8.1 Introduction

Visual research is becoming increasingly relevant in many disciplines (Knoblauch 2012; Knoblauch & Schnettler 2012), including health and mental health (Petros et al. 2016), as video technology and recording equipment grow more accessible and pervasive for private use, and less invasive as a result of their widespread use. Videography is unique in its capacity to capture a variety of information and the nuances of interactions, events, and surroundings in real-time, all of which may be revisited numerous times for in-depth analysis with a level of ease and accessibility not possible with fieldnotes, audio files, or transcripts (Knoblauch 2012; Knoblauch & Schnettler 2012). The potential to repeatedly view whole episodes of fieldwork and data collection in the later phases of research, and widening the temporal concerns of fieldwork and analysis, is provided by visual data recorded as an extension of researcher memory. Moreover, the opportunity to study films and recapture an event with discursively fresh and seasoned eyes supports the iterative process of analysis and discovery, which adds to the benefits of visual analysis (Knoblauch 2012).

This video analysis is part of the ethnographic study to better understand Pasung practice. When ethnographers create videos, the visual texts they create, as well as the process of creating and discussing them, become part of their ethnographic knowledge. Images, like sounds, aromas, textures, and tastes, as well as language and any other aspect of culture and society, are ubiquitous in ethnography (Banks 2018; Banks & Morphy 1997).

The video analysis was the most difficult aspect of the study to research and write up. Despite having similar content to the photographic data, which also captured images of PIPs, analysing the videos was particularly challenging as they were highly variable in length (3 minutes to 45 minutes) and the quality was sometimes poor as they were taken by a camera or phone that was not designed for high-quality video recording. Moreover, the video-maker (the researcher) is a non-professional user of video equipment and had never learned how to make a ‘professional looking’ video prior to conducting or as part of this research; for example, defining the right angle. Another issue in my interpretive practice of image data analysis was how to produce a holistic interpretation of all the features (sounds, visuals, symbols) reflected in the video. Some of the content was even hidden from the researcher. However, considering that all aspects of a visual image may be essential sources of knowledge for analysis, the important issue is how the interpreter of the videos can detect and sort them into a meaningful narrative.

While I recognise the importance of visual methodologies and visual data in answering my research question, I also recognise their limitations. Visual methods, for example, frequently require much time and technical knowledge. Ethical concerns and sensitivities associated with visual-based research exacerbates the more standard ethical challenges involved in such research, necessitating a much deeper understanding of the research subjects, their relationships, and the norms of the research context. However, as previously stated, the use of visual methods has its advantages and adds a significant contribution of knowledge to this study, as well as providing an alternate way to comprehend the meaning of Pasung. So far, no single research approach has been able to properly develop an accurate narrative of Pasung, based on the findings of our systematic review (Hidayat et al. 2020). As a result, in this study, I used visual methods in addition to other qualitative enquiry approaches with the aim of capturing the complexities of Pasung in the community.

8.2 Methods

Methods are the skills, techniques, and equipment used to answer research questions, whereas methodology is the reflection on the methods, ranging from comparison of technical aspects to a more general theory of methods (Engler & Stausberg 2021). The term ‘video analysis’, as it was earlier detailed in Chapter 6, point 6.3.2, refers to any type of methodology applied to video data (Knoblauch 2012). It is used here solely as it relates to video recordings of social interactions that take place involving a mentally-ill PIP. This means interactions in the broadest sense, ranging from health staff interactions with the PIP to community interactions with the person, family, and community, to technically mediated interactions, interaction with oneself, and even interactions with invisible actors (e.g., spirits and gods when the PIP may talk to themselves). Social interaction, as defined here, is conceived of within an interpretive framework, as mentioned previously in the methodology. This type of video analysis builds its ideas by interpreting the recorded social interactions as elements that have meaning on their own, or to be more precise, by inventing their very meaning through the acts captured audio-visually. In this respect, video analysis of this type must be classified as not only qualitative but also interpretive (Knoblauch 2012; Knoblauch & Tuma 2011b).

However, given that video analysis is not suitable for every type of video (Knoblauch & Schnettler 2012; Knoblauch et al. 2012; Knoblauch & Tuma 2011a), this research used a modified version of videography that combined different types of analyses. In addition to the notion that not every analysis is compatible with all video data, the broad range of approaches presented in this research highlights the fact that the data have been recorded by the researcher themselves in a more or less naturalistic social situation (Knoblauch & Tuma 2011b). A natural setting in this research implies that the researcher did not aim to construct the scenarios they examined, but rather, strove to document interactions where and how they were thought to occur without the

researcher's interference. Audio-visual recordings and analysis of 'real' social interactions require the researcher to travel to 'where the action is,' which is where people were living in Pasung. That is, the researcher using this form of video analysis frequently enters particular scenarios in an anthropological manner. In this sense, video analysis is ethnographic. It is also known as videography (Knoblauch 2012). The details of the videos analysed for this study are shown in Table 1 below.

Table 8-1: The Pasung Video

No	Name	Content	Duration
1	Video 1	The video around the Pasung, the family, the community and the treatment during Pasung	34.36
2	Video 2	The meeting, the assessment	19.04
3	Video 3	The referral system, the assessment, the community	21.34
4	Video 4	The advocacy, the community health centre, the treatment and drug medication	18.09
5	Video 5	The meeting, the treatment, the involvement of top bureaucrat	10.44
6	Video 6	The return to the community and the community health centre	2.47
7	Video 7	The Free Pasung understanding from the perspective of tertiary services and treatment inside the hospital	8.27
8	Video 8	Pasung in an urban area	3.25
9	Video 9	The early assessment, the information to family	4.09
10	Video 10	Pasung with physical illness and the communication with the PIP and family	10.21

From a total of ten videos, three were identified that provided a more thorough explanation of Pasung (Numbers 1-3). Initially, the entire ten videos were viewed by the researcher and the supervisors. We analysed each video through three processes: the input (internal and ethnographic sampling); the process of fine-grained analysis; and the output analysis (see Chapter 6, Section 6.3.2). My supervisors and I exchanged views on the video findings. I mentioned in Chapters 1 and 5 that I come from the Sundanese culture where the study was conducted. In the earlier stages of conducting the research, I therefore, made a number of assumptions about the data, given that I live and have grown up within that culture. My supervisor, in contrast, who comes from a Western culture that is completely outside of the Sundanese culture, had a different shape and view of the data, asking many questions about what they observed in the video data and

photographs. This questioning enabled me to become more aware of the richness and nuances within the data that I had previously overlooked as part of my everyday cultural experience. Additionally, by responding to the supervisor's questions, I was able to articulate and explain in greater detail the rich cultural context of Pasung and the environment in which it occurred, which I had hitherto taken for granted. After the discussion, we decided to look further at the three videos (videos 1-3) as a sample, given that we had made a judgement that the other videos had similar frames, that would best be represented by the three selected videos.

The videography largely posed answers to research question 3, 'How is Pasung perceived and experienced from the perspective of PIP, their families, community, health professionals, non-health professionals, policy-makers, and health system managers?; research question 4, 'What are current understandings regarding the FPP's implementation, its effectiveness, and how it is practised?', and question 5, 'How have Indonesia's policies on FPP and mental health influenced Indonesia's efforts towards eliminating Pasung?'. The videos looked at Indonesian Free Pasung initiatives apart from the nature of the person and the family in Pasung. I characterise Free Pasung initiatives as those that use multi-sector partnerships, emphasise the importance of community members as vital to the intervention, and/or provide services in community settings. This intervention is being studied in numerous areas, including collaborative care, community-based interventions, social justice, global mental health, and mental health promotion/prevention, as mentioned in the MoH (2017) (see the details in Chapter 4: Policy analysis). All the names of the actors depicted in the videos included in this research are not their real names; pseudonyms have been used. The included dataset has been stripped of all identifying information, and there is no way for the researcher or other investigators to link it back to the subjects from whom the footage was originally obtained through a key to a coding system or any other means.

8.3 Results

The Social-Ecological Model (SEM) was adopted as the overarching theme for the analysis, as the model provides a framework for comprehending community intervention actions, which in this research is the FPP. The study findings emphasised the connection between mental health, interpersonal relationships, and the social determinants of health, which revealed one overarching theme, namely **the multiple barriers to receiving mental health services**.

The video analysis has highlighted the multi-level barriers to mental health services (see Figure 8.1). The SEM conceptual model laid the groundwork for reporting on the emerging themes. At the individual level, the findings revealed that PIPs were unable to receive effective therapy owing to both physical and psychological issues. Prior to the person being placed in Pasung, access to proper mental health care was hampered by avoidance of help due to a lack of insight into illness. The family in contrast were unable to continue to deliver the needed care for the PIP due to work

obligations, a lack of funding, or other activities they were compelled to do. Many of these families confined the PIP to their homes or other locations until they stopped being aggressive. Negative attitudes towards the diagnosis and treatment of people with mental illnesses, which view the PWMI as not being a member of the community and as unable to function, have also hampered access to treatment. These individual-interpersonal level problems were made worse by insufficient resources, fragmentation of services, and poor multidisciplinary communication at the community level. The inability of this group of PIPs to obtain services was also significantly hampered by structural constraints, including inadequate policy execution.

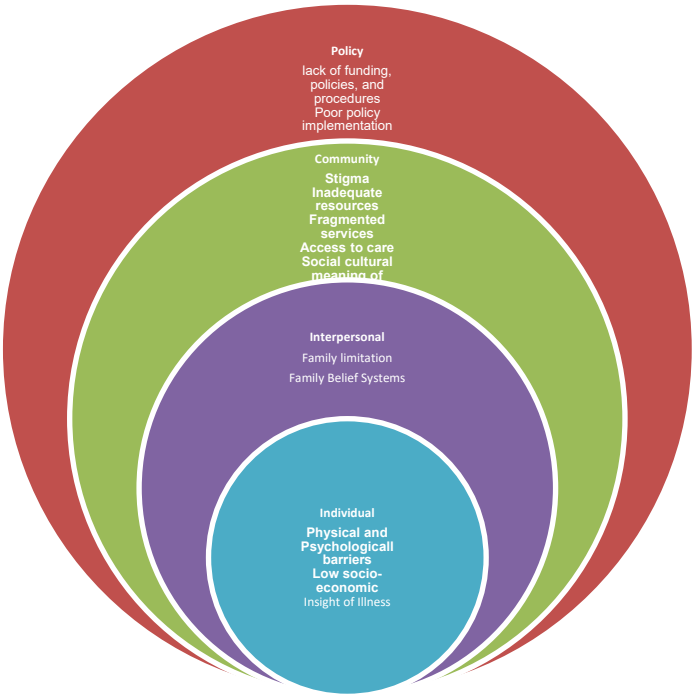


Figure 8-1: Onion Diagram of The Multiple Barriers to Receiving Mental Health Services

8.3.1 Individual level

The individual level includes the knowledge, attitudes, beliefs, and capabilities of the individual, in this case, the PIP. I identified three themes related to individual factors, namely: physical and psychological barriers, low socio-economic status, and lack of insight into illness**.**

1. Physical and Psychological Barriers

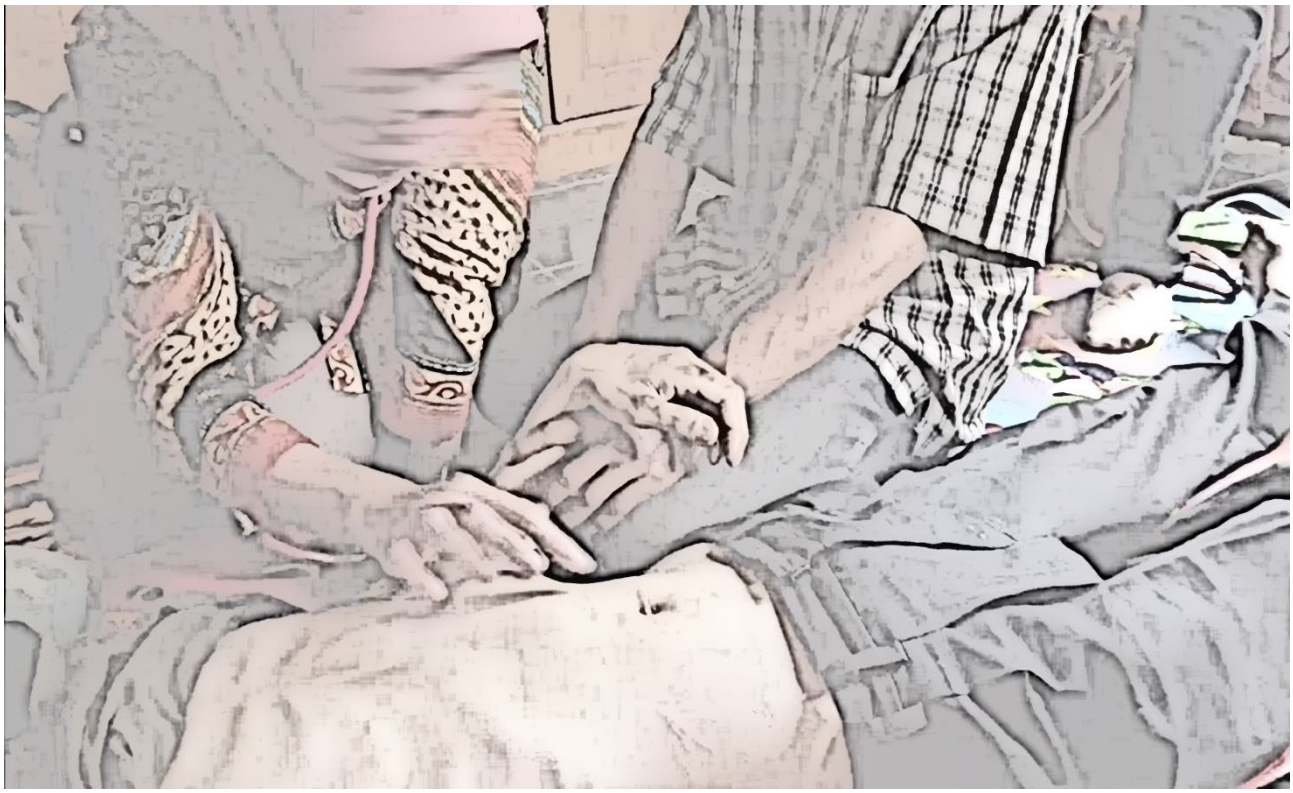
Pasung victims performed their everyday routines, including eating, showering, and toileting, in the same location where they were kept. A person who was subjected to Pasung was completely reliant on the care of others, particularly their family. This required a significant amount of effort to keep their surroundings clean and safe to live in. They were completely cut off from people, other than those who fed them and cleaned their surroundings. The course of Pasung was often indefinite, often resulting in physical and psychological difficulties.

Still Photo 8-1: Alone in the crowd

The man in Still Photo 8.1, taken from Video 2, showed no enthusiasm for interacting with others. He smoked while he sat and behaved as if he were living in his own world. When we enquired about his health, he did not even look at us as we waited for his response; he just sat there. Instead, he asked one of his family members for a cigarette and then lit up. His family went on to say that he (Mr U, as we referred to him) only spoke when requesting food or cigarettes and never corresponded with other people. Even though their family kept in touch with him while he was chained, he hardly ever spoke. He mostly interacted and communicated with people non-verbally by using gestures, body language, and his outward appearance. Since he became ill and stopped communicating with family members on a regular basis, his family has claimed that he has been acting strangely. His condition has deteriorated since he has been chained. According to the records we have from the CHC, this man had been there for more than 7 years due to aggressive behaviour, wandering, and disturbing the neighbours. He was 33 at the time the video was taken, although his appearance looked older.

In line with what I found during the photo analysis, the video analysis revealed that the PIP's social interactions appeared to be significantly impacted by Pasung, particularly prolonged Pasung, leading to social rejection and disengagement, and fewer emotional ties, most of which were quite strained. Pasung practice appears to have deprived those subjected to it of the ability to develop and actualise their potential as individuals and social beings; this had been taken away from them. The condition may aggravate the person's health and their help-seeking activities.

In addition to psychological problems, the analysis revealed that physical ailments caused issues for PIPs as they became more dependent on others for treatment. This issue extended beyond the act of seeking help; physical examinations and on-site medication administration were challenging tasks as well because the FPP team had to build a relationship of trust with the person. If trust was not established, the person may withdraw or even turn violent. The FPP team needed to frequently transport the PIP by stretcher from the location where they were chained to their home in order to perform a physical examination (see Still Photo 8.2 below).



Still Photo 8-2: The Physical Examination

As mentioned earlier in Chapter 7, the FPP involved many people from a wide range of sectors, one being the Community Health Centre (CHC). In the still photo above, the staff from the CHC conducted a physical assessment on the PIP because he was suspected of having a physical illness. His body was already emaciated. Physical examination revealed poor skin turgor indicating severe dehydration, and a pulse rate of more than 100 beats per minute with an irregular rhythm. It was suspected that abnormalities in the heart, liver, and kidneys existed. The person was then referred to the nearest hospital for physical treatment as a result of his condition. As noted in Chapter 3, the most challenging issue was the referral system for those with physical problems, because psychiatric hospitals lacked the expertise and services for physical illnesses. The general hospital likewise rarely offered psychiatric care. As a result, the FPP team frequently failed to refer the PIP to the general hospital if a physical illness was present.

2. Low Socioeconomic Status

The socio-economic conditions, in which the majority of PIPs depicted in the videos were unemployed, was another problem that prohibited them from accessing proper mental health services. The lack of available family to care for them financially hampered the situation. For example, in the first video, a man who had been in Pasung for the past 15 years was initially placed in Pasung when he was in his late 20s, jobless, and without any relatives to rely on. Fifteen years ago, he returned home to his family after a period in Pasung as a young man. Within one month of discharge from a psychiatric hospital, his family was unable to continue his treatment, so they returned him to Pasung and he had been there ever since, until the day of this filming. The man's parents who were his carers had recently died, and other extended family had been providing the man with food since that time. His divorce from his wife exacerbated his illness after he became recurrently unwell.

Despite living relatively close to the psychiatric hospital, about 2.5 hours drive away, and other health facilities (around 10 minutes driving), the individual did not have access to adequate mental health treatment during his time in Pasung. He also lived in a neighbourhood that was densely populated with families, yet the neighbours had no idea this man was in Pasung. Economic factors hampered the situation, as discussed by a Major in one district in the second video, who commented:

> Because they come from the middle to lower economic class, most families give up when taking treatment. The drugs for mental disorders are expensive, and very difficult to reach for residents who, on average, work as farmers. Even though they can pay, for example, it is not available in many CHCs in our regency. That is the biggest problem. But it is better late than never. The government has already taken care of it. The Public Health Office and Social Service Office had gone to the field to conduct research and estimate the problem. This is important to map out what is the real problem and of course the health history of the residents and what factors might trigger mental disorders there (Video 2).

Moreover, in the same video, a family member discussed the absence of the PIP's father, as follows:

> His father lives in another regency for work, which is about 7 hours away by car. While his father, my eldest brother, is away, I am caring for him because he has no close relatives who still live in this village (Video 2).

As many of these people depended heavily on their families on a daily basis, their family also had a say in their autonomy and choice of therapy. When the family was not there, it was more difficult to make decisions, which would also affect the administrative procedures and the intervention as most of the informed consent and paperwork needed to be signed by the family.

3. Insight into Illness

Another obstacle preventing the patient from seeking treatment identified in the video analysis was their lack of insight into their illness, which relates to the ability of someone diagnosed with a mental illness to acknowledge and accept that they are experiencing a mental illness. The patient in the video was a 42-year-old man with a history of being chained for the past 5 years. Prior to this, he had been working at a hotel as a kitchen assistant. He displayed hostile behaviour against other hotel employees and was constantly carrying a knife, which made other employees nervous. His mother said that her son did not feel ill, and did not want to go to a psychiatric institution or a community health centre. The family tried to take him to the community health service but was unsuccessful. Similarly, when the team assessed him, he kept saying that he was healthy.

> “What are you going to do? Why should I be examined? My health is excellent, and my blood pressure is normal. Look at me; I am in perfect health. I continue to work while watching television for myself,” the PIP said (Video 2).

As he appeared increasingly violent, the team attempted to give him psychiatric medication to calm him down, but he refused and attempted to fight the team. After giving him an injection and placing him under restraint, the team drove him to the mental hospital.

The patient's continued non-compliance with the recommended treatment plan remained one of the main management issues.

> "When the team gave him the medicines a couple of days ago, he threw them away. He is uncooperative and refused the meds we offered him,” the community health staff added (Video 2).

As demonstrated in the example above, health professionals often disguised medications as other substances, such as vitamins, in an effort to increase adherence, and ultimately, the quality of care provided to patients. The person in the above example was initially brought to a psychiatric hospital, but after learning that his family had concealed his medication in his food, he became more suspicious of his family, stopped taking the medication, and ended up in Pasung again. In this situation, the family turned to hiding the medication in his food and drink due to the PIP’s lack of insight into having an illness.

In summary, the results showed that PIPs were unable to receive effective therapy on an individual level because of a confluence of physical and psychological problems. Due to their socio-economic status and reliance on their families on a daily basis, these individuals struggled to seek help. Their families can also influence the PIP’s autonomy and therapy preferences. Furthermore, due to a lack of insight into their illness, some PIPs refused to accept the diagnosis of mental illness and the treatment offered by their families, which created barriers to receiving mental health services.

8.3.2 Interpersonal

The interpersonal level in this video analysis includes opinion leaders, family, and friends as external influencers. At this level, social identity, role definition, and norms develop and function, which might affect health care decisions.

1. Family Limitations

The study revealed that as primary caregivers for an ill family member, families faced limitations in providing care. There were several reasons why a family would use Pasung on an ill family member. Video analysis revealed that the families viewed Pasung as an effective way to protect the person from harm, prevent them from harming others, as a remedy, or to achieve all of these goals at once. Whatever form Pasung took, families believed that using it was necessary to limit potential damage and, to some extent, improve the person's condition.

Still Photo 8-3: The Family and Onlooker

In the still photo taken from Video 1 above, a group of approximately 12 people, including various family members and others from the community, and predominantly women, came to watch the activity in front of the family house. The house in which the family lived was a permanent structure made of brick with a cement floor. Three families from two generations (i.e., the PIP's sister and her children lived together) lived in the house, indicating low socio-economic status. One older woman became distressed and started crying, and moved back to be comforted by another woman. "I can't stand to see him like that. Really sad." The other woman tried to console her and said, "Be patient, keep strong. It will be over soon." Children were looking on and moved around among the adults; most of the onlookers just stood still, taking in the scene. One young man

prepared water for the PIP (we called him Gunner) to take a bath. The many onlookers added more burden for the family as they were stigmatised for having a family member in Pasung. This demonstrates that the impact of Pasung was felt not only by the person suffering from the illness, but also by their family members and the community from which the patient came, which limited the PIP from getting better access to health services.

One of the CHC staff from Video 2 further expressed that:

> There are many questions from the family and community regarding the situation (Pasung). What should we do if we are working? What should we do to the person to avoid him/her doing something harmful to other people or things? Will we go to jail or get fined because of locking someone in the house? Many of them are farmers that live in poverty. Although the media mentioned that there were 60 cases, based on our survey it is 51 cases. For these 51 cases, we are now trying to validate what kind of problem they have. If having a mental illness, then we will refer them to the psychiatric hospital for treatment and if not then we will refer them to the general hospital. Until now we are not sure. From the previous survey, many of them in Pasung are locked in their house, chained. The reasons given for doing Pasung were aggressive behaviour, disturbing the neighbourhood, and carrying sharp tools like knives.

Furthermore, in this video, the typical family members that used Pasung were women over the age of 50 who had no education and worked as farmers on a casual basis. In the second video, the family explained that they had to chain their family member for several years due to aggressive behaviour, wandering, and disturbing the neighbours. “I think 7 or maybe 5 years. I could not remember exactly.” Families also revealed that PIPs frequently had disturbing experiences that were precipitated by stressful situations or which remained unexplained. Stressful occurrences may have been related to exposure to violence during childhood, economic hardship, or more personal issues such as a relationship failure or an unmet goal.

2. Family Belief System

In a collectivist community such as West Java, the care of a person with mental illness is reliant on family support. Families are responsible for monitoring the progression of the illness and determining how far a person's health deviates from normalcy or wellness. The family will also determine where to seek aid and what treatment to receive.

> “But even after several visits (mental health service), he isn't any better. As a result, we kept him there [in Pasung]. Otherwise, he'd be wandering around and causing havoc. When someone called him crazy, he would get upset. He rarely sleeps at night,” the family stated in Video 2.

The reasons for the illness given by the families ranged from biological to supernatural, and both biomedical and traditional treatments were applied separately or simultaneously. Families may

regard certain attitudes, emotional expressions, or conduct of their members as deviant when they do not conform to social standards and values, and when there is some concern about the nature of the behaviour. Local religious authorities, community leaders, and/or traditional healers/shamans (dukun) have traditionally been referred to initially when a person displays abnormal behaviour. The problem worsens when the person engages in long-term behaviour that is both disabling and damaging to herself/himself and others. The requirement for more care and resources may be the main factor preventing a family from reaching any degree of self-sufficiency in already poor circumstances.

While health care professionals may view biomedicine as a standard resource for mental health issues, others including this family, believe otherwise. They used a non-medical system that included self-care medication, traditional healing, and other professional services. Even though the family depicted in Video 3 eventually consented to the person being treated at the hospital, they repeatedly refused to visit the nearest CHC. "We took him to Galunggung," a family member stated. This name was taken from the mountain, and the location was on the lower part of the mountain. The place provided a spiritual healer and a traditional herb that was very popular among the residents of the area, and was commonly the first choice when self-medication was unsuccessful. Typically, the person would live there for a few months, participating in religious activities and taking traditional herbs. The healer rejected modern medicine and believed that mental illnesses were caused by the possession of the Jinn or evil spirit. As a result, the patient needed to be liberated through purification and prayer.

To summarise, most families in this video analysis used traditional methods for interpersonal communication, with some turning to more contemporary approaches such as mental health services after exhausting all their local options. Most of the time, this treatment was administered against the PIP's will while he or she was chained or restrained. Many of these families confined the PIP to their homes or other locations until they stopped being aggressive. The primary reason cited was the inability of families to care for PIPs due to work obligations, a lack of funding, or other activities they were compelled to do, consequently preventing the PIP from receiving appropriate care.

8.3.3 Community

At the community level, the videos revealed a number of factors related to barriers to help-seeking, including resource shortages associated with infrastructure, service fragmentation, sociocultural factors (e.g., cultural challenges), and geographical area.

1. Negative Attitudes Towards Pasung and Mental Illness

Being mentally-ill had a negative stigma in society, but many Sundaneses experienced a double disadvantage. They worried that their employer would find out. Many PIPs who were working or

applying for jobs were hesitant to formally indicate they had a mental illness because they did not want to be expelled or stigmatised by others as incapable. One family member expressed this in Video 3 by saying:

> Everything is okay; he was employed prior to becoming ill. He had a part-time job. He accepted whatever position that was offered to him. He works very hard. However, he never takes his medication during the night since his family claims he would fall asleep, and others will notice that he is ill.

The family emphasised this by expressing their discomfort with being videotaped or providing access to medical records that might have included them. Additionally, in three areas, the CHC reported that PIPs had declined treatment due to concerns about taking psychotropic medications, including the perceived stigma and feelings of failure as a father, child, or other roles they had, fear of harm to their families, and concerns about dependence on, and the side-effects of, the drugs.

There had been claims of stigma, remorse, and shame connected to receiving a mental illness diagnosis and therapy. Mr IS, the Mayor of C Regency, stated during the opening ceremony that they were shocked by the news of a large number of Pasung cases in his region (Video 2). Even though he admitted that the C district government had overlooked this issue, he regretted that the community kept silent when one of their family members was experiencing mental health concerns:

> There is a culture of people who want to hide the fact that a family member has a mental disorder. Because they are hidden, often these patients are not registered by the Puskesmas/CHC as primary health services closest to the community. Perhaps because of the culture, there is shame in reporting family members with mental disorders. Because of shame and lack of information, eventually, the sick person is taken to traditional healers or worse, put in shackles and left untreated.

Similarly, The Deputy Mayor of C, Mr J, stated in the previous meeting that he was perplexed by this situation, as described by the mayor:

> The Regency Government (Pemkab) was conned since it was unaware of the existence of many people in our community who suffer from mental illnesses and only learned of it after it was publicised in the media. It was sadly missed. We didn't know before; we just found out after hearing about it in the news. But we will work intensively with the Central Government and Provincial Government to overcome and address this situation.

The stigma was also expressed by the Regency Public Health Officer who stated:

> Mental health problems are caused by a combination of factors. It is frequently stigmatised that it ends in Pasung. The patient's freedom, including the right to proper treatment, was taken away by the community or family. Many countries consider these practises to be violations of human rights.

The negative attitudes towards mental illness also appeared in the cultural context such as in building construction, as depicted below:

Still Photo 8-4: The Hut with The Spiritual Symbol

The hut in which the man had been held was approximately 3 x 1.5 metres and 3.5 metres high with a pitched wood and tin roof, and made of concrete. It had a number of houses attached to it, so it was counted as a single distinct building with a resident living inside. There were no windows, except for two small 15cm square opaque glass bricks set into one wall approximately 3 metres up under the shaded roofline, and one wooden door which was secured with a large chain, bolt, and padlock. At the back of the hut, approximately 0.5 metres from ground level was a small rectangular opening of approximately 20cms x 10cms. It was through this opening that food and water was passed to the man. It was also the only source of light and airflow to the inside of the hut. The man could reach through this opening with his hand and part of his forearm. Above this opening was a metal plaque nailed to the wall on one side and hanging lop-sided. The writing on it was in Arabic and read: “I ask forgiveness in God. We undeniably belong to God, and we shall return to Him." These words are used when a person suffers a disaster in life, when learning that a person has died, or when a person is placed there to ward off evil spirits.

2. Inadequate Resources

The main organisational challenges cited by CHC staff for providing effective care for PIPs were a lack of adequately trained employees and limited service availability. There were comments from

the health care professionals about the patient and the dilemma the CHC was in while treating the mentally-ill patient. The CHC bemoaned the fact that they did not have enough time to treat PWMI, especially in their acute phase, as they needed to attend to more than one-fifth of physically-ill patients each day. Employees at the CHCs expressed frustration because they felt there was little attention paid to the issue by the government in terms of both funding and resources. The CHC staff were also concerned about the limited availability of medications and the complicated integration of the service with social and other services, such as referrals.

> When someone is in an acute period, the drug is not available, either orally or via injection. Not all staff have received training. We have to service more than 60 patients per day, and even one mentally-ill patient could take hours. We do wish to treat them. All we need is someone or a team of people who are solely dedicated to mental health. Alternatively, we may devote one day only to serving mentally-ill patients which is somehow impossible given the number of patients we serve. So, now, if a patient is declared mentally-ill or hostile, we just refer them to a secondary hospital to be transferred to a psychiatric institution directly without any assessment (Video 3).

Several respondents indicated a lack of understanding regarding the care pathways for PWMI among family members and/or the community. Community health professionals expressed a perceived lack of competence, knowledge, and trust in their ability to refer the PIP to the proper resources. The CHC also mentioned that a lack of knowledge of local district services contributed to perceived delays in getting treatment, particularly in complex situations and crises.

3. Fragmented Services, Role Clarity, and Conflict between Stakeholders

Working with many people from different professions was a daunting task, particularly when coordination during the evaluation process was not working properly and when job descriptions of all sectors involved were not available. Still Photo 8.5 below depicts the cultural divides between the rescuers and the rescued.

Still Photo 8-5: The Family, The Health Staff and the Onlooker

This still photo also demonstrates that there was little coordination between stakeholders, as well as what and how each stakeholder's roles and responsibilities were defined. The participation of multiple stakeholders was obviously a good indication that there was an intention to free the PIP, and that they recognised that Pasung was a violation of human rights, but all stakeholders must understand their functions and responsibilities as a team. This is a reality from the previous framing when the Local Administration and the CHC were concerned that FPP only temporarily addressed the situation. The Local Government Official further stressed:

> The initiative to free them from Pasung has noble goals, but we don't want to add another burden to the community or the family. Rather than a short-term fix, we need to get to the bottom of the problem. The community also does not understand that the treatment takes time to work; all they know is that, after being given medication, the person returns to normal. Then we must provide them with mental health education. It has to do with culture and mindset. Culture is something that is passed down from generation to generation and is held dear by the large population in this village and possibly elsewhere. Culture influences how these communities seek healing when someone exhibits unusual behaviour," the Local Government Official concluded (Video 3).

Other reasons for non-disclosure of PIPs included perceptions of inadequate continuity of care and not knowing which health service to contact. Some Health Care Professionals (HCPs) discussed how access to adequate care was negatively impacted by perceived shortages of specialised services and lengthy procedures. Access to care for PIPs was hampered by perceptions of fragmented services among HCPs, which were seen to be the root of the issues with multidisciplinary communication between professional groups.

> "It wasn't a new case; everyone in the neighbourhood was aware of the situation [re: the condition that many of them were in Pasung]. The community health centre was aware of the problem; but, due to a variety of factors, the situation became neglected. This, in my opinion, needs to be resolved because it may happen again in the future if the appropriate measures are not implemented," the Community Health Centre staff stated (Video 2).

When a patient needed to be hospitalised because of an emergency, communication between primary care providers and mental health services was thought to be especially poor. The CHCs in one video (Video 3) expressed frustration over this and felt isolated from their peers. The CHC personnel emphasised how fragmented services led to misunderstandings regarding the CHC's function within the referral process. Similar to this, family members had questions about how the CHC would help them receive the right care, particularly when it came to coordinating with social care providers. Uncertainty was expressed by the family and the community over the best health care provider to contact for a Pasung.

4. Access to Mental Health Services

Another problem with access to care was the direct and indirect costs such as transport, medication, and geographical area. Despite the video depicting that some PIPs lived in suburban areas where the proximity to mental health care was close, the transport to go there was not easy.

> We want to find a solution, and the family and the community want to. However, how we reduce the impact of this Free Pasung on the continuation of family and community life should be considered as well. Even though the programme is free, the family will still be required to spend a small amount of money. For transportation, food, and clothing while they are hospitalised. Re-entering the community after hospitalisation is also a problem. This is something I've seen in other villages where people are struggling. The family could not afford the medication because it was not available at the Local Community Health Centre. To be admitted to a psychiatric hospital; in order to go to the psychiatric hospital is something hard to do, a 5 to 6-hour journey and then the cost is very high. I hope this is also being considered (Video 2).

In addition, many PIPs did not have national insurance to cover the costs of medication, which made it more difficult for them to get proper treatment at the mental health services:

> We may not be able to take everyone there at this moment for a variety of reasons. There are families who have refused to allow the person to be treated at the hospital, while others have not completed the administration such as national identity, national insurance, and some are waiting in line due to the hospital's limited space (Video 2).

The MOH also expressed a similar view that most of the mentally-ill patients did not have national insurance, which meant they had to pay the cost of the medications out-of-pocket. Hence, once

they were stuck with economic problems, they sought alternative treatments. If the treatment failed, then the patient was locked in the home, or wandered the streets.

5. Sociocultural Meaning of Pasung

A further problem is the definition of Pasung itself. Much of the community refers to Pasung as being a person locked in a wooden log, as described below:

> They didn't call it Pasung, and from what I understand, it is not. They do not use physical restraint, only isolate or lock them, and most of them use it temporarily while working. This may be the definition of Pasung that the community needs to understand. And how to manage the person if the family is absent due to work, illness, or something else – Local Government Official (Video 2).
>
> When we told them that doing Pasung could result in a significant fine or imprisonment, they raised their eyebrows and began looking, ... – Local Government Official (Video 2).

This problem with the understanding of Pasung and mental illness was also echoed by one of the psychiatrists who mentioned that one of the factors was the lack of health education to the community delivered by the mental health service:

> First and foremost, the education to the community about mental illness, what is mental illness, how to treat a person who has become unstable, and most importantly, how to prevent this from happening. As a result, in the future, fewer and fewer families will use Pasung. That is the task assigned by the Public Health Office via the community health centre. At the hospital, we do the same thing, but on a smaller scale because we are focused on the medication. We treat people who have been diagnosed as mentally-ill. While in the community, a healthier individual. As a result, it must be prioritised for inclusion in the programme. Don't let it happen again (Video 2).

To summarise, in those experiencing Pasung, mental health stigma is regarded as a significant barrier to seeking help and accessing care. Stigma can be a barrier for people suffering from mental illnesses because it made them afraid to seek help for fear of being labelled and discriminated against. These issues were exacerbated by a lack of resources, service fragmentation, and poor multidisciplinary communication at the community level.

8.3.4 Policy

At the policy level, obstacles to receiving mental health care for PIPs were observed in the videos. The use of mental health care is dependent on the effectiveness and accessibility of the services and the policy. The factors influencing help-seeking behaviour regarding mental illness are important for programme planners to understand in order to enhance the proportion of PIPs with mental illness who seek effective treatment and counselling:

> "That is a political decision; aside from that, the truth is that we are prepared to roll out. We have discussed this scheme (re: how person in Pasung to get free access to mental health service and the availability of mental health service at the nearest Community Health Centre) with the House of Representatives, and they have agreed to it," staff from the Ministry of Health responded (Video 2).

Despite the fact that Pasung was prohibited by Indonesian law, implementation was difficult to carry out locally due to a lack of funding, policies, and procedures.

> “But we have a Mental Health Act issued in 2014 which is a breakthrough. And despite the implementation being far from what we expected so far, we have to believe that it will be implemented fully later on. Of course, there we need patience, we have to wait because not all the decision sits within the health sector solely, there are a lot of decision-makers who are still unaware of this legislation. And our job is to communicate and advocate this legislation to broader groups of people including those in decision-making roles,” said staff from the Ministry of Health (Video 2).

Ministry of Health staff further stressed that in order to improve mental health, it was necessary to pay attention to the cooperation of all parties, both government and non-government. This included improving the quality of, and access to, mental health services, provision of drugs, increasing human resource people in the field of mental health, and advocating and socialising. In the future, mental health will be one of the health indicators in each regency and province. The budget will be increased by 5% from the current level of 1% of the total health budget.

In summary, at the policy level, mental health remains a neglected priority, low on the agendas of national and provincial policy-makers and funders. While this is evolving with the plan to increase the budget, there is still a significant need to address the under-prioritisation of mental health and wellbeing.

8.4 Summary and Concluding Statement

This chapter has investigated the video analysis associated with the use of Pasung practises in the treatment and care of people with mental illnesses. Seclusion and restraint in the community, or Pasung, have a long and tumultuous history, and despite ongoing controversy and proactive national and local policies to reduce or eliminate these practices, they are still widely practised in West Java and other parts of Indonesia. One of the reasons is that there are multiple barriers to receiving mental health services, indicating that multiple layers exist across the SEM levels to prevent people from receiving proper treatment at mental health services. At the individual level, the findings revealed that PIPs were unable to receive effective therapy at the individual level because of a confluence of physical and psychological problems. Due to their socio-economic status and reliance on their families on a daily basis, these individuals struggled to seek help. Their families can also influence their autonomy and therapy preferences. Furthermore, due to a lack of

insight into illness, some PIPs refused to accept the diagnosis of mental illness and the treatment offered by their families, which created barriers to receiving mental health services.

Due to a lack of understanding of mental illness in the family and the community, symptoms were overlooked, and referrals were delayed. Most families in this video analysis used traditional methods for interpersonal communication, and those who turned to more contemporary approaches like mental health services, did so after exhausting all their local options. The majority of the time, these treatments were administered against the PIP's will while they were chained or restrained. Many of these families confined the PIP to their homes or other locations until they stopped being aggressive. The primary reason cited was the inability of families to care for the PIP due to work obligations, a lack of funding, or other activities they were compelled to do, consequently preventing the PIP from receiving appropriate care. Individual and interpersonal problems were exacerbated at the organisational level by factors such as insufficient resources, service fragmentation, and poor multidisciplinary communication. The inability of this group of PIPs to obtain services was also hampered by structural constraints, such as ineffective policy implementation. Mental health continues to be a neglected priority, low on the agenda of both national and provincial policy-makers and funders. While the budget is going to be increased, there is still a significant need to address the under-prioritisation of mental health.

The next chapter (Chapter 9) presents the interview analysis with PIPs, their families, community members, health professionals, non-health professionals, policy-makers, and health system managers who were involved in the Pasung programme. The interviews were one of the data collection techniques used in this study in addition to photographs and videos, which added further understanding to the practice of Pasung.

9
THE MULTIDIMENSIONAL NATURE OF PASUNG AND THE FREE PASUNG PROGRAMME (IMPLEMENTATION, EFFECTIVENESS, AND PRACTISE)

9.1 Introduction

The extent, nature, and experience of restraint in community settings (Pasung) in Indonesia are understudied (Hidayat et al. 2020). Anecdotal evidence suggests that it is a common experience among people with schizophrenia in this setting (Alem 2000). These circumstances suggest the need to conduct large-scale ethnographic and epidemiological studies to improve the understanding of Pasung (Minas & Diatri 2008). Seclusion and Restraint (SR) in institutions, such as psychiatric hospitals and traditional healing centres, are frequently discussed in the academic and human rights advocacy literature (Asher et al. 2017; Drew et al. 2011; Guan et al. 2015; HRW 2016; Yamin & Rosenthal 2005), while SR in the family home is frequently overlooked. This study addresses an important area of research that has previously been neglected. This is because in many countries, and particularly in Indonesia, most People with Mental Illness(s)/PWMI do not receive institutional care; instead, they live in the community and are primarily cared for by family members.

Interviews are one of a number of data collection techniques used in this study in addition to photographs and videos, which adds further understanding of the practice of Pasung. Interviews have distinct characteristics that make them useful in gaining a thorough insight into Pasung practice, i.e., to obtain a comprehensive understanding of Pasung practice, such as eliciting narratives, chronologies, reflections, and opinions from those directly and indirectly involved in the experience (PIPs, carers, mental health professionals, non-health professionals, and community members), the perceived reasons for its use, current interventions, and potential solutions. Interviews are designed to elicit a rich, detailed, or 'thick' description of events by encouraging participants to speak freely and comprehend the researcher's quest for understanding into a phenomenon witnessed by the participant. Interviews with key informants are frequently included in an ethnographer's toolbox of data collection procedures (Atkinson & Hammersley 2007; Given 2008).

Understanding and contextualising why restraint occurs in a specific context is critical because the factors that contribute to human rights violations are complex, and simple solutions are unlikely to be effective (Asher et al. 2017; Suryani et al. 2011). Pasung is likely to be nuanced, and solutions may need to be nuanced as well to account for the various contexts. An inadequate understanding of the reasons for restraint in community settings may result in the development of ineffective interventions and legislation to address the issue. As such, this current chapter delves into

understanding the experiences of, and reasons for, Pasung of PWMI in community settings in West Java in order to develop viable interventions, particularly with the existing Free Pasung Programme (FPP) intervention. In this chapter, I explain the study's research findings under four key themes that arose from the data. The data were organised into four broad components that were guided by the Socio-Ecological Framework.

9.2 Methods

9.2.1 Setting

The study was carried out in West Java Province, across 11 cities throughout West Java (see Figure 9.1 below) as part of the FPP.

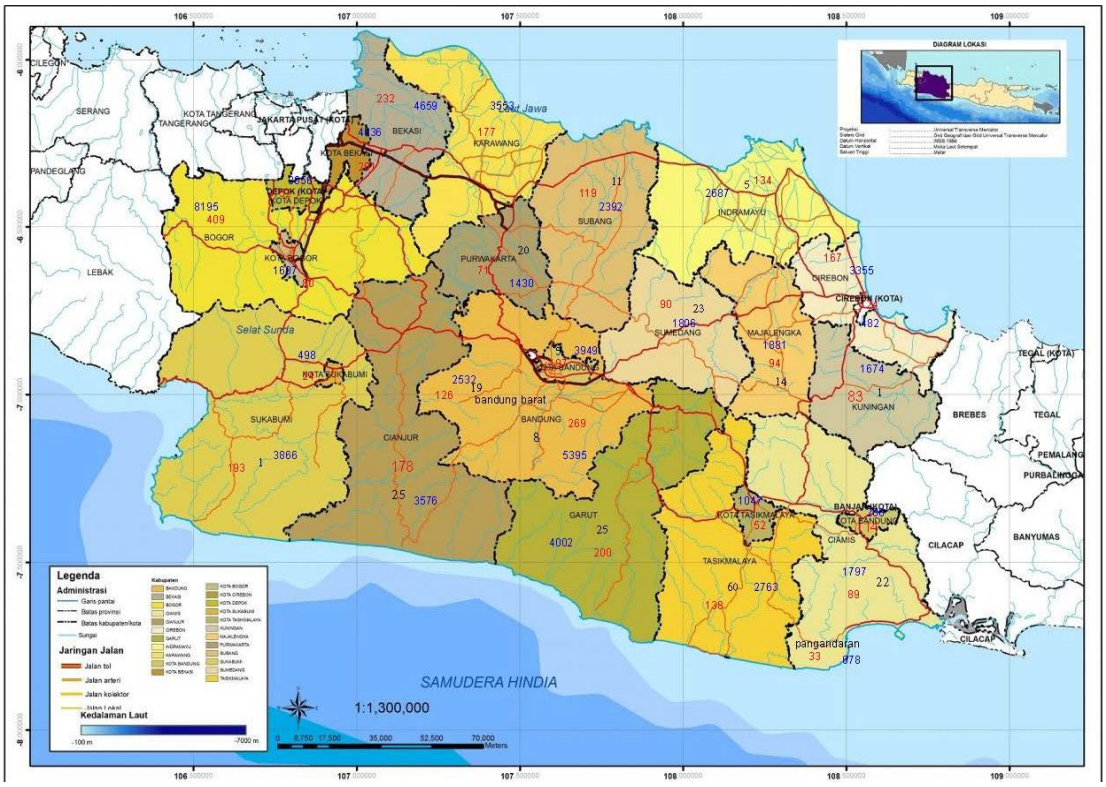


Figure 9-1: The Free Pasung Programme Catchment Area 2012-2019 (FPP Was Postponed during the Pandemic 2020 to September 2021 and Then Run Partially to October 2022)

Figure 9.1 shows the estimated number of PWMI in each District across West Java (blue number), with the number of estimated persons in Pasung (red number) and the number of persons being evacuated by the FPP (black number). I chose three areas to represent the closest and farthest distances from the psychiatric hospital, as well as the geographical areas, rural and urban. The vast majority of families who were interviewed lived in rural areas. The topography was varied, encompassing both cool mountainous areas and hotter lowlands. The majority of the population were subsistence farmers who lived in semi-permanent houses. Most people in West Java are

Muslims, and spiritual healers and holy water are commonly used to treat mental health issues in this community. Other types of traditional healers include herbalists, animal sacrifices, and rituals, as well as the imam who are believed to have magical/spiritual powers.

9.2.2 Data Collection

The participants for the interviews ranged from PIPs, families, community members, and bureaucrats (health professionals, non-health professionals, policy-makers, and health system managers). The selection process and participant sample size have been discussed in Chapter 6, Section 6.3.3.1: participant selection. Hence, in this findings chapter, I only highlight the details of the methods that were not presented in Chapter 6. A total of 30 interviews were conducted, each lasting between 25 and 60 minutes. The details of the participants are shown in Table 9.1 below:

Table 9-1: The Interview Participant

	PIP	Carer	Community Leader	Primary Care	Secondary Care	Tertiary care	Regulator	Social
Number of participants	5	5	3	3	2	7	3	2
Age								
<25	1							
25-35	1					2	1	
36-45	3		1	2	1	2		2
46-59		2		1	1	3	2	
≥60		3	2					
Gender								
Male	3	1	3	1	1	3	2	
Female	2	4	0	2	1	4	1	2
Occupation								
Farmer	1	2						
Merchant	1							
Unemployed	3	2						
Pensioner		1	2					
Nurse				3		2		
GP						1		
Psychiatrist						2		
Social work								2
Manager					2	2	3	
Non-Health Worker			1					

The interviews were conducted between April 2018 and May 2019 as part of the FPP. The FPP activity was mostly conducted in single episodes. The team would go to the person's location, take an examination, evacuate the person to the hospital, and the PIP would be returned to the community. This situation restricted the amount of time available for evaluating or conducting

interviews. The majority of these interviews were conducted after the PIP had been returned to the community, which was after their hospitalisation. There were several reasons why the interviews were conducted after hospitalisation. First and foremost, the interviewee was involved in the FPP and was aware of the situation that arose during implementation. Second, some PIP patients were able to communicate 'well' after hospitalisation. Third, conducting the interview during the hospitalisation would have been insufficient because most family and community members would have been preoccupied with the evacuation process, and the PIP would have been in the process of treatment at the time.

The interviewees were asked about their experience in Pasung, or in caring for someone in Pasung, what they thought were the reasons and drivers for its use, the current implementation of the FPP, what barriers they faced when implementing the programme or mental health service, and what they saw as the solutions to rectify the programme and mental health service for more effective implementation and results for the PIP (see Appendix VII). There were no new data collected after the FPP was stopped during the pandemic from March 2020 to September 2021. Despite the fact that the 'new normal' was imposed in West Java in early September with the issuance of Ministerial Decree No. 47 of 2021, the FPP was not fully operational, with many districts still restricted at level 3[1] and level 2[2] of the COVID response in Indonesia. Furthermore, the Indonesian border remained closed to international flights until March 2022 (MoHA 2021). With the issuance of Ministerial Decree No. 38 in October of 2022, West Java faced no restrictions at all across its Districts. This allowed outreach programmes such as the FPP to be conducted (MoHA 2022). However, the study had only nine months left at this point, making the timely gathering of further interview data extremely difficult. Hence, the use of the existing secondary data was the most viable option to address the questions during this difficult situation.

9.2.3 Data Analysis

Data analysis was undertaken using six steps of thematic analysis, as described by Braun and Clarke (2006). This approach to analysis was taken due to its independence from any pre-existing theoretical framework. Thematic analysis has the advantage of being able to be applied across a wide range of theoretical frameworks and for a variety of purposes (Braun & Clarke 2006). Together with my supervisors, I began by reading through all the transcripts and taking notes on first impressions. The supervisory team coded all the transcripts independently, and a meeting was held every two weeks to discuss any points of difference, reach agreement about how to proceed, and make minor changes to the coding scheme. Once a consensus had been reached, I indexed

[1] Area with less than 50% coverage for the first dose of COVID-19 vaccination. Masks are required both indoors and outdoors. Travel between areas requires proof of a second dose of COVID-19 vaccination and a negative PCR 48 hours before departure.
[2] Area with 50% coverage for the first dose of COVID-19 vaccination. Masks are required both indoors and outdoors. Travel between areas requires proof of a second dose of COVID-19 vaccination and a negative PCR 48 hours before departure.

all the transcripts using the final developed coding scheme, but also added additional codes as needed to the data. Next, the codes were categorised into potential themes and sub-themes by looking for repeating patterns of meaning across the dataset. I created a map of the relationships between the themes, which was discussed and finalised with the supervisory team. The themes and sub-themes were examined by determining whether the collated quotes for each theme were coherent, and by collapsing or expanding sub-themes as needed. I then re-read the entire set of transcripts to ensure that the final thematic framework adequately reflected all the data collected.

The supervisory team and I summarised and interpreted the themes using a contextualist approach which sat between essentialism and constructionism, which meant that we focused on the data and the individuals' reported experiences while also attempting to understand how the larger socio-ecological context, such as living conditions and access to health care, shaped those experiences (Braun & Clarke 2006). The associations between themes and patterns relating to participant characteristics were noted; for example, we compared reports of PIPs to carer reports. After discussion with the research team, I chose quotes to represent each theme and sub-theme. Because the data were analysed sequentially after collection, data saturation could not be achieved concurrently with the data analysis. Furthermore, I was unsure how many participants would be required to reach saturation, which will be discussed in greater detail in Chapter 11 (Limitations). There is, however, no one-size-fits-all solution to data saturation. This is due to the fact that study designs differ. Researchers do, however, agree on some general principles and concepts, such as the absence of new data, themes, or codes, as well as the ability to replicate the study (Francis et al. 2010; Fusch, Fusch & Ness 2018; Fusch & Ness 2015; Guest, Bunce & Johnson 2006; Hagaman & Wutich 2017)

The study design will usually determine when and how these saturation levels are reached. Although the concept of data saturation in studies is useful, no practical guidelines for when data saturation has been reached have been established in the literature (Fusch & Ness 2015; Guest, Bunce & Johnson 2006). Depending on the population sample size, data saturation can be achieved in as few as six interviews (Guest, Bunce & Johnson 2006). Other researchers have suggested 20-40 interviews for heterogeneous, large samples and cross-cultural sites (Hagaman & Wutich 2017), 10 interviews prior to checking saturation, 13-17 interviews for sufficient saturation (Francis et al. 2010), and 30-60 interviews for ethnographic studies (Guest, Bunce & Johnson 2006; Ryan & Bernard 2000). With 30 interviews and no new data, themes, or codes, I concluded that the data was saturated. Furthermore, this study considered the data to be very rich (quality) and thick (quantity) (Dibley 2011; Fusch, Fusch & Ness 2018). Rich data for this study were multi-layered, intricate, detailed, nuanced, and more, as evidenced by the fact that it was gathered from multiple districts. Thick data were apparent from the large amount of information gathered from the various stakeholders. In addition, the coding was conducted by four different people to ensure that

data saturation had been reached; a strategy to improve rigour, as suggested by Brod, Tesler and Christensen (2009).

9.3 Findings

Lack of alternatives to Pasung leading to ineffective implementation of the FPP emerged as an overarching theme, indicating that families and communities believed there were no effective, accessible alternatives to these practices. Eleven related themes across the individual, interpersonal, community, and policy levels of the Socio-Ecological Model (SEM) contributed to this perception, as presented in Figure 9-2

Figure 9-2: Onion Diagram on Multidimensional of Pasung

This onion diagram reveals the multidimensional nature of Pasung, where Pasung is defined from multiple perspectives. For PIPs, restraint is torture. On the other hand, families see Pasung as an expression of love and minimising risk to the individual, family, and community. For the community, Pasung is a way of protecting the safety of the neighbourhood, while health care workers saw Pasung as a problem that needed to be tackled in hospitals where funding and resources were insufficient. For policy-makers, Pasung was a problem that needed to be addressed in order to reach zero Pasung. These different points of view resulted in a lack of alternatives to Pasung, leading to ineffective FPP implementation.

9.3.1 Individual Level

Living in Pasung can be a daunting experience for PIPs. The PIPs reported that they were constantly restrained, which had a significant negative physical and psychological impact on them.

1. Multiple Restraints and Prolonged Duration of Pasung

At the individual level, PIPs were subjected to multiple occasions of seclusion and restraint (SR) in their lives, both at home and at the hands of traditional healers and hospitals. Two PIPs explained as follows:

> *I was locked at home, then somewhere in the mountains. My family escorted me there. I couldn't remember where I was. They gave me numerous herbs, a mantra, and performed the animal sacrifice. I couldn't figure out why. But I'm not feeling anything (Participant 17).*

> *I was taken to the hospital after a fight with my next-door neighbours. That was done by my mother. I'm not sure if it was once or twice. They admitted me to the self-contained ward for a few days. Put me under restraint. After that, I was sent home (Participant 20).*

Due to their multiple times in Pasung, most of the PIPs were unable to accurately describe the duration of Pasung.

> *I had no idea how long I had been in Pasung until some people took me back to the hospital (Participant 20).*

> *I (cried) can only see the dark. I did not know if it was day or night. The day just pass by similar to me. Every day I just hope to live normally and come out from the hut where I live. But it never came (Participant 18).*

One community leader also emphasised the length of the restraint, but these stories were frequently offered in general terms without reference to specific persons.

> *Many of these people (in Pasung) were there for years. Some families forget where they started to Pasung their family members. In recent cases, the keys to the doors have also been rusted or missing. It showed us that they have been there for years. As long as I work with PWMI in Pasung, I have never found a case where the person just recently in Pasung (Participant 11).*

2. The Negative Impact of Pasung

Pasung is experienced as having a significant negative effect on the PIP. Physical injuries, sometimes permanent, could result from restraint. Two PIPs expressed their situation.

> *I couldn't walk without a crutch anymore. (Before), I was able to walk by myself (Participant 20).*

> *My leg is getting smaller. I could only move or use the restroom while crawling. I (can) ask my family for assistance if they are at home (Participant 21).*

A primary health care provider also expressed their concern regarding physical illness among PIPs.

> *Physical illness among PIP is not uncommon. We found many of them had diarrhea, skin problems due to lack of hygiene, fungus, and the most observable is the contracture in the knee joint and the laceration on the back because of floor ridden (Participant 26).*

Similar experiences were expressed by a psychiatric hospital health worker.

> *Taking care of PIP is a bit complicated given the dual diagnosis they had. For example, most of them had tuberculosis which requires isolation to prevent the spread to another patient. However, we do not have a ward or dedicated ward to treat tuberculosis. Even when we have (or made emergency isolation), it is below the standard for tuberculosis (Participant 10).*

Apart from physical illness, Pasung had a negative impact on the person's psychological condition. Observations made during the implementation of the FPP revealed that many of these individuals were observed to act as if they were uninterested in people, while others were unable to interact properly, displaying irritation and anger, light sensitivity, deterioration, and talking to themselves. However, there were instances where the PIP could still provide an adequate response in terms of responding to what was asked and directed to do. The photo analysis revealed more information about this situation (see Chapter 7).

One of the PIPs expressed her experience of the negative impacts of being in Pasung.

> *My symptoms worsened, I relapsed, I couldn't sleep, I was depressed, and I was upset because I was told to pray and dhikr without sleeping. When my condition worsened, I was denied treatment. There is no psychotherapy, place, or person I can speak about my symptoms, which I believe will help (Participant 9).*

Community leaders emphasised the negative psychological impacts of restraint, recognising that it could worsen the illness or increase the risk of violence against others. One of the community leaders expressed his concerns as follows:

> *Throwing them in Pasung and keeping them at home will aggravate their illness. That will make the individual hopeless. That will dim their optimism (Participant 11).*

Primary health workers expressed similar experiences regarding Pasung.

> *In my case, I've seen some of them deteriorate in terms of symptoms, such as they used to go on controls to the CHC alone and now they were unable to communicate aggressive, and relapse (Participant 16).*

3. Punishment and Feeling Tortured

For PIPs, restraint was experienced as a form of punishment and torture.

> *I was transported to a room and confined for three days and three nights using restraints on my hand and legs. I didn't get a blanket or anything to keep the cold at afar (Participant 9).*

> *The log (for Pasung) was heavy and painful. The log attached to my skin tightly, so I barely even move. My skin was bleeding. My ankle and my knee could not bend anymore. I could only sit waiting and waiting to be free (Participant 21).*

During their time in Pasung, PIPs expressed being denied access to personal needs such as toileting and food. They also reported being embarrassed and ashamed.

> *I defecate and urinate in where I sit. Nobody comes to unlock the hut to let me out. Sometimes, they bath me naked with the sprayer. They have never given me proper clothes and only this sarong (Participant 18).*

> *Eat, then defecate and urinate there as well. I was denied the opportunity to use the restroom. After three days, I was released, but I remained locked in my room and given food and water on the floor. I also did not use the restroom or pee through the hole in the room. I didn't meet anyone during those 40 days (Participant 9).*

Participants also described Pasung as a form of punishment; for example getting into an argument or insulting people could put them in Pasung. Two PIPs expressed their feelings:

> *I was tied and restrained at home when I got sick like talking to myself, yelling for the first time (Participant 21).*

> *But I have never harmed or been hostile to anybody. I was shouting as I walked through my neighbourhood. When I tried to escape the house, I was beaten by everyone. I don't recall being beaten by anyone other than my family. Then, when being beaten wasn't working, they shackled me in the toilets (Participant 18).*

PIPs also experienced being mocked and embarrassed by others. In some cases, the neighbours, especially the younger ones, occasionally mocked the PIP with harsh words (gelo). As a result, the PIP acted aggressively. Otherwise, they described themselves as shy and reserved.

> *I don't pick fights with people. I don't touch people, and I don't touch other people's property either. If I do, they will bind me and bring me here [to the hospital] (Participant 18).*

> *If I argue with people or say hurtful things to them, they say I'm sick, tie me up, and bring me here. Even if I only stay at home and nobody will watch me, they will lock me in my rooms (Participant 21).*

4. Losing Hope and Gods Will

Some PIPs also expressed the feeling of losing hope and then accepting Pasung as God’s fate.

> *It was dark, and cold. I can see anything. A lot of voices. So loud. It keeps talking. So loud. The voices began innocently enough. I couldn't figure it out, but I assumed it was family trying to communicate with me. This did not bother me. However, the voices changed in mood and content over time. They became increasingly dictatorial and cruel, relishing control over my every move. I want to kill myself, but I'm afraid God will be angry (Participant 20).*

> *They think I am crazy, and I could only cause trouble for everybody. I used to dream about going to school and living a normal life, but I buried all of my imagination right where I was secluded. I have stopped dreaming and believing. Poor people should not dream (Participant 21).*

PIPs stated that they felt exposed and judged by others in their community, that there was nothing they could do about it, and that they had given up hope.

> *I was naked. They won't let me wear underwear. They claim I am not shy because I am patient. Sometimes I think that death would be a better option. Everyone seemed to be judging me, and everyone seemed to be leaving me behind (Participant 17).*

> *There was nothing here and I couldn't see anything around me, so there was nothing to turn to, nobody to turn to ... so I felt even more lost (Participant 18).*

9.3.2 Interpersonal Level

Families were torn between the care of the person and being the main perpetrator of Pasung towards the person. The situation was described by the family as a struggle to deal with PIP's safety, community pressure, the burden of care, and a sense of powerlessness.

1. Family Torn Between being a Carer and Perpetrator of Pasung

Families' roles as carers influenced their experiences with Pasung. They saw their role in ensuring the PIP's safety as an ethical and moral responsibility. As a result, they were conflicted when they were required to impose Pasung on a family member who was ill. The main explanations given by the family for restraint were to protect the individual, the family, and the community. These reasons were underpinned by the limited availability of mental health treatment options, the consequent heavy family burden, and a sense of powerlessness amongst carers. The family believed that Pasung was the only option for protecting others and the PIP from aggressive and destructive behaviours.

> *There is no other option but Pasung, because most of the time nobody is at home, and we need to feed other family members in addition to him (the PIP) (Participant 19).*

Pasung was regarded as a practical solution for persons suffering from mental illnesses and was widely accepted in the community. The person occasionally expressed a desire to see a doctor or

be admitted to a mental hospital, but families tended to ignore such requests for a variety of reasons.

> *Of course, my son wanted to flee, and he kept saying, O mother, I will follow every rule and everything you say. I'm scared, so let me out. Many ghosts are present. Please take me to the doctor. Please allow me to leave. He sobs. What mother's heart will not weep? Every time I feed him, my heart breaks. I cried all night. What a life I've led. But I have to keep him there for everyone's sake (Participant 30).*

The individuals triggering the use of restraints were almost invariably reported to be family members. Despite the fact that Pasung was typically carried out by the family, restraint appeared to be universally tolerated and also facilitated by the larger community. There were also reports by participants of families seeking help from other members of the community to help place the PIP.

> *My father called people and makes sure they gang up on me and lock me up (Participant 17).*
>
> *They said I'm insane, they said I'm crazy, and I should be locked up (Participant 18).*

Some carers reported a different pattern of confinement, in which the individual was confined and then unrestrained for short periods of time, stressing that they had no other option.

> *We don't always confine him. We release him when we believe he is doing well. We chain and shackle him back when he becomes hostile and tries to injure someone. But what are you going to do about it? (Participant 19).*

2. The Burden of Pasung on the Family

The harmful effects of Pasung extended beyond the PIP to family members and the community from which the person came. Caring for someone in Pasung had a significant impact on social ties, employment, and finances, as well as psychological wellbeing.

> *I took care and bathed IR by myself. Her sibling, her mother, and even her children were all afraid of her. You know ... (breathing heavily), I never dream or wish that one of my children had a mental illness. People say she is “crazy”. I feel sad to hear that (Participant 5).*

In addition to the burden of caring for a sick family member, most families were concerned about their and their family members’ own future health.

> *We are still fortunate to have government-provided and supported national insurance. We hope that in the future, his condition will improve and that we will not have to be concerned about his future (Participant 2).*

Socio-economic problems also had a great impact on how the family chose their treatment option. Family members tended to be reluctant to go to the psychiatric hospital as the cost of transportation was very high.

> *I have to think of other family members who live in my house apart from him (the PIP) (Participant 2).*

Pasung impacted not only older family members, but also the children of Pasung households and their relatives. For a variety of reasons, including stigma, financial hardship, the strain of caring for ill parents, and hereditary predisposition, these children were perceived to be at higher risk of acquiring physical and mental illnesses. The long-term effects on children were perceived to affect their adult health and relationships.

> *We were three brothers, the eldest being me, and my other two sisters were 10 and 9 at the time. Except for our neighbour, who mocked us as crazy, we had no idea what had happened to our father. "Your father is insane, as are you all." I could handle it, but my sisters sobbed at times, and I frequently had to stand up to those who bullied us. They grew exceedingly shy and had few friends as a result of this situation (Participant 22).*

Some family members stated that because it was ingrained in children's culture and religion, they had a duty to care towards their parents. Others even experienced an emotional bond with their confined parent.

> *I did not finish my secondary school. Around year 9, I left school to help my mother. We were poor and I could just relax and saw my mother working from 3am to 9pm to provide us food and schooling. Someone has to take care of and help her. Neither of them (extended family and community) helps us (Participant 22).*

Similar views were expressed by another family participant who expressed a strong belief that they were left to bear the burden of care alone, frequently without assistance from other family members or the wider community.

> *There is no help from a relative or other significant people. There is no support for patients, I'm getting old, and I'm not sure who will look after my sons after I'm gone (Participant 5).*

The magnitude of the burden in relation to the quantity of time spent on caregiving, and the load at the household level was experienced by families. Apart from perceiving the ill family member who was in Pasung as a burden, the family also expressed how life should continue for themselves, other family members, and the PIP.

> *It's difficult, like a never-ending problem. Taking care of someone who is ill is one thing, but taking care of other family members who live in the same house is even more difficult. Because life must go on, and we must consider the future, patients, children, education, food, and everything else. Not to mention the therapy costs (Participant 30).*

Some families additionally said they had assessed the impact of the illness on extended family members, such as grandparents and family members who lived in separate households who had no direct contact with the PIP.

At first, I don't know her problem as she lives with her family (husband), but then I have to intervene (Participant 5).

However, other families described how tough it was to care for a parent who was under Pasung. Having a family member with a mental illness made them feel uneasy, anxious, and concerned, particularly if the PIP exhibited aggressive conduct that included hitting or hurting others. The PWMI might also become the target of bullying or even suffer physical abuse from others. Therefore, the family believed that restraint and confinement remained the wisest course of action.

We have to further stress that we don't want it (Pasung and mental illness) to happen, to have someone with abnormal behaviour in our family. But if we did not do that, he will wandering and scare off the neighbour. We have to work (Participant 19).

3. Lack of alternative treatment

As described above, the interview results indicate that Pasung is indeed against human rights, and damaging to PIPs which prevents them from receiving good care. Participants clearly expressed that they should be treated better. Pasung also placed a burden on the family. The family and community described that they had several alternatives to Pasung from which people could choose when they or their family members were mentally-ill: they could go to a kyai, an Islamic religious leader, for prayer and or Islam-inspired Arabic-based amulets; they could go to a dukun, a magic specialist who could offer trance healing and other indigenous ritual healing practices and herbal medicines; they could be placed very cheaply in a local state-run mental hospital where they would receive something approaching Western-style institutionalised psychiatric care, but in a somewhat Dickensian setting; they could be placed in a very expensive private mental hospital where the care and the environment were more westernised or be treated with outpatient care by a psychiatrist; or they could be locked in wooden stocks or chained and left in a shed, bamboo cage, or an enclosed back yard, sometimes for years at a time, fed and watered by family members in a kind of confinement reserved only for the severely mentally-ill. However, in reality, families indicated that they had few options other than to use Pasung.

I tried a variety of things to help her recover, including enlisting the services of a spiritual healer (wise man/clever man). The wise man (ustad) once invited me to sleep on the second floor with her numerous times while reciting specific ayahs from the Qur'an. It has no effect on her, however (Participant 5).

Even after hospitalisation, participants said there was a probability the person would be returned to Pasung again. This was because patients who had been discharged from a psychiatric hospital frequently relapsed due to infrequent medication consumption or the consumption of multiple medicines at once. Furthermore, families believed that sending a person in Pasung to health care institutions or alternative health services was costly, required too much energy, and resulted in no

meaningful improvement in the person's mental health. The person's condition was therefore usually perceived as permanent, and became a burden or source of ongoing worry for the family.

> *I was concerned when she was not at home, because she had been raped and had one child while wandering down the street (Participant 5).*

> *When I am not at home, I am concerned about my sons if they are unlocked. He could be anywhere, taking whatever groceries he wanted without paying. The neighbour is terrified of him. They will object to me because they have discovered that my son is ill. I ask them what happened to my son, I look everywhere, and now I've tied him because I believe he should die right here with me. Now he's asking us to untie him; we said we'd do it, but didn't mean it (Participant 19).*

A key reason given for the belief that there was no other option but Pasung, was the need to manage risk. A community leader emphasised that restraint for protection should not be used for all PWMI, but only for those who were aggressive or disrupted the peace and safety of others. They also discussed the challenges that families faced when balancing the needs of the PIP and the needs of the family and the community.

> *Well, even if there is advice [not to restrain people suffering from mental illnesses], if they are not restrained, they may cause harm. If those are not restrained, the damage will be greater. And they might die if they are hit by a car, so it is difficult in both cases (Participant 11).*

Family decisions about restraint were frequently motivated by apprehension about the consequences of the individual's unrestrained behaviour. The overall impression was that family members frequently felt hopeless and helpless, with no choice but to restrain their relatives. In making their decision, families attempted to balance the perceived needs of the individual, the family, and the community. On the one hand, there was a desire to protect the individual from harm and to assist them in accessing treatment, although the participants did not focus on the individual's treatment preferences. On the other hand, there was a need to safeguard the community. The families were in the middle, often distressed by the task of restraining, and the stress of Pasung and unlocking from Pasung.

> *What can I do? I don't want this to happen to me (Pasung and illness). I absolutely love my son, but if I let him out, what will the neighbour say? They don't want to know that my son is sick and needs their help. People are aware that my son is ill, but they refuse to understand him (Participant 19).*

Opinions on whether someone suffering from a mental illness should be detained were divided. While some participants mentioned the authorities had prohibited the practice, others expressed the need for proportionality; for these participants, restraint was viewed as a selective measure. This will be explained in the next section on the community.

> *Process (Pasung) that does not apply to all people with mental illnesses, but only to those who are aggressive or have a long history of untreated illness. There are many here (people with mental illness), but only a view in Pasung which is considered dangerous (Participant 19).*

9.3.3 Community Level

The key factors influencing the ongoing use of Pasung identified at the community level were stigma and fragmented service.

1. Stigma

While stigmatising attitudes towards PWMI did not appear to be the sole cause of restraint, they did appear to be present in the background, beliefs, and comments made by some participants, particularly those from the community.

> *Of course, it is forbidden or against the law, and we knew it. Some of the neighbours were aware of it. But we don't have a choice. For example, what would people say if a person did not tie him up and he accidentally bit people? The family will be sued for allowing their son to bite someone ... If a ("gelo")/crazy person is not restrained, if he does not cause harm to another person, it is another problem; a complaint may be filed, and they may be held accountable. Of course, as a leader, they (the community) complain to me (Participant 15).*

There appeared to be a belief among leaders that people suffering from mental illnesses were dangerous and unpredictable. The community put a lot of pressure on families to act responsibly and restrain their relatives with mental illness. One community leader said:

> *Now, someone with a mentally-ill child has done harm to his family, his neighbour, he starts a fire in a neighbour's house, he starts attacking the passer-by. Because this has societal implications, society must take it seriously (Participant 11).*

In other cases, stigma was expressed towards the PIP who was seen as insignificant or lacking usual needs; either being just 'a patient', not feeling pain, or being compared to animals needing to be restrained. One PIP could not pinpoint any rationale for her restraint, stating simply,

> *They inflict violence on me because I am a patient, I have nothing else you know (Participant 9).*

Another community leader, on the other hand, stated that the community would not tolerate restraint.

> *It (Pasung) is a bad situation. But sometimes after we educate them (family and community), they still doing that (Pasung) (Participant 15).*

Similarly, two carers reported they felt they had no choice but to keep their children restrained, because of the fear of a complaint from their neighbour. Two families explained:

My older daughter has leg chains and then a large wooden log. She is extremely difficult to control; even three or four men cannot handle her. So, we chained her up and sometimes forced her to take her medications if they were available. Unless that is done, she will break through the walls. It (the behaviour) will scare everyone around (Participant 22).

My neighbour and a lot of people say I should take the shackles off; they say there are good children; that they've never even seen the outside world. I told them, you don't know how I suffer and that I'm at a loss for how to deal with this, that I couldn't come up with a better solution, and that's why I'm keeping the Pasung (Participant 5).

2. Fragmented service

Participants described that the FPP had a good objective in terms of addressing the needs of the mental health service. This was expressed by a health worker as follows:

The goal of the programme itself is good, the approach to the community and the patient. As we know, the aetiology of mental diseases does not arise from a single source; other factors such as the environment, social life, and family life all have a role (Participant 1).

However, the participants also stated that one of the main obstacles to implementing an FPP was the fragmented nature of care. They identified this was happening when different health care providers and/or health care organisations did not collaborate well. Participants stated that each health care provider operated in their own silo, resulting in a lack of collaboration.

Ideally all the team members should be involved. There is room for discussion, but sometimes it did not work as planned. Either we are occupied with another task, or anyone is also preoccupied with their own responsibility. We were unable to meet prior to the evacuation or implementation process, thus we frequently only knew the patient when we saw them in the community (Participant 1).

The FPP was designed as a three-tiered national follow-up programme intended to eradicate Pasung. Individuals who met the criteria were accepted into the programme, but participants pointed out that the implementation of the programme was conducted only by tertiary health care providers with minimal involvement from secondary and primary health care providers. The psychiatric hospital at the tertiary level appeared to be solely responsible for the FPP in West Java with no active involvement (less participation) of other related agencies. One of the participants expressed his views as follows:

Second, integrating non-specialists in the first care (e.g., Community Health Centre, Social Rehabilitation, Volunteer). Unlike the current situation, where we take the patient immediately to the community (by the psychiatric hospital with the Ministry of Health (MOH) and Provincial Public Health Office and apply it there (Participant 1).

Participants also described having limited capacity to network with other responsible agencies due to its function as a hospital focusing on medical treatment.

> *First, policies that are in conflict with those of other organisations. For example, social services have their own policies that are in conflict with ours and the policies of other stakeholders. So, everyone holds onto their ground and declares that they are on the correct track (Participant 3).*

> *There is no such thing as a single passion, a single voice, or a single goal. In the distribution of authority, who led this case, the Department of Health or the social services office? The policies are confusing (Participant 1).*

Misaligned funding, laws and regulations, data management, and training were identified as contributing to these disparate systems. As a result of mental health and Pasung policy confusion (see Chapter 4), the programme's implementation was identified as also being challenging, particularly at the grassroots level of bureaucracy, as the following participant described:

> *There are numerous issues. However, the programme that we have created thus far has been limited to the absolute minimum. We work in a referral hospital and then go out into the community to do things like Pasung, which is the jurisdiction of the community health centre. However, various factors, including funding, human resources, and so on, prevent primary and secondary services from doing so. There is no other way to liberate the Pasung patient in the community than what we do as a tertiary hospital (Participant 4).*

Another participant expressed their point of view about the objectives of the programme resulting in the lack of integration of health care workers, as follows:

> *I am unclear as to what this programme's specific objective is. For example, there are many questions about what team members should do and how it will be organised (Participant 3).*

The FPP intervention was described as care delivered by a diverse range of services without partnership working agreements aimed at ensuring continuity of care.

> *Sometimes the CHC (Puskesmas) are apathetic and are uninformed that such a programme exists. Even weirder, the puskesmas and the community are sometimes unknowing that mental patients (who are shackled) are present in their neighbourhood (Participant 3).*

9.3.4 Policy level (Free Pasung Programme)

At the policy level, participants pointed out that low prioritisation and FFP as a top-down policy were the issues that impeded FPP implementation.

1. Low prioritisation

Mental health has received little attention at the policy level in Indonesia. The main difficulties in implementing the FPP were described as being largely due to a lack of attention and investment (budget or human resources). This lack of investment was expressed by the participants as follows:

> *We are fully aware that our budget is limited. Frequently used in mental health forums where mentally-ill people participate in activities such as games and sports throughout Indonesia. However, if the budget improves, we can include it in the case management (treatment patients in the community including those in Pasung) (Participant 13).*

One of the top managers also expressed his concern for the programme:

> *(Meanwhile for) mental health is in a very low percentage ... what percentage? (less than 1 per cent). That viewpoint originated from the Ministry of Health's point of view. So, what role do mental hospitals play? Once again, the size is really modest (Participant 4).*

There was also the problem of funding provisions to deliver the programme at the primary level, as they are the closest provider to the community, as expressed by the CHC:

> *"We don't have the funding to execute a community mental health programme in general, let alone for Pasung (Participant 24).*

Another CHC personnel expressed a similar point of view, pointing out that human resources and medications were not available at his service.

> *We don't have any medication, either orally or intravenously. Furthermore, only one member of staff, the GP, has received training. Sometimes the doctor is unavailable to see the patient because they have administrative duties, such as a meeting. We have to serve many patients per day, and even one mentally-ill patient can cause delays. Nothing we could do about it. So, if a patient is subjectively mentally-ill or hostile, we simply refer them to a secondary hospital without any assessment (Participant 26).*

Many mental health services faced the challenge of providing adequate human resources for the delivery of essential mental health interventions. The interviews demonstrate the severe shortage of human resources for mental health, particularly in primary and secondary health, as pointed out by a public health office manager.

> *Medication is sufficient in some CHC, but not all. At the secondary level, the general hospital do have some (medicine) also, but what we have is different to what they have (psychiatric hospital/tertiary hospital). Some medications could be covered by National Insurance (JKN) and some are not (those in second generation). Which means they have to pay outright. The problem is that most PIP does not have either JKN or money. They are poor or below the poverty level. So, we have to wait (medicine) from the psychiatric hospital or MoH to give aids (Participant 25).*

In addition to the budget, infrastructure and human resources at any level of mental health services were also identified as a concern, as further stated by one of the top managers of a psychiatric hospital:

> *I simply want to underline that, although we obviously want to extend the rehabilitation facilities for psychosocial infrastructure, we also want to increase the ability of our personnel, whether through internal or external training (Participant 4).*

Apart from medication, the majority of PIPs required extensive rehabilitation, either in a hospital or in the community. According to one of the managers, the problem was that rehabilitation after Pasung was limited or non-existent.

> *Of course, when we talk about rehabilitation, we must give or construct the necessary structures, infrastructure, and so on. Do we need a 24-hour shift, where we take turns every 8 hours, do we need psychiatry on standby or just the GP? Another further thought is that do we need it, and can we establish it? In terms of this service, we'll need to go further into our master plan to see whether it's already stated there. If not, we'll have to work even harder as we need to build a new one (Participant 4).*

A focus on prevention and interventions to eradicate Pasung were also described by the participants as being overlooked. It was anticipated that patients who took part in multi-layer health promotion had a higher quality of life than patients who did not. However, what was being done, and what was anticipated at the grassroots level were very different to what was planned by the central government.

> *There's nothing we can do. Only the large buildings serve the community's mental health needs, but the insides are identical. Clinic for psychiatry (Participant 6).*

2. Top-down policy

The FPP is an innovative project that promotes collaboration and provides training and technical assistance to local service systems to improve their capacity to address Pasung. Although the FPP was initiated in 1977, more people became aware of the programme in 2010 when the MoH of Indonesia officially launched it. This theme describes how participants positioned themselves within national FPP networks, as well as how other important actors and stakeholders contributed to Free Pasung policy implementation in West Java at the provincial and district levels.

One participant from the community health department spoke about the FPP, which she claimed was a top-down policy that did not consider the situation at the bottom level, and that local policy-makers needed time to implement the programme.

> *It was started in 2010 when the Central Government through MoH campaigned for free against Pasung. I came in 2013 (as part of the community service). There is a record since 2012, but the condition may be not good (Participant 13).*

The national policy, however, was not followed up with the required capacity either at the provincial or district level in terms of funding and human resources, as expressed by one of the middle managers at the public health district level.

> *So, the MoH launched the programme nationally in 2010, but we don't have any funding or resources to implement it at the district level. As a result, we rely on the central government (MOH) and the provinces to carry out this*

> *programme. It is not that we do not obey or reject the programme, but at the lowest level of government, we are required to follow local regulations. Although the rule is not available at the district or provincial levels. I believe that the provincial level already agreed on the mental health system this year (2018), but we may get it at the end of the year and learn the regulation to be implemented in our district (Participant 25).*

Some of the interviews clearly communicated the research participants' worries regarding the roles of the various levels of government, as well as the belief that all levels of government should have a role in the Free Pasung Programme. One middle manager at the public health office of The West Java Provincial Government (WJPG) expressed his concern:

> *It's a complicated story. I would say that back in 2010, I was the planner before moving on to become the head of non-communicable diseases, one of which is mental health. At the time, the Ministry of Health aimed to eradicate the Pasung, which was one of the new president's visions. However, they (MoH) disregard the issue at the grassroots level, which we as the provincial government did not have the instruments or policies to implement. I mean, when the programme first started, we had to adjust to the programme's regulations, which required a lot of effort and negotiation. As a result, it was a perplexing task for us (Participant 23).*

The central government, in this case, the MoH, serves as a policy-maker and policy disseminator for local governments, while the district government serves as the executor. The WJPG is viewed as a link between districts (regencies and cities), while district governments are meant to rule over community mental health initiatives as they have sole power and authority to organise, prioritise, and distribute resources for their people. One top manager expressed the following point of view:

> *“We will endeavour to negotiate, holding discussions with various parties about regulations. Naturally, if there is a Ministry of Health and a Health Service (Public Health, hospital and community health centre) here (Participant 1).*

Participants also stated their opinion that the policy sometimes overlapped with the previous one, as Indonesia implemented a new system that replaced the former system of centralised administration and development planning with a wide range of decentralisation projects, including the FPP, in 2010. The changes delegated greater authority, political power, and financial resources to regencies and municipalities, rather than the provinces. One participant expressed the following point of view:

> *We are at the district level and have the authority to provide direct health care, including mental health care, in the CHC. The provincial level gives assistance in the form of training, medication, tools, and programmes, for example, but we are under no responsibility to report our progress to them. We are in charge of reporting to the major. Although there is a collaboration between the provincial public health office and the MoH. Again, cooperation and planning are required, but we have the freedom to implement a modified programme or our own programme if it is judged necessary in our region (Participant 25).*

Despite the fact that the FPP and the Mental Health Act of 2014 were launched as national policies, the participants expressed confusion, because there was no technical regulation governing how the Pasung programme should be implemented. According to the participant, the lack of technical regulation caused the programme to fall short of its goals, which was revised numerous times up to 2019. This condition was expressed by two tertiary-level participants in the following ways:

> *Regrettably, there is no consistency. The programme collapsed after only a few months of development and because the funding was no longer available. This concludes my remarks (Participant 10).*
>
> *The continuity of treatment would be another issue. Not the whole programme which is apparent that is not a sustainable programme (Participant 7).*

9.4 Summary and Concluding Statement

The interview findings presented here have been organised into the four layers of the SEM. First, I presented the individualised Pasung experiences provided by PIPs. I then discussed the findings from the family and community level interviews. Finally, I discussed the interviews with bureaucrats regarding policy options for reducing Pasung. This method of presenting my findings elevated individual and family voices from the start, focusing squarely on the lived experiences of those struggling with mental health issues in West Java. As a result, I gradually shifted the focus away from individual experiences towards the community level and policy conditions that underpin individuals' lived experiences.

The PIPs described Pasung as a form of punishment. These conditions led to severe mental and physical consequences which were often permanent. They described how they were frequently embarrassed, and felt exposed and judged as ‘crazy’ by members of their community, which caused them to be in Pasung multiple times. Despite the launch of the FPP, the practice of Pasung persisted because the primary perpetrator was the family, and it was tolerated by the wider community. The main explanations given for the use of Pasung were to protect the individual, the family, and the community. These reasons were underpinned by a limited number of mental health treatment options, the consequent heavy family burden, and a sense of powerlessness among carers. All types of participants cited increasing access to treatment as the most effective way to reduce the incidence of Pasung. Pervasive stigma towards PIPs at the community level, and lack of mental health literacy have led to a deterioration in the already problematic situation.

This chapter has revealed that families saw Pasung as an effective way to protect the person from harm, prevent them from harming others, as a remedy, or all of these simultaneously. Whatever form Pasung took, families believed that using it was necessary to limit risk and, to some extent, improve the person's condition. Furthermore, families had reasons for using Pasung that were

strongly related to the socio-economic situation the family was experiencing during the person's treatment. While legislation and policies do exist on Pasung, the participants said that they were, at best, based on flawed assumptions, and efforts to implement them had encountered numerous challenges such as fragmented services, the low priority placed on mental health by government funders, and professional apathy at the policy level. Nevertheless, the government's claimed success of the programme has not, according to the participants, resulted in the implementation of effective mental health care in the community. The vast majority of the population is excluded from these programmes, particularly those without insurance who continue to lack the basic facilities suggested by the policy. Despite its good intentions, participants said that the FPP has, so far, fallen short of expectations. The complete lack of cost estimates and the absence of budgetary support were cited as significant contributors to its failure.

The next chapter provides a discussion of the issues raised in this thesis, which includes detailed visual (photography and videography) and interview data to gain a rich and deeper understanding of Pasung. In this process, pre-existing theory from the systematic review provides valuable insights about Pasung. I discuss the findings under four key themes that arose from the data. The data are organised into four broad components that are guided by the SEM framework.

10
DISCUSSION

In this discussion chapter, I present the findings across the three different types of data of my exploration of the practice of Pasung in West Java. This research aimed to understand the use of Pasung in Indonesia, including the socio-cultural meaning of Pasung, the experiences of those involved, perceived reasons for its use, current interventions to address Pasung, barriers to eradicating Pasung, and potential solutions. This PhD research is the first to conduct a comprehensive examination of this issue that includes the social and cultural meanings of Pasung practice from the perspective of PIPs, their families, the community, health professionals (e.g., physicians, nurses, psychologists, social workers), non-health professionals (e.g., budgeters, planners), policy-makers (e.g., Ministry of Health, Public Health Officers), and health system managers (e.g., hospital administrators, community health administrators). Prior to this work, there had been relatively little research undertaken on this topic in Indonesia and internationally, as shown in the systematic review (Chapter 3). A comprehensive ethnographic study on Pasung was suggested, to gain an understanding of the cultural aspects that are rarely or infrequently considered in mental health treatment procedures, including in Pasung. The thesis has made a significant contribution to the Indonesian and international literature on Pasung both because of the study design used, which extends the understanding of how video and photo analysis can be applied as research methods, as well as the outcomes of the research on Pasung.

The overarching theme of this research found that Pasung gave the PIP and the systems of support around them, particularly their families ‘No room for escape’ from the use of Pasung. The findings inform us how Pasung is multidimensional, socially and culturally accepted within the community, and how there are dynamic inter-relationships that exist across Socio-Ecological (SEM) contexts that reinforce its use. ‘No room for escape’ is a term used by the author to indicate that Pasung occurs over time for PIPs, sometimes for the remainder of their lives, which creates barriers to receiving mental health services. This key finding also identifies a lack of accessible alternatives to Pasung, showing that the family and community believe there are no effective, accessible alternatives to these practices. This situation leads to ineffective implementation of the Free Pasung Programme (FPP). The overarching theme, ‘No room for escape’ encapsulates the idea that Pasung, although regarded as a last-option form of treatment, is perceived as the only effective, accessible means participants had to manage persons who were deemed as having aberrant behaviours given the significant barriers to accessing mental health services. ‘No room for escape’ implies a major unbalanced power relationship across the four layers of the SEM. The detail of the findings using the SEM is discussed in the sections below.

10.1 Individual Level

10.1.1 The Nature of Pasung

The findings from the photo analysis revealed that the nature of Pasung entails varying degrees of material resources that either improve Pasung practice or are harmful to the health of PIPs. Some of the findings of the photo analysis indicate similar patterns of Pasung use that have been reported in other studies in Indonesia (Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011), other Asian countries (Tay et al. 2017), and in Africa (Asher et al. 2017) where the most prevalent mechanical tool used for Pasung is a wooden log, combined with other types, to make it robust and ensure no room for escape. However, in the more densely populated West Java suburbs, a cage made of metal, bamboo, or wood is typically used, which has not been documented in previous studies. Since most of the photographs obtained in metropolitan areas were of the use of isolation or chaining, I argue that the variations between the chosen types are likely to be related to the geographical area. Furthermore, I also consider that this type of Pasung might be related to the availability of space and availability of materials, as open land and wood are scarce in the city. Given the types are different, I propose that Pasung can take many forms and differs according to geographical area and the availability of materials, but the intent is the same; each type is designed to keep the person there for long periods of time, with no room for escape.

10.1.2 Pasung and Exposure to Physical Health Concerns

The physical health effects of Pasung further emphasised the inability of PIPs to escape the practice. Although a large body of evidence suggests that PWMI have higher rates of physical illness than the general population and have a reduced life expectancy (Morgan et al. 2021; Pack 2009; Robson & Gray 2007), there is no current research on the prevalence of physical illness among those who are confined in Pasung, apart from general records of physical injury (e.g., pressure ulcers, abrasions, joint contracture) and wasting (Asher et al. 2017; Read 2012; Yusuf & Tristiana 2018). The photo and interview analyses revealed that most PIPs were confined for very long periods of time. The impact of Pasung on people suffering from serious mental illnesses can be enormous.

The photographs, videography, and interview data depicted many PIPs suffering from a variety of chronic illnesses, including diarrhea, tuberculosis, cardiovascular disease, malnutrition, and skin infections. Emaciation as an impact of the lack of adequate food intake and unhygienic conditions, contractures due to immobility, and other physical illnesses were all depicted in the photographs. These findings from the thesis are also supported by other international research; for example, in an African study by Asher et al. (2017), two PWMI had physical injuries resulting from restraint, including bruising, contracture, and deformity of the leg. Mostly, the physical injuries happened because the PIP could not move freely or because they were held in wooden stocks in one position for a long time. Likewise, another study by Yusuf and Tristiana (2018) found that many PWMI

subjected to Pasung in Indonesia experienced atrophy and contractures, mostly in the lower limbs. Another finding was that many PMWI experienced cachexia (wasting syndrome) due to being undernourished or being denied food and water (Read, Adiibokah & Nyame 2009).

For the PIP, physical inactivity was unavoidable as most were ‘floor-ridden’ (see photographs where it was apparent that many of them were kept for months in the wooden logs). Furthermore, because they had been confined for such a long time, some of them became elderly during their time in Pasung, creating the potential for them to die predominantly as part of natural ageing. This does not discount, however, that the FPP team also found younger people who had passed away while in Pasung, far earlier than would be expected for their age group as a consequence of the severe treatment and conditions in which they were confined. There is little evidence of investigations of death records of PIPs to date. This is an area that requires further investigation. Further research should be conducted to determine the scope of the problem and the specific mechanical devices associated with injury and possible death.

10.1.3 Pasung and Psychological Harm

The findings from this study demonstrated that the effects of Pasung on PIPs were also psychological and likely led to deterioration of existing mental illness, further increasing the likelihood of ongoing Pasung. According to our findings, Pasung alters one's life story and forces the person to reconsider their identity. Suffering occurs when the person becomes aware of the losses he or she has suffered as a result of Pasung. Many had become psychically bewildered and disoriented in the pitch-black environment. The only reliable markers for many were the foot-shaped anchors on the wooden logs and the immediate surroundings. Previous studies similarly reported that many PIPs experienced psychological problems (Asher, Fekadu & Hanlon 2018; Buanasari, Daulima & Wardani 2018; Daulima, Rasmawati & Wardani 2019; Rasmawati, Daulima & Wardani 2018). Yusuf and Tristiana (2018) noted that PIPs experienced depression, isolation, and hatred towards those who had put them in Pasung. Participants in my study also reported being traumatised by the Pasung experience and avoided contact with other people as a consequence of their experience. Community leaders and community health workers also highlighted the detrimental psychological impacts of being restrained and acknowledged that Pasung could make the illness worse or increase the risk of violence towards others. Similar research has reported that seclusion and restraint increase vulnerabilities and heighten mental ill-health in institutional settings (Chieze et al. 2019; Larue et al. 2013). Several studies have suggested that confinement experiences contribute to several physical disorders that also contribute to subsequent mental illness (Huckshorn 2006; Larue et al. 2013; Ross, Campbell & Dyer 2014).

While previous research (Asher, Fekadu & Hanlon 2018; Buanasari, Daulima & Wardani 2018; Daulima, Rasmawati & Wardani 2019; Rasmawati, Daulima & Wardani 2018) provides some

information on the occurrence and nature of these psychological problems, many issues remain unresolved, and there is currently little information on their prevalence. As a result, determining the magnitude of the problem is unclear and this needs to be further researched. It is not clear, for example, whether PIPs develop mental illness due to their confinement environment, whether confinement worsens pre-existing conditions, or whether their mental illness symptoms and/or physical health conditions appeared before their confinement. In our study, we found that some of the participants had never been treated or visited mental health services, and several had no medication history or firm diagnosis. Here, deprivation models can offer an explanation. These propose that the symptoms and deterioration of cognitive functioning associated with these PWMI in Pasung led to increasing difficulties in function and maintaining living standards, or that the accumulation of exposure to environmental risk, such as the Pasung environment, reduced access to health care, causing mental illness to develop (Lee et al. 2020; Vargas, Conley & Mittal 2020).

Given the absence of research on the use of seclusion and restraint in the community, reference to in-patient research in hospitals and prison settings may offer some insights, acknowledging that the situation of PIPs in certain states may be far worse than for these groups. Researchers have reported how people are changed and affected by long confinement and prison-like environments for many years (Coppola 2019; Haney 2017; Richards 1978), including the degree to which certain conditions of confinement constitute violations of the person's rights. Studies involving patients secluded at in-patient units have revealed that many adverse and complicated implications of the practice of seclusion, with or without restraint, have been reported by them. Many patients who are placed in seclusion have difficult emotions about the experience. Feelings of anger (Frueh et al. 2005; Kontio et al. 2012) were common, as were recalling traumatic memories or having experienced trauma and feelings of abandonment and isolation (Haw et al. 2011; Steinert et al. 2013).

Moreover, the findings in this thesis have revealed that PIPs typically had extensive trauma histories that included chronic poverty and deprivation, severe forms of emotional, physical, and sexual abuse, and abject neglect. This was also mentioned in many other studies on Pasung (Asher et al. 2017; Buanasari, Daulima & Wardani 2018; Read, Adiibokah & Nyame 2009). Despite some studies proposing that most cases of Pasung were because the PIP had discontinued their medication (Eka & Daulima 2019; Idaiani & Raflizar 2015; Minas & Diatri 2008), our findings revealed that several PIPs had been hospitalised for mental health issues extending back to early adulthood/childhood and had been prescribed a variety of psychotropic medicines over the course of their lives. Many had never received adequate therapy and ended up in Pasung as a result of their violent behaviour or failure to improve while still continuing to take anti-psychotic drugs (see Photograph 7.35, page 173 of the family showing the drugs to the FPP team).

This thesis found that while the PIP was confined, some members of the family continued to provide medication. This indicates that the family relied on medicines to improve the condition of an ill member of the family. When this method failed, the family had no choice but to use Pasung. This also suggests that the health worker may have indicated that medicine should be administered without the need for any additional therapy, at least at home. This finding reflects research and commentary on how a narrow understanding of mental health that focuses on biological factors has likely resulted in a disproportionate amount of mental health practice being viewed predominantly through an 'illness' lens and requiring treatment by medical experts, with a much smaller focus on the patient's perspective (Rose, N 2007). Clark (2014) added that framing mental illness as a purely biological disease has led to a false perception that only medical treatment is effective in psychiatric treatment in the absence of any broader context in which the person is situated. As a result, the mental health practitioner mentioned earlier in Photograph 7.54 (page 190), saw the patient as a passive individual who needed treatment, but did not actively participate in it (Ahn, Proctor & Flanagan 2009; Clark 2014).

Suicidal thoughts, sadness, and hopelessness were only a few symptoms of the mental suffering that PIPs might experience, particularly in medium- to long-term extreme isolation and in sparse situations. Lack of social engagement also led to psychological harm for many PIPs in this study. Many studies have extensively documented a link between social isolation and the experience of social pain, which includes painful feelings following social rejection or social loss, as well as the adverse impact of social pain on physical and mental health and psychological wellbeing, including low self-esteem, humiliation, and a sense of abandonment (Coppola 2019; Eisenberger 2011, 2012; Eisenberger & Cole 2012). Socio-environmental deprivation may be harmful to the brain and long-term recovery, with many of these effects likely to be permanent (Coppola 2019; Haney 2017). Extrapolating from the findings of this thesis, it is proposed that solitary confinement, particularly from the perspective of the person being confined, constitutes torture in and of itself, even under established criteria, for example, such as imprisonment (Coppola 2019; Haney 2017; Moore, L & Scraton), or being secluded and restrained in a mental health facility (Haw et al. 2011; Kontio et al. 2012).

Unarguably, many PIPs were living for an indefinite time in confinement with no meaningful social contact, with maybe only some sporadic communication with their families or passersby and living in precarious conditions. For example, many of the PIPs depicted in the photographs analysed for this study were living in dark and filthy conditions that were separated from the home, with some even deep in the woods. By contrast, most photographs of PIPs in metropolitan areas showed them placed within, or relatively adjacent to, the family house. This may be why some of these people were still able to answer and reply when asked questions by the FPP team. One explanation for why some PIPs displayed more capacity for social interaction may be because confinement was new for them, or the family were taking care of them with frequent interaction on

a daily basis. For example, the man in the urban area (Photograph 7.33, page 171) who showed good communication had high muscular density and appeared to be neat, implying that he showered and ate adequate food. Some of these proposed reasons for the variations observed for PIPs need to be confirmed, as there may be many missing connections and variables, especially for why some PIPs became disengaged and in social distress while others did not. I recommend that further study be conducted in order to shed light on these issues.

10.1.4 Gender, Harassment, and Pasung

During the photograph selection process, it was apparent that approximately 63% (N:326) of the total sample of photographs were of men. This finding has similar patterns with previous studies (Marthoenis et al. 2016; Puteh, Marthoenis & Minas 2011), which identified that people subjected to Pasung were predominantly male, aged 18-60 years. While more men were in Pasung than women, they were confined in the same manner, irrespective of gender. Both women and men appeared to be in the same state of Pasung in the photographs. Both genders were also subject to the full range of types of Pasung. The young girl in Photograph 7.16 (page 156) who was confined with a heavy wooden log (an extremely harsh method of Pasung) is an example of how the use and type of Pasung made no distinction between gender or age.

Although there do not appear to be many differences in Pasung cases between men and women, there were significant differences in the patterns and symptoms perceived as a cause of the person being in Pasung, with men more likely to be in Pasung due to perceived aggression. These differences varied across age groups. For example, regarding Photograph 7.17 (page 157) depicting a boy around 9 years of age who was reportedly chained for 11 months, the reasons listed in the FPP report were that the child was hyperactive, sometimes displayed tantrums, played with sharp tools like knives, and was also displaying ‘juvenile delinquency’ behaviours. Another photograph showed a young girl of similar age being held in a wooden log because she was unable to sleep at night and was verbally aggressive, which the family believed was due to her being possessed by an evil spirit. These findings aligned with a previous study that described the risk factors for aggressive behaviour among psychiatric patients, which included being of a younger age, male, unmarried, having previous mental disorder history, and having a history of violence or self-destructive behaviour (Dack et al. 2013). However, another study by Steinert (2002) argued that gender, diagnosis, and substance use played a minor role in predicting violence in the community, while the history of previous violence played a significant role. The study also suggested that environmental factors could lead to violence, a factor which was mostly underestimated.

On the other hand, women appeared to be more vulnerable than men, in general, as many of them were naked. From my experience with the FPP, I am aware that harassment, sexual abuse, and even rape are said to be widespread among women with mental illnesses, particularly those in

Pasung, especially when they are naked. The rapist is frequently released because the PIP is unable to identify the perpetrator. This has also been noted in the literature. For example, one study in Indonesia reported that a 16-year-old girl was raped while imprisoned. After both her parents died, she was left alone in her house with no-one to look after her. She became pregnant after being raped, and her infant was placed in a social affair shelter to be adopted (Fahrurozi 2017). The literature further emphasises this problem, stating that while a great deal of media and professional attention has been devoted to this population as a whole, the suffering of individuals who have been abused or are seriously mentally-ill has been largely disregarded, adding to the trauma (Harris & Landis 2016).

Even though women are arguably more vulnerable than men when they are naked in Pasung, this does not mean that men have zero probability of being harassed or abused. A number of the photographs depict community members, particularly children, laughing at these unfortunate men. In his studies in Banggai, Indonesia, Broch (2001) found that many people treated mentally-ill persons as a form of entertainment. Many people followed them, clapping and laughing at the mentally-ill person, just as they would behave if they were being entertained by a comedian. He went on to explain that the Banggai distinguished between 'entertaining' examples of craziness and cases that they considered to be exceptionally dangerous.

To conclude, men and women had similar experiences of Pasung, according to the findings of the photo analysis. Women, on the other hand, were likely more vulnerable due to their nakedness and gendered stereotypes within these communities. Furthermore, both genders had various symptoms and causes for being in Pasung. To create a gender-specific treatment for people with serious mental illness in Pasung, and address community attitudes about Pasung, more research is essential to understand the causal roles of gender differences in PIPs.

10.1.5 Insight into Illness

The findings revealed that prior to being placed in Pasung, some people’s access to proper mental health care was likely hampered by avoidance of help due to a lack of insight into illness on the part of the PIP. Some people who have had Pasung experiences denied being labelled as mentally-ill, citing the complexities of when, and to whom, they revealed or concealed information about their illness. Hence, when symptoms appeared, the PIP and their family would typically practise self-care by self-medicating or by taking conventional medications. They would seek professional medical assistance if they thought the symptoms were still present. They would next try different conventional or alternative treatments if that did not work. The majority then sought out professional or informal health care practitioners, frequently combining or switching out medications from multiple providers. The most notable example of this pattern in the findings was when the family thought Pasung was an efficient method to treat the ill family member if both

conventional and alternative treatments had failed. This finding represents a coherent picture of specific cultural features that affected the PIP in gaining access to mental health services.

Our findings were supported by previous researchers who argued that between 50% and 80% of patients diagnosed with mental illness were found to be partially or completely unaware of the presence of their mental illness (Lincoln, TM, Lüllmann & Rief 2007; Osatuke et al. 2008). These people could dispute the existence of certain symptoms, the negative effects their disease had on their lives, and/or the necessity of receiving treatment (Osatuke et al. 2008). Although there was a clear causal link between poor insight and poor treatment adherence, and thus poorer outcomes and functioning, numerous studies investigating the correlates and long-term impact of insight on longer-term compliance have produced conflicting results (Lincoln, TM, Lüllmann & Rief 2007). It is not clear, however, whether PWMI and their families chose between self-medicating and taking conventional medications due to a lack of insight. Furthermore, Subandi and Good (2018) argued that shame and stigma were associated with the emergence of insight. This could explain why, in our findings, a traditional healer was among the first choice of Sundanese people when their family members were deemed to have a mental illness, and they would seek professional medical assistance if they thought the symptoms were still present. In conclusion, while more and better research on the phenomenology, etiology, and impact of insight is needed to estimate insight into their own illness among PIPs, the current research appears to highlight the importance of insight in determining the choice of mental health care.

10.1.6 Employment and Social Protection

Lack of employment, intimacy, and social relationships were some of the significant problems expressed by the PIPs who participated in this study. When negotiating intimate relationships, going for job interviews, or looking for ‘safe places’ to take medication, PIPs tried to maintain self-control, avoid embarrassment and discrimination, and avoid becoming the subject of public conflict. The socio-economic situation of unemployment, in which the majority of PIPs were depicted in the videos, was another problem that either prohibited PIPs from accessing proper health services or escaping from Pasung. The lack of available family to care for them financially also hampered the situation. For example, in the first video, a man who had been in Pasung for the past 15 years was placed in Pasung when he was in his late 20s, jobless, and without any relatives to rely on for support. Fifteen years ago, he returned home to his family after a period in Pasung as a young man. Within one month of discharge from a psychiatric hospital, his family were unable to afford to continue his treatment and returned him to Pasung, and he has been there ever since, until the day of this filming. The man’s parents who had been his carers had recently died and other family members had been providing the man with food since that time. His divorce from his wife exacerbated his illness after he became recurrently unwell.

The social exclusion of people with mental illnesses is still a global public health and human rights issue, indicating a need for underpinning policy and practice reform (Cordier et al. 2017; Drew et al. 2011; Hall et al. 2019). There is no consensus on the definition of social exclusion, although the World Health Organization (WHO) defined it as the dynamic, multidimensional processes fueled by unequal power relationships that interact across four main dimensions: economic, political, social, and cultural, and at various levels including individual, family, organisational, community, government, and global (WHO 2008). Previous research has reported that many people with mental illnesses are excluded from employment (economic exclusion), denied the legal right to vote, marry, or own land (political exclusion), and are socially isolated (sociocultural exclusion) around the world (Corrigan & Watson 2002; Hall et al. 2019; Schomerus & Angermeyer 2008), with stigma considered to be a major predictor of social exclusion (Corrigan & Watson 2002; Hall et al. 2019; Hartini et al. 2018). Both mental illness and social exclusion are linked to premature death via direct and indirect pathways involving chronic disease and lifestyle factors (Holt-Lunstad et al. 2015). Stigma and discrimination associated with mental illness also affect help-seeking and access to health care, impeding recovery (Clement et al. 2015; Corrigan & Watson 2002). Despite Indonesia issuing several policies to increase the participation of PWMI in all aspects of economic, political, and social life, the success of their implementation is so far unknown and there is little research among Indonesian researchers on social exclusion among PWMI, particularly those in Pasung. Thus, the findings of this thesis make another significant contribution to research on Pasung, and future research could focus on this issue with photovoice, for example, to capture the voice of those in Pasung in relation to social exclusion.

In conclusion, at the individual level, Pasung entails varying degrees of material resources that either improve or harm the health of PIPs. As a result, many PIPs suffer from physical illness and psychological problems, which contribute to their having ‘No room for escape’. As a result of their illness, they also had greater difficulty obtaining adequate health care which further reinforces the ongoing use of Pasung.

10.2 Interpersonal

10.2.1 Burden of Care

The harmful effects of Pasung extended beyond the PIP to family members and the community from which the person came. Caring for someone in Pasung had a significant impact on social ties, employment, and finances, as well as psychological wellbeing. This study found that family carers frequently bore the burden of care, and were thus the decision-makers when it came to restraining their family members. Pasung was typically described as a pragmatic action, viewed as a strategy to manage the illness, based on protecting the PIP or the wider community, or was deemed necessary in order to allow other family members to attend to and maintain work. At the same time, families were portrayed as powerless in the findings, with few options and frequently forced to act

out of fear. Nevertheless, in the end, the main person responsible for deciding to place the PIP was the primary caregiver.

The findings also depicted families suffering from physical and emotional stress as a result of having family members with mental illnesses. Despite Pasung inflicting human rights violations, the stressors experienced by families led them to believe that Pasung was the only option for protecting others and the PIP from aggressive and destructive behaviours. The levels of burden can be identified in families depending on the patient, the caregiver, or environmental factors. Previous research indicated that the patient's level of impairment, symptoms, and gender all had an impact on the family burden. Coping abilities, level of education, and relationships with patients (for example, being parents) all contributed to considerable variation in the stresses of family care that led to Pasung (Daulima, Rasmawati & Wardani 2019; Dewi, Daulima & Wardani 2019; Hartini et al. 2018; Katuuk, Daulima & Wardani 2019; Laila et al. 2019).

The term ‘family burden’ refers to all the difficulties and challenges that families face as a result of someone's illness (Acero et al. 2017; Ennis & Bunting 2013). To some extent, family burden is related to caring/caregiving, but the two concepts are not synonymous. Caring is commonly thought of as involving the provision of practical assistance with personal care, medication management, activities of daily living, and/or financial management (Acero et al. 2017; Sales 2003), whereas family burden includes both subjective and practical/objective elements such as emotional difficulties and challenges. Furthermore, family burden focuses on the difficulties and challenges that arise as a result of someone's illness, or more specifically, a caregiving role, whereas caring/caregiving is acknowledged to have both positive and negative aspects (Acero et al. 2017; Ennis & Bunting 2013; Sales 2003).

Previous studies have shown that family burden creates long-term stress for the entire family with a PIP (Asher et al. 2017; Eka & Daulima 2019). Families of PWMI in general may experience high levels of conflict, with the PWMI becoming both an objective and subjective burden, causing family members to blame one another and resulting in family feuds (Acero et al. 2017; Ennis & Bunting 2013; Sales 2003). Furthermore, the burden can become a source of stress for the rest of their lives, leading to ineffective coping with physical, financial, and psychological stressors that exacerbate the family's stress levels (Yunita et al. 2020). The findings demonstrated that poverty, either in the family or the patient, was a common factor in many cases of Pasung leading to ‘No room for escape’. A similar finding from this thesis that the family were ageing and poor has been highlighted in many studies (Laila et al. 2019; Reknoningsih, Daulima & Putri 2014).

In most families, parents are the primary carers for their children, but this is not always the case in Pasung where children were also affected, with many required to step up as carers and breadwinners. The children cared for their ill family member at home due to financial constraints, access issues, and the family member’s illness relapse after being discharged from the hospital.

For a variety of reasons, including stigma, financial hardship, the strain of caring for ill parents, and hereditary predisposition, these children were perceived to be at higher risk of acquiring physical and mental illnesses. The long-term effects on children were perceived to affect their adult health and relationships. One of the participants described that they had grown exceedingly shy and had few friends as a result of having a parent in Pasung. Participants also described that they needed to step up as breadwinners to cover the family needs. Buanasari, Daulima and Wardani (2018) have also reported life changes as a result of having mentally-ill parents occurring in children living with parents in Pasung. These changes included alterations to their roles, and to the psychological and social aspects of their lives. Furthermore, children who had parents in Pasung tended to be highly dependent on being supported (e.g., financially) by others, as they had to take care of their parents (Buanasari, Daulima & Wardani 2018; Dewi, Daulima & Wardani 2019).

The burden on the family most likely influenced the care given to the PIP, which was often not optimal for the PIP's wellbeing, which led to families placing their family members in Pasung and contributing to PIPs having ‘No room for escape’. Creating employment opportunities for PIPs and their family members through a social support system is probably an important element of the actions needed to reduce Pasung, as a lack of time to care for, or the lack of availability of a carer, may also result in Pasung.

10.2.2 Family Torn between being a Carer and a Perpetrator of Pasung

Families' roles as carers influenced their experiences with Pasung. They saw their role in ensuring the PIP's safety as an ethical and moral responsibility. As a result, they were conflicted when they were required to impose Pasung on a family member who was ill. The main explanations given by the family for restraint were to protect the individual, the family, and the community. These reasons were underpinned by the limited availability of mental health treatment options, the consequent heavy family burden, and a sense of powerlessness among carers. The family believed that Pasung was the only option for protecting others and the PIP from aggressive and destructive behaviours.

As mentioned above, family members were almost always reported to be the main group instigating Pasung (Asher et al. 2017; Laila et al. 2018; Yusuf & Tristiana 2018). However, positioning the problem of Pasung on the caregiver within a policy lens, including the decision to put the family as the perpetrator in prison, seems unjust. If family support is present, it may help to improve outcomes (Buanasari, Daulima & Wardani 2018; Daulima, Rasmawati & Wardani 2019; Dewi, Daulima & Wardani 2019). This is a significant omission given that in many countries, the majority of people with mental illnesses never receive institutional care; instead, they live in the community and are primarily cared for by family members (Asher et al. 2017; Asher, Fekadu & Hanlon 2018; Hall et al. 2019). Furthermore, the family's capabilities to de-escalate violent behaviour when it appeared was inadequate (Buanasari, Daulima & Wardani 2018; Daulima 2018;

Minas & Diatri 2008; Read, Adiibokah & Nyame 2009; Suryani et al. 2011), which led families to place their ill family members in Pasung, which contributed to PIPs having ‘No room for escape’.

The findings also revealed that families were faced with the difficult choice between Pasung on the one hand and the person wandering or being seen as a social nuisance on the other. The findings described how families faced difficulty in finding a balance between supporting the person at home without Pasung and community safety. Families also believed that the use of Pasung was essential to keep the PWMI safe. Therefore, Pasung was usually described as a pragmatic action, where the decision to use it came after a long period of discussion with relatives and community leaders, with the main person responsible for making the decision being the main caregiver (Asher et al. 2017; Laila et al. 2018; Yusuf & Tristiana 2018).

The patient's or family's knowledge of mental illness as well as its acknowledgement were also important considerations. Recognising symptoms is a prerequisite for accessing and using mental health services. The meaning given to the ‘symptoms', the attribution of causation, and the ideas held about appropriate and effective therapies were therefore of utmost importance to the persons affected and those in their immediate vicinity (Kurihara et al. 2006; Lesmana, Suryani & Tiliopoulos 2015; Suryani et al. 2011). Many mental illnesses are symptomatic, manifesting later in life, hidden, or with relatively non-specific symptoms. Some illnesses are stigmatised, whereas others are not; some are contested, whereas others are not; and some are classified as disabilities, whereas others are not. These distinctions matter because they exist for social rather than biological reasons (Conrad & Barker 2010). Therefore, symptom recognition and consequent action are only one part of the entire picture. Who is consulted once the symptoms are recognised will depend on pre-existing beliefs about the likely meaning of the symptoms, the efficacy of different approaches (traditional, spiritual, western medical) for such conditions, and the availability and accessibility of the various potential sources of help (Tanra & Roosdy 2017; Winkelman 2008). For example, in our findings, the aspects of aggressive or violent behaviour, raising worries about patients roaming or escaping, the likelihood of homicide, and the absence of family supervision were all raised as concerns by families of PIPs.

Apart from cultural background, the stigma experienced by PWMI might have harmful impacts on social and cultural attitudes, such as misunderstandings of the mental disease, which will be discussed in the next section (10.3.2). Disagreements in opinion about how to respond to the person might generate negative impressions about PWMI, leading to Pasung. Pasung is regarded as an acceptable practice, and the community believes that allowing those with mental illnesses to remain locked up for the remainder of their lives is preferable because they feel that releasing the PIP from Pasung will generate negative issues in the community (Hartini et al. 2018; Hidayat et al. 2020; Minas & Diatri 2008). This contributes to the PIP having ‘No room for escape’ from the use of Pasung by family members.

10.3 Community

10.3.1 Social and Cultural Meaning of Pasung

The findings depicted that PIPs were secluded in their homes, in a separate room or hut, and many were not classified as being ‘in Pasung’ by their families and communities. The possibility that people behave differently in different places, and even have different viewpoints, is due to the structure of specific cultures and how communities are socially organised. As a result, theories developed to answer questions that are relevant in one setting may not be meaningful in another (Arie & Wolfgang 2012; Cohen, D 2001). Pasung as a cultural practice can be interpreted as a consequence of a set of core themes whose accessibility varies depending on the situational context. For example, during the FPP, when a health worker asked the participants a more direct question such as “Do you have someone in Pasung?”, some participants directly answered “No”. However, when broader questions were posed such as “Do you keep him/her at home all the time?”, most participants said “Yes”, and then explained their reasons further, noting the situational contexts.

Despite the fact that the term Pasung is widely used in the literature (Broch 2001; Hidayat et al. 2020; Minas & Diatri 2008), and that policies to address the practice exist in Indonesia (MoH 2010, 2017; MoHA 1999; MoSA 2017), I found there was little consensus among the participants about its meaning, beyond that of its core elements of using mechanical restraint (e.g., a wooden log). Indeed, the fact that some families and communities referred to ‘locking up at home’ as non-Pasung suggests that there were different perspectives, particularly among mental health workers and the community. The findings of the interviews, which revealed the multidimensional nature of Pasung, then highlighted how communities interacted and attempted to assess what was going on in Pasung using cultural approaches and processing information about the social world differently (Broch 2001; Leigh 2010a). These disparate views have led to a lack of alternatives to Pasung on the part of the family which has resulted in the ineffective implementation of the FPP. These different views of Pasung need to be taken into account in attempts to reduce the practice of Pasung.

Although the possible psychological and bodily harms associated with restraint were mentioned by families and other community members in their environment, they did not clearly characterise restraint as a human rights issue. This is arguably compatible with West Java's social and cultural milieu, which includes patriarchal power connections among families, between community elders and families (Ekajati 2005; Hancock 2000; Mustapa 2022), and between medical professionals and families. These power dynamics typically extend to health care decision-making, with the perspectives of people with mental illnesses given less weight than those of health care professionals or family members, if they are considered at all. For instance, Sundanese people hold the concept that deviant behaviour is connected to ancestral trance. ‘Karuhun’, the ancestor

who is thought to watch over the land, occasionally manifests in physical form (Danasasmita 2006; Ekajati 2005). Additionally, the majority of Indonesians believe that they are healthy if they are able to go about their daily lives without interruption.

Other conflicting views appear in the existing literature about the reasons for Pasung and how it relates to mental health literacy. In our findings, many individuals, families, and the wider community obtained information about mental illness and types of treatment, whether medical or alternative, from relatives, neighbours, and the community. One clear example was the videography of the family who took their ill family member to the religious healer because of the information provided by the community that the therapy was regarded as successful and that the cause of the illness was something beyond the physical. While this can be understood as a form of social support to families, the information is sometimes inaccurate, with mental illness often believed to be associated with the occult. Two articles supported the argument (Laila et al. 2019; Tay et al. 2017) that lack of mental health literacy contributed to Pasung practice, while Asher et al. (2017) and Idaiani and Raflizar (2015) disagreed. In line with these findings, Jorm (2000) stated that mental health literacy in the community was often ignored by the public, and that much of the readily available information is misleading. As a result, many PWMI were only brought to treatment settings once they were in a chronic state of mental ill-health.

Another significant finding is that Pasung practice was socially and culturally acceptable within the wider community, which created a community context in which there was ‘No room for escape’ from Pasung practice. The analysis of the photographs and videos revealed that Pasung was passed down from generation to generation. The video analysis revealed children being among the onlookers communicating directly with the PIP inside the hut, which is one example of how Pasung was revealed to a child and other community members as an acceptable and everyday occurrence. Oyserman and Lee (2007) argue that culture can be passed down from generation to generation in a specific time and place, and that culture is continuous and specific. Furthermore, family members, peers, and other members of the community assist people in learning to accept social phenomena that are erroneous, such as Pasung. Individuals become ‘insiders’ of their own cultures, develop a sense of identity, and can fit into and survive in their society; a process known as enculturation. These processes occur as a result of both conscious and unconscious conditioning, via formal and informal means, and are frequently regarded as lifelong processes (Cohen, D 2001; Tan 2014). As a result of the nature of Pasung being embedded within the culture, the PIP lives in prolonged confinement, isolation, and quite often multiple times, which negatively impacts their physical and psychological condition, as previously discussed.

10.3.2 Stigma

At the community level, stigma has also contributed to ‘No room for escape’ through the use of Pasung by families and caregivers. An example of stigmatising that led to the perception that

PWMI are dangerous was evident in Photograph 7.43 (page 180), with the phrase "berbahaya in Bahasa" which means "dangerous in the Pasung shelter." Another warning sign "Beware dangerous environment, do not provide any dangerous tools" was another finding that emphasised this statement. The fact that most people were aware of the stereotypes, at least to the onlooker, implied that they agreed with them. Rejection and stigmatisation are common experiences for people with mental illnesses (Corrigan & Watson 2002; Wright, Gronfein & Owens 2000), including for PIPs, and have wide-ranging negative impacts on their lives (Corrigan & Shapiro 2010). In fact, Pasung is one of the outcomes of stigmatisation. The widespread use of Pasung has been linked to myths and ideas regarding mental diseases in the general community across generations which have viewed PWMI as dangerous and/or possessed by bad spirits (Broch 2001; Eka & Daulima 2019; Idaiani & Raflizar 2015; Laila et al. 2019; Malik & Bokharey 2001; Stratford et al. 2014).

The stereotype of violence remained unclear in the findings of this thesis because the people were already in Pasung and the stories of violence were mainly from the family and the community. However, as the person remained stable even as they were being freed from Pasung, some questions arose about whether PIPs were actually displaying violent behaviour prior to Pasung or whether stigmatising views about the PWMI being dangerous were the dominant reasons for them being in Pasung in the first place and being kept there. While aggressive behaviour can be associated with some psychiatric illnesses and is an important clinical issue, a standard and clinically useful definition has eluded researchers due to the inter-relationship between biological, cultural, environmental, and social elements that influence aggression (Liu, Lewis & Evans 2013; Swanson et al. 2002).

The previous study by Laila et al. (2019) showed that people with mental illness with aggressive or violent behaviours were five times more likely than non-aggressive people with mental illness to be exposed to Pasung. Moreover, Reknoningsih, Daulima and Putri (2014) echoed the aforementioned findings, stating that the family's fear of the person’s violent behaviour caused them to utilise Pasung with their relatives on multiple occasions. Other research confirmed that violence was a factor in the family's decision to utilise Pasung (Minas & Diatri 2008; Puteh, Marthoenis & Minas 2011). Those who are close to people with mental illness are more likely to discriminate against and isolate them because of this preconception (Asher et al. 2017; Broch 2001; Suryani et al. 2011; Tay et al. 2017).

Community stigma is also related to the notion that mental illness is caused by unsettled spirits, being possessed by demons, black magic, or being triggered by a person having supernatural skills. Spirits, it is widely assumed, interfere with the ‘crazy’ person's verbal and other behaviours. The PWMI is frequently thought to be possessed or under the spell of certain spirits. As a result, it may be necessary to establish communication with spirits in order to determine why the PIP is troubled. This finding was revealed in Photograph 7.46 (page 183) which showed a wooden cross,

which was positioned diagonally on the external wall of the place used for Pasung. It was meant to serve as a warning to others that someone or something potentially dangerous was present in the vicinity. It could also be used as a medium to ward off bad spirits or people possessed by the devil. As a result, anyone passing by, or strolling through, the hut should avoid unsettling or addressing it. A second aspect of this finding was the direct illumination of the PIP by the sun and moonlight, which the family said was done to rid their child of a demonic spirit. For example, as shown in Photograph 7.47 (page 184), putting this man deep in the woods was believed by the family to help him calm down by allowing him to reflect on his rage and reduce the likelihood of violence in the neighbourhood. The roof was tiled with a glass roof in one place, allowing the sun and moonlight to directly illuminate his body. The family believes this was done to free their child from a malevolent spirit.

Mental illness and bad spirits have been mentioned in many studies. For instance, mental illness stigma in Muslim communities may be attributable in part to a widespread belief among some Muslims that mental illness is caused by supernatural forces (Ally & Laher 2008; Rishi 2012). Although the original sources of this belief are unknown, some Muslims believe that mental illness is caused by metaphysical forces (i.e., jinn/demon possession) brought on by the sufferer's immoral life, weakness, or sin. Another study set on a remote rural island In Indonesia similarly found that the majority of the villagers, based on their beliefs and religion, thought PWMI were possessed and dangerous, and that mental illness was caused by an evil spirit (Jin) that needed to be exorcised by spiritual or traditional healers (Broch 2001). According to other studies, some families believed that the person’s mental illness was attributable to God's will (Riany, Cuskelly & Meredith 2016; Tanaka et al. 2018). They viewed having a family member with a severe mental illness as a punishment for their previous crimes or as a temptation. Some family members blamed themselves for having mental illnesses in their family (Riany, Cuskelly & Meredith 2016; Tanaka et al. 2018; Wulandari, Daulima & Wardani 2019). The photo analysis revealed some of the signs related to this view and that the person with mental illness needed to be isolated to prevent further damage to the community.

The impact of stigma on PWMI can be immense (Corrigan & Watson 2002; Stier & Hinshaw 2007); the illness alters one's life story and forces the person to reconsider their identity. The impacts of stigmatisation may exacerbate the effects of mental illness symptoms. This can either energise people into using the coping techniques of secrecy and social retreat (Corrigan & Shapiro 2010; Wulandari, Daulima & Wardani 2019) or energise them into anger about stigmatisation (Corrigan & Watson 2002; Stier & Hinshaw 2007). While the decision to use Pasung was likely not taken lightly, stigmatisation by family and the community played an important role in allowing the practice to flourish. Stigma towards mentally-ill people in Pasung appears to be insidious, characterised by stereotypes, prejudice, and discrimination. Firstly, negative stereotypes were held about PWMI as dangerous. Because stereotypes convey commonly agreed-upon views of groups of people, the

community can quickly form perceptions and expectations about persons as dangerous (Broch 2001; Corrigan & Shapiro 2010; Eka & Daulima 2019; Idaiani & Raflizar 2015; Laila et al. 2019; Malik & Bokharey 2001; Stratford et al. 2014). In the context of this study, the family and community did not want the person with mental illness around because they were afraid of them. Secondly, prejudice is primarily a cognitive and emotive reaction that leads to discrimination, which is a behavioural response of distancing, isolation, and/or exiling the person (Asher et al. 2017; Eka, Daulima & Susanti 2022; Tanaka et al. 2018; Tay et al. 2017; Ulya 2019). This was evident in this study where discrimination and prejudice-related behaviours towards PIP were seen in avoidance and the withholding of assistance by the community.

The findings of this thesis provide important insight into stigma in Pasung, especially through the use of photography as a data source, and how these experiences and contextual factors need to be taken into consideration when implementing strategies to alleviate stigma and behaviours towards PIPs. Policies addressing these activities must be complemented by a broad range of anti-stigma actions, such as providing appropriate education and assistance to families and the community and addressing ethical and workplace culture challenges for health professionals and staff in community organisations working with families.

10.3.3 Fragmented Services

At a community level, a further significant reason for the continuance of Pasung in the Indonesian community, in particular in West Java, is the lack of sufficient resources, the fragmentation of services, and poor multidisciplinary communication. Participants stated that one of the main obstacles to implementing the FPP was fragmented care. They identified this was happening when different health care providers and/or health care organisations did not collaborate well. Participants stated that each health care provider operated in their own silo, resulting in a lack of collaboration. The FPP was designed as a three-tiered national follow-up programme intended to eradicate Pasung. Individuals who met the criteria were accepted into the programme, but the participants pointed out that the implementation of the programme has been conducted only by tertiary health care providers with minimal involvement from secondary and primary health care providers.

Collaboration in health care is a multifaceted process that brings together two or more people, sometimes from different professional disciplines, to work towards common goals and objectives (Fewster-Thuente & Velsor-Friedrich 2008; Houldin, Naylor & Haller 2004). Health care providers and patients alike benefit from interdisciplinary teamwork. The level of collaboration among providers can have a direct impact on patient outcomes (Godolphin 2009). The use of multi-sector partnerships for the FPP emphasises the importance of community members as being vital to the intervention, and/or for providing services in community settings. Due to the large number of stakeholders involved, each actor has a different interpretation of how to manage Pasung

depending on their organisation's interests. For example, a PIP who has a physical disease that should be treated in a general hospital before being admitted to a psychiatric institution frequently goes untreated and is left in Pasung because no stakeholder can holistically manage these comorbid conditions.

While there is growing recognition of the need to integrate various health services for PWMI (Asher, Fekadu & Hanlon 2018; Ayuningtyas et al. 2018; Irmansyah et al. 2020; Jones et al. 2009; WHO 2015), not only to provide more coordinated care but also to contain the rapid inflation driven primarily by the curative sector, there is little research on how to implement this initiative, particularly for Pasung. According to previous studies in LMICs, both research and practice regarding health service integration are in their early stages of development (He & Tang 2021; WHO 2015). Many studies have suggested integrating long-term mental health care with curative and preventative care, particularly in community settings (Asher et al. 2017; Mendenhall et al. 2014; Minas & Diatri 2008; Nurjannah et al. 2015a). However, these models have a number of drawbacks in terms of capacity, perception, and operation that necessitate additional scientific and policy examination (Anjara 2019; Mendenhall et al. 2014).

The psychiatric hospital at the tertiary level appears to be solely responsible for the FPP in West Java, with no active involvement (less participation) of other related agencies with a focus on curative intervention. This focus on biomedical understandings of mental health has contributed to a disproportionate amount of mental health research being situated within a narrow scope that has been medicalised; that is, viewed predominantly through an ‘illness’ lens and requiring treatment by medical experts with a much lesser focus on the patient’s perspective (Rose, N 2007). Clark (2014) added that framing mental illness as a purely biological disease has led to the false perception that only medical treatment is effective in psychiatric treatment, but in the absence of any broader context in which the person is situated. As a result, the development of non-pharmacological therapies has been relatively limited (Ahn, Proctor & Flanagan 2009; Patel et al. 2018). Hence, the mental health practitioner has historically viewed the patient as a passive person, which means receiving, but not being an active participant in their treatment and care (Ahn, Proctor & Flanagan 2009; Clark 2014) which has led to a shortfall in Free Pasung intervention.

To summarise, the findings reveal that multiple factors affect the practice of Pasung at the community level. This thesis has found that people opted for conventional remedies when they believed diseases had divine causes and that the biomedical system was unable to address the person’s mental condition. People's perceptions of mental illness and its aetiology have an impact on the choice of care as well. The condition was also hampered by the fragmentation of care and inadequate policy. Interventions should then be implemented to improve access for PIPs to mental

health care. Multilevel strategies that address individual, interpersonal, organisational, and sociocultural barriers at various stages of care are recommended.

10.4 Policy

10.4.1 Inadequate Policy

The inability of this group of PIPs to obtain services was also significantly hampered by structural constraints, including inadequate policy execution (as discussed in Chapter 5) (Hidayat et al. 2023). For example, the high rates of comorbidity of mental and physical disorders are rarely considered in the planning of health services and the education of health professionals. This situation is exacerbated by the limited number and ability of community workers and the limited number of specialists and treatment facilities. In low- and middle-income countries, policy support for mental health problems is inadequate; and where it exists, implementation is problematic (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011; Miller 2012; Patel & Bhui 2018; Patel, Goel & Desai 2009). The absence of law enforcement creates another barrier in eradication pasung practise (Irmansyah, Prasetyo & Minas 2009; Saribu & Napitulu 2009). Saribu and Napitulu (2009) contended that the action of placing a person in Pasung is not qualified to be classified as criminal conduct as defined by the Penal Code. Although Article 86 of the Mental Health Law prohibits confinement, this article does not explain the criminal sanctions, as mentioned in Article 333 of the Penal Code which does not specify the type of deprivation of liberty.

The policy-related findings reveal that the intervention to free a PIP involves many stakeholders and people. It is a long and complicated process because of the range of bargaining positions between the stakeholders involved, as discussed in Chapter 5. This was also seen in the photo analysis. For example, Photograph 7.52 (page 188) depicted the FPP team in a huddle before the evacuation process. The huddle was held to discuss the evacuation process, transfer to the hospital, the post-hospital phase, and continuing treatment. This process is very common, bringing together many people with different stakeholder interests who might have their own goals, aims, and agendas which need to be managed. This can make communication, planning, and decision-making processes long and complex for the FPP team to navigate. At the policy level, there are various reasons why these types of collaboration appear to be failing in the context of addressing Pasung, with lack of job description of all stakeholders being first and foremost. There has been no technical policy or instruction that formalises the job of each stakeholder since the release of the FPP implementation in 2010. It took until 2017 for the technical policy for Free Pasung to be released (MoH 2017), despite the programme having been in operation for nearly two decades. The lack of detailed guidance has caused health workers at the grassroots to feel perplexed about how to implement the FPP, creating disarray in interdisciplinary collaboration among stakeholders involved in the FPP.

The central government's transition of the FPP from the Ministry of Health (MoH) to the Ministry of Social Affairs (MoSA) in 2017 added to the complexity of the collaboration. While the MoH developed an FPP on a more institutional basis to care for those who had experienced Pasung, the MoSA, on the other hand, established community-based pilot initiatives with a focus on social rehabilitation which differed from the MoH focus, further contributing to inadequate policy. The MoSA has been implementing recovery-oriented practises in accordance with their 2013 Social Rehabilitation Programme Development Plan, which aims to enable people with mental illnesses who have been in incarceration or experienced homelessness to return to their families as participating and productive citizens, as well as providing accessible support services for people in their local communities (MoSA 2017; Stratford et al. 2014). At the grassroots level, policy shifts and task uncertainty generate additional challenges.

Another problem is the lack of consumer participation in policy advocacy and implementation. Despite the fact that health care provider-patient interaction is fast evolving towards more active collaboration, fuelled by increased access to treatment information and consumerist attitudes in modern society (Irmansyah et al. 2020; Légaré et al. 2011; Li & Chapman 2020), the shift towards consumer involvement has not been visible in the FPP. An example is the process of releasing a PIP depicted in Photograph 7.54 (page 190). The family was left in limbo while the team continued to communicate, negotiate, and plan together. The family was just sitting there, looking perplexed and silent as they watched from afar. Equally, the role of the PIP, beyond being the object of the activity, was unclear.

While changing the manner in which the intervention is carried out may be important to attain Free Pasung based on consumer participation, how to do so across health care interactions is less obvious. Article 85, Mental Health Act No. 18 of 2014 (MoH 2014), for example, allows the community to participate in mental health treatment if the person needs assistance with little or no explanation as to how to operationalise this form of cooperation in the longer term. Despite the fact that patients want more input into treatment decisions, doctors are often hesitant or unprepared to involve patients in clinical decisions (Li & Chapman 2020; Shay & Lafata 2015). Also, the physician is described as the authority figure in decisions about treatment and overshadows the nurse-patient relationship (Fewster-Thuente & Velsor-Friedrich 2008). Shared decision-making has been identified as a critical component of health care quality and safety improvement (Caverly & Hayward 2020; Shay & Lafata 2015), but for a variety of reasons, it rarely occurs, is difficult to accomplish, and is not taught. Most health care workers' attitudes and communication skills training does not include talking with patients about their options (Caverly & Hayward 2020; Fewster-Thuente & Velsor-Friedrich 2008; Shay & Lafata 2015). Thus, with the dominance of the biomedical system on the one hand and the penal code on the other, lack of access to mental health support and lack of community support continue to leave families with limited care options.

While other countries encourage autonomy, independence, and free thought, in Indonesia, the family, community, and other officials have the ability to confine someone who is regarded as mentally-ill to a mental institution (see penal code 1946 in Chapter 5). Close relatives of mentally-ill patients may petition the chairman of the district court to have the individual treated in a mental health facility for the purpose of peace and public order, or to heal the mentally-ill person themself, according to Article 10 of the Indonesian penal code (Government of Republic Indonesia 1946). This implies that individual autonomy is ignored, and that shared decision-making is still a long way off, leaving the family's options for caring for someone with mental illness very limited. On the one hand, they are prohibited from depriving a person of their liberty, but on the other hand, they cannot allow the person to roam as they will encounter severe consequences. When the family cannot send the individual for treatment because it is either inaccessible, or the hospital is overcrowded, they might choose to hide the sick family member, and Pasung might be one of the few options available to the family.

To summarise, health care providers, as well as other stakeholders, may have recognised that interdisciplinary teamwork is critical in achieving quality treatment for people and groups in the community through the Free Pasung intervention, as shown by the photographs of teamwork and attempted collaboration between the many stakeholders. However, cooperation measures, including those put forward in policy, have been limited in breadth and complexity. Furthermore, adequate policy implementation, including consumer and caregiver involvement, has yet to take place, with little or no explanation as to how to operationalise this cooperation. In addition to consumer and caregiver involvement, it has been determined that implementation should be aligned with improved coordination among all stakeholders, including health professionals, non-health professionals such as those in social affairs, non-government organisations, and the public at large (Irmansyah et al. 2020; Susanti et al. 2020).

Overall, the findings revealed that none of these policies provide guidance on safety interventions for the family in jeopardy when the patient has relapse episodes of mental illness (see Mental Health Act 1966, Mental Health Act 2014, West Java Regional Legislation 2018). The absence of defined and precise goals, targets, plans, and implementation methods to reduce the burden of Pasung was shown in our research of important policy papers (see Chapter 5) on Indonesian Pasung policy (Hidayat et al. 2023). Some of these objectives may not have been met, notably in terms of intervention implementation and service delivery, particularly at the primary and community levels leading to ‘No room for escape’.

10.4.2 Lack of investment in Community Mental Health Service and Top-Down Policy

The thesis has further identified a lack of investment in community mental health services and top-down policy as contributing to the ongoing practice of Pasung. Mental health is not regarded as a priority. The main challenges are largely the result of a lack of attention on, and investment in,

mental health. Where legislation and policies do exist, they are at best, ineffectively implemented, and efforts to modernise mental health systems have encountered numerous barriers (Maramis, Van Tuan & Minas 2011). In Indonesia for example, nearly 90% of government mental health funding is dedicated to psychiatric hospitals, with very limited focus on prevention or early intervention support services in the community (Maramis, Van Tuan & Minas 2011). This situation is exacerbated by the limited number and capabilities of community mental health workers, as well as the limited number of specialists and treatment facilities. Mirrored in other LMIC countries, policy support for mental health problems is currently inadequate and, where it exists, implementation is problematic (Irmansyah, Prasetyo & Minas 2009; Maramis, Van Tuan & Minas 2011; Miller 2012; Patel, Goel & Desai 2009; Patel et al. 2018).

Although the FPP aims to eliminate Pasung, participants described the programme as a top-down policy that fails to recognise the everyday reality of the primary care delivery system in many areas of Indonesia. Programme personnel at the central and middle levels do not appear to understand the ground-level reality in which the programme operates (Ayuningtyas et al. 2018). Lack of general health infrastructure, overburdened and inefficient health care delivery systems, the scarcity of trained health and mental health professionals, the burden of infectious and physical diseases affecting PIPs, and limited funding are rarely considered, as is the magnitude of the scaling-up required to address Pasung in practice (Praharso, Pols & Tiliopoulos 2020). Although Indonesia has tried to organise its services in catchment areas through their National Insurance Health Scheme (Aspinall 2014a; MoLH 2011), specialist mental health services remain the predominant component of the system. Therefore, mental health service provision has become primarily hospital-based. Patients can access tertiary psychiatric hospitals directly, bypassing the primary and secondary health care levels. This partly reflects the disproportionate concentration of health resources in large cities.

10.5 Summary

The continuance of Pasung is attributed to the complex interaction of many factors that exist across SEM contexts which reinforce its use. The findings show that Pasung is not solely a result of individual symptoms or the refusal of the family to accept psychiatric treatment. It can more accurately be attributed to a range of interconnecting factors across the SEM, including the government's failure to provide basic mental health services for PWMI, stigma within the community and culture, the fragmentation of hospital and community services, and policy inadequacy. Despite these concerns, numerous efforts have emerged not just at the national level inside various ministerial offices, but also at the province, district, and even grassroots levels, including the establishment of mental health-focused non-governmental organisations (NGOs). Pasung is a problem that is unlikely to be fully addressed by simply offering mental health treatments in a hospital. The systematic review and narrative synthesis have referred to various

Free Pasung programmes, each with its subtle distinctions. Even in Indonesia, where FPP are being implemented, the emphasis is on providing psychiatric medicine and basic psychoeducation rather than ongoing outreach, recovery, or rehabilitation. Instead, a comprehensive model is required which includes caregiver support, a community development approach to enhance economic independence, a coordinated effort to increase health care adherence, and community education to reduce stigma.

The next chapter provides a summary of the thesis, a solid argument for its significance, recommendations for future work, a critical analysis of what needs to change, implications for clinical practice, the strengths and limitations of the thesis, and an argument for the inclusion of the unique needs of the PIP.

11
CONCLUSION

11.1 Introduction

This chapter provides a summary of the thesis and a solid argument for its significance, which includes recommendations for future work, a critical analysis of what needs to change, implications for clinical practice, and inclusion of the unique needs of the PIP. The overall aim of this research has been to explore the use of Pasung in Indonesia including the socio-cultural meaning of Pasung, the experiences of those involved, perceived reasons for its use, current interventions, barriers to eradicating Pasung, and potential solutions. This research aimed to balance the many perspectives on this problem in order to understand how to overcome the use of Pasung and to inform how Indonesia can develop more effective interventions for PWMI in Pasung, their families, and the Indonesian community. The substantive area of enquiry was the continuation of Pasung in Indonesia, particularly in West Java, where the research was conducted, which was prompted by the issue of Pasung as an acceptable practice, the disparity between the work of the Free Pasung Programme (FPP), and the need for ongoing comprehensive treatment by FPP recipients, including support for their families who care for them.

The thesis has made a significant contribution to the Indonesian and international literature on Pasung, both in the research design, which extended the use of videography and photography, as well as in the outcomes of the research on Pasung. The photo and video analyses had never been used in prior studies on Pasung in Indonesia. This was conducted in ‘real-world’ non-institutional settings where people were in Pasung, and findings of these visual data added a significant contribution to knowledge on Pasung specifically, and mental illness in general. The collection of visual data in the form of videos and photographs is a vital way to explore the practice of Pasung as it is predominantly a hidden and stigmatised practice and is also experienced by people who may not be able to fully express their perspectives using other forms of communicating their experiences and circumstances via the use of other research methods. Visual representation plays a variety of roles in research and offers a holistic understanding of the participants. Many participants in this research could not speak clearly in terms of expressing their experiences of Pasung. Some participants had become mute as a consequence of their experience; therefore, visual methods were an important way to capture their experiences.

Prior to this work, there had been relatively little research on these topics in Indonesia and internationally, including no previous systematic review of Pasung. The systematic review in this thesis was the first to be conducted internationally on the topic of Pasung which was undertaken to identify the socio-cultural contexts for Pasung use and interventions to address it. The analysis

draws on the Socio-Ecological Model (SEM), which focuses on the relationship between the individual and their environment. The review highlighted the scope of the problem and what had been researched so far around Pasung. The findings of the systematic review (Chapter 3), in particular, suggested there would be value in conducting ethnographic research on Pasung. This systematic review has been published in the International Journal of Mental Health Systems (see Appendix I).

Moreover, the review of Indonesia's policies (Chapter 5) offers an examination of the topic that to date has not been explored in Indonesia. It provides important findings to identify limits or boundaries for future actions that are necessary to complete the goal of FPP and lead the development of further research in the future. The policy analysis examined existing policies, plans, and initiatives in Indonesia targeted at eradicating Pasung. Policy gaps and contextual constraints were identified in order to propose stronger policy solutions. This policy analysis has also been published in the International Journal of Mental Health Systems (see Appendix II).

This thesis has further contributed to two international conferences. The first conference presentation on 'Using Lived Experience Advocacy to Address Pasung', was presented at The International Academy of Law and Mental Health in Rome in 2019. Consumer participation in efforts to address Pasung is yet to bear fruit, with issues appearing to determine what this involvement should look like, how inclusive it should be, and the level of participation required and shared by each of these groups. Hence, the presentation was important as it involved Australian and West Javan consumer advocates and experts in seclusion and restraint to foster the development of skills, knowledge, and capabilities through interpersonal and institutional connections between academic, government, civil society, and the private sector in managing Pasung. The second presentation on physical illness and Pasung was presented at The Mental Health Services (TheMHS) Conference (the largest Australasian mental health sector conference) held in Sydney in 2022. We presented the findings of the photo analysis to an international audience, which revealed that many PIPs live in deplorable conditions, yet there has been little research into the issue. The way participants reacted to the findings and questioned why such practice exists in modern society demonstrates how important these research findings are to the body of literature on Pasung in particular, and seclusion and restraint in general.

This thesis is one of only a few (Anto & Colucci 2015; Asher et al. 2017) that have focused on the confinement of individuals with mental illness in community settings in Low- to Middle-Income Countries (LMICs) using ethnography as the method of enquiry. Unlike the previous two studies, which focused entirely or partially on traditional or spiritual healing centres, this thesis has focused more broadly on seclusion and restraint in the community with privileged access to the actual living environment of PIPs and the management and delivery of the FPP, which had never previously been undertaken. This thesis is the first to comprehensively research Pasung using visuals,

interviews, as well as a systematic and a policy review. It is also the first to comprehensively position the analysis of this topic which proposes dynamic inter-relationships that exist across SEM contexts that reinforced the use of Pasung. Understanding these interactions across these layers of the SEM is critical for developing multi-level interventions to effectively reduce Pasung. Hence, this thesis extends knowledge and understanding about the nature of Pasung and the social and cultural meanings of Pasung practice from the perspective of PIPs, their families, the community, health professionals, non-health professionals, policy-makers, and managers.

Next, I discuss the findings across the three different types of data of my exploration of Pasung practice in West Java. I present recommendations for future research in this area of health, which I follow with a discussion of the strengths and limitations of the research and concluding remarks.

11.2 Summary of the findings

This research was conducted in West Java. As detailed in Chapter 2, around 50 million, or more than 20% of the total Indonesian population reside in this province, with the ratio of men to women being approximately equal. The overarching theme of this research found that Pasung gave the PIPs and the systems of support around them, particularly their family, ‘No room for escape’ from the use of Pasung. Overall, ’No Room for escape‘ from Pasung resulted from a complex interplay of individual, family, community, and policy elements. Each of these elements had a cumulative influence on the individual's health condition (i.e., the general level of sensitivity and vulnerability to being in Pasung), in the sense that they combined and interacted with each other and built throughout the course of the individual's life.

Analysed through the lens of the SEM, a range of factors was identified across the individual, interpersonal, community, and policy levels, and this thesis has demonstrated the interconnection of factors within and between these levels. Individuals who were diagnosed with, or deemed as having, mental illness often experienced human rights violations such as indignity, discrimination, exclusion, the inability to live independently, and notably, Pasung. These people were vulnerable to conditions such as Pasung, as they were partially or completely dependent on their families and the community for their basic financial, social, and personal needs. This included support for food and shelter, and to continue medication and any other treatment for their overall health and wellbeing. Their risk of being subjected to human rights violations was elevated by the fact that many PWMI were living without adequate support from their family, and in contrast, families were the most common perpetrators of using Pasung.

The practice of Pasung is fraught with danger; it is dehumanising and PIPs are likely to experience all the negative emotions that such an experience engenders. Despite this practice, which was claimed to protect the public from injury and to act as informal punishment to reform the aggressive behaviour of wrongdoers, it was indeed an established practice that had at its core the use of

containment and restraint as a fundamental means of addressing and treating mental ill-health in the longer term for many within the West Java community. These attitudes and beliefs that Pasung was necessary to protect the community and that the person was dangerous were the very antitheses of a treatment-oriented milieu that promotes openness, caring, and mutual concern. The consequences of these attitudes and beliefs were visible in Pasung throughout the photo analysis, with many PIPs languishing in squalor and pain, often for many years. As a result, many PIPs suffered from physical illnesses and psychological problems, which contributed to them having ‘No room for escape’. As a consequence of their illness, they also had greater difficulty obtaining adequate health care which further reinforced the ongoing use of Pasung. Similarly, many countries' psychiatric hospitals frequently lack equipment that could aid in the diagnosis of physical illness, as well as medications and other materials that would allow physical illness to be recognised and treated.

Although there do not appear to be differences in the overall Pasung cases between men and women, there were significant differences in the patterns and symptoms perceived as a cause of the person being in Pasung, with men more likely to be in Pasung due to perceived aggression. Access to proper mental health care was likely hampered by avoidance of help due to a lack of insight into their own illness on the part of the PIP. Some people who have had Pasung experiences denied being labelled as mentally-ill, citing the complexities of when and to whom they revealed or concealed information about their illness. Hence, when symptoms appeared, the PIP and the family typically practised self-care by self-medicating or by taking conventional medications. Lack of employment, intimacy, and social relationships were some of the significant problems expressed by the PIPs who participated in this study. Despite Indonesia issuing several policies to increase the participation of PWMI in all aspects of economic, political, and social life, the success of the implementation is so far unknown, and there has been little research among Indonesian researchers on social exclusion among PWMI, particularly those in Pasung.

As the care of the PIP relies heavily on family, it is the family unit that is in charge of monitoring the illness and evaluating how far a person's health deviates from normalcy or healthiness. The family will also decide where to seek help and what kind of care to get. When some attitudes, emotional expressions, or behaviours of family members do not fit society's standards and values, and there is some concern about the nature of the behaviour, families may see them as deviant. Caring for someone in Pasung has a significant impact on social ties, employment, and finances, as well as the psychological wellbeing of family caregivers. Poverty and an ageing caregiver at the interpersonal level compounds the situation by making the caregiver unavailable owing to an inability to provide sufficient care and support. The family burden most likely influences the care given to the PIP, which is often not optimal for the PIP's wellbeing, which has led to families placing their family members in Pasung, and which contributes to PIPs having ‘No room for escape’.

Hence, Pasung became the main treatment option due to the lack of other available options. However, the family were faced with a difficult choice between Pasung on the one hand and the PWMI wandering or being a social nuisance on the other. Families believed that the use of Pasung was essential to keeping the PWMI safe. Therefore, Pasung was usually described as a pragmatic action, where the decision to use it came after a long discussion with relatives and community leaders, with the main person responsible for making the decision being the main caregiver.

These individual-interpersonal level problems deteriorated further as a result of stigma, insufficient resources, fragmentation of services, and poor multidisciplinary communication at the community level. Fragmented service happened as people tried to distinguish between psychological and biological phenomena by assuming that they have different content, structure, and causal mechanisms. This situation was exacerbated by the limited number and ability of community workers and the limited number of specialists and treatment facilities. In LMICs such as Indonesia, policy support for mental health problems is inadequate, and where it does exist, implementation is problematic. Moreover, stigmatising the PIP as aggressive and violent, the community plays an important part in the continued use of Pasung. There are pervasive negative beliefs about mental illness that persist. The Sundanese people hold the concept that deviant behaviour is connected to ancestral trance. Hence, traditional healers are preferred in the absence of adequate social support and mental health services, which are either non-existent or inadequate to meet the needs of the community.

Despite various policies enacted to abolish Pasung, Indonesia has made only very modest progress in reducing this practice. The reliance on policy alone to address Pasung in the absence of other measures being enacted and implemented has been regarded as one of the core issues associated with the persistence of Pasung in the Indonesian/West Javan community. Indeed, the Mental Health Act of 2014, as well as other health regulations and the overall enhancement of mental health services, have helped to elevate mental health, particularly Pasung, to a priority on the national health agenda, but have not been enough to deliver mental health services to the entire population, especially at the community level where Pasung has tended to persist. Indonesian Pasung health policies and strategies, particularly those in West Java province, lack the clarity and direction needed to implement existing evidence-based treatments to prevent a chronically high burden of Pasung. Failure to obtain curative therapy, in particular, tends to contribute to despair; this, along with a perception of PWMI as a threat to the safety and economic stability of the family, obstructs attempts to eradicate Pasung.

While acknowledging that shackling violates human rights, the government has been having difficulty putting an end to this practice. Efforts are being made, however, to increase departmental collaboration in a coordinated programme to stop Pasung. Many agencies, primarily health and social agencies, have continued to call for the development of legislation and policy to address

these abuses. Nevertheless, such initiatives exemplify a top-down approach to promoting human rights which historically has had limited impact at the level of those living with mental illness and their families. Efforts to promote the human rights of those with mental illness must engage with the experiences of mental illness within affected communities in order to grasp how these may underpin the use of practices such as mechanical restraint/Pasung. Interventions which operate at the local level with those living with mental illness within rural communities, as well as family members and healers, may have greater potential to effect change in the treatment of the mentally-ill than legislation or investment in services alone. The current intervention (the Free Pasung Programme) involves the person being taken to the hospital and receiving treatment for their mental health for a limited time before being returned to the community with no further follow-up or support provided to the person or the person's family or community. After hospitalisation, the problems that led to the use of Pasung frequently resurface, and the family and community return to using Pasung. Another significant finding is that, while legislation is already in place, its implementation has been poor, with little or no regulation of policies aimed at addressing Pasung.

The continuing practice of Pasung suggests that there continues to be a large gap in our understanding of the reasons given by families and the community for its continued use, and that there may be unmet needs that are not yet fully recognised. The findings of this thesis revealed that, while the family is the main perpetrator of Pasung, blaming all the mistakes and failures to address Pasung on families is unjust. Pasung is not solely a result of family callousness, ignorance, or refusal to accept psychiatric treatment. It can more accurately be attributed to a range of factors from an individual, community, and system level, including the government’s failure to provide basic mental health services for people with severe mental illness and poor policies. Pasung is frequently used as a last resort for families with limited resources, and as these findings show, fear also motivates Pasung.

Pasung is a problem that is unlikely to be fully addressed by simply offering mental health treatments in a hospital. Even in Indonesia, where Free Pasung Programmes are being implemented, the emphasis is on providing psychiatric medicine and basic psychoeducation rather than ongoing outreach or rehabilitation. Instead, a full package of care and support is likely required which includes caregiver support, a community development approach to enhance economic independence, a deliberate effort to boost treatment uptake, and broader community education including education of bureaucrats to decrease stigma.

11.3 Reflection during PhD research

This research has its roots in my work during 2016-2019 when I joined the West Java community mental health team to work closely with people with mental illness in the community. I then saw and started to reflect on the issue of culture around the practice of Pasung. My background is as a

clinician with more than 20 years of experience working in the psychiatric nursing discipline across many areas, i.e., emergency, inpatient unit, forensic, adult, child, adolescent, outpatient, and in the community. This research took place in West Java Province, which is predominantly comprised of people from Sundanese culture, as described in detail in Chapter 2. The ethnographic investigation of this cultural landscape took place across multiple locations and multiple levels, including the administrative level and health sector priority levels (primary, secondary, tertiary, and community) throughout 11 cities across West Java.

As previously stated, the primary goal of this research was to collect first-hand ethnographic data. However, because the pandemic occurred in the middle of data collection, using previously collected data was the only viable solution. I used a set of data that included photography, videography, and interview data that had been collected during my time working with the Free Pasung Programme. Following a thorough literature search, I came to understand that there is no set method or procedure for analysing ethnographic data, particularly those involving the collection of visual data. General analytical guidance did not provide me with detailed instructions; it could only suggest some possible workarounds. It was a difficult task because all visual data were taken from the researcher's point of view, which was very sparse in previous research.

Moreover, because the data collection and analysis were undertaken separately with some time elapsing between them, it was difficult to maintain the commitment to a discursive interaction between the data collection and analysis. This necessitated extended withdrawals from the field to process and analyse the data, with no way to return to collect additional data. Furthermore, there was the possibility of a conflict between an ethnographic concern with dense description and theorising. As a result of these practical and methodological issues, when it came to focusing on the analysis, it was frequently discovered that the data required to check a specific interpretation was missing; that the typicality of critical items of data could not be assessed; or that some of the comparative cases required for developing and testing an emerging set of analytical ideas had not been investigated. Furthermore, there was little or no time to rectify the situation. As I faced a trade-off here, as elsewhere perhaps, decisions about how much analysis could be done in addition to the main data collection were made in light of the research goals and the nature of the contexts in which the data were collected. The complicated analysis was simplified thanks to the invaluable process of cultural, belief, and knowledge exchange with my supervisors, who offered a very rich perspective.

I discovered during this ethnographic research that the research problem must be developed over time and may need to be transformed in some situations; eventually, its scope must be clarified and delimited, and its internal structure must be explored. In this sense, I frequently reflected on what the research was really about well into the investigation process; and it turned out to be about something quite different from the initially foreshadowed problems. I conducted research that

began with a concern about Pasung and how to develop models that fit within the culture of people in West Java, but eventually focused on the discursive structure of 'No room for escape' displayed by PIPs, and that the problem was too complicated to be solved by a single intervention.

11.4 Strengths and Limitations of this Research

I should restate that, although I was researching Pasung through an ethnographic lens, I am not a traditional anthropologist in the same way that the eminent Malinowski, Geertz, Mead, and other major ethnographers are. I am not even a medical anthropologist or a nurse anthropologist. However, I have ethnographic experience in the fields of nursing and community mental health, as well as many years of learning in both fields. Since its inception in 2012, I have been a member of the West Java Provincial Government's Community Mental Health Department. This insider knowledge was invaluable in the development of this thesis and became one of the many strengths of this research. This research was conducted in a natural setting and tried to capture the objects and interactions that occurred naturally as part of the daily life of the participants and the community in which Pasung exists and for which there is very little reported in the current literature.

As an insider, however, this also became a potential limitation of this research. Many of the participants, particularly in the interviews and videography, were my professional colleagues. However, I ensured that I followed the ethical practice standards and regulations established for all staff of the WJPH and the community as a whole and respected all participants' privacy; they could elect not to be involved in the research without adverse impact on their standing in their established roles in the services. The data (videos, photographs, interviews, and field notes) were only used for academic purposes and not for commercial or service governance purposes.

Another strength of this research was the ability of the methods used to uncover how the Indonesian community conducts Pasung, particularly the Sundanese community, which was obtained directly from the participants through ethnographic research and presented using the participant and researcher perspectives. As previously mentioned, this research used photographs and videography that had never been used in prior studies of Pasung in Indonesia. The overall sample of photos and videos was large. However, there was potential for bias as part of the selection process used to reduce the number of photos and videos analysed. However, this limitation was addressed by the richness of the analysis that was undertaken, the use of more than one person (the PhD candidate and the primary supervisor) making the selections and following detailed discussion between them and the broader supervisory team.

In addition, given that the research was conducted in the researcher's familiar cultural group – as an Indonesian with a Sundanese background investigating Pasung within the Indonesian cultural context broadly and Sundanese more specifically – I, therefore, made a number of presumptions about the data, given that I live and grew up within that culture. When I presented the early data,

thoughts, and social context of the research at a supervisory meeting, for example, I mentioned that I had discovered very little information in the data. My point of view was described based on my clinical lenses and cultural understanding at that time, and the supervisors then provided another perspective as an outsider. As a consequence, it prompted me to think more deeply about the data, particularly the visual data and the process of analysis.

In the analysis phase, I shared my values and interest in the research findings very thoroughly with my supervisors. On the contrary, my supervisors who come from a Western culture that is completely outside of the Sundanese culture, had a different shape and view of the data, asking many questions about what they observed in the video data and photos. This questioning enabled me to be more aware of the richness and nuances within the data that I had previously overlooked as part of my everyday cultural experience. Additionally, by responding to the supervisor's questions, I was able to articulate and explain in greater detail the rich cultural context of Pasung and the environment in which it occurred, which I had hitherto taken for granted.

Furthermore, I accepted that I could not separate myself from the research by bringing my personal experiences, values, and perspectives as a clinician. In other words, I brought my bias to the research, shared it with the reader, and strove to mitigate my personal bias through the process of undertaking detailed analysis with my supervisory team in order to interpret the data. Similarly, I contended that I brought my personal beliefs, as well as the social environment, which eliminates the possibility of conducting value-free research. My experience of living within the Sundanese culture and routinely seeing the practice of Pasung as an insider in some ways placed me in a position of personal bias. I was therefore mindful of my cultural background and its potential influence on my capacity for objectivity based on the data gained. Conversely, involving the supervisory team as outsiders in this study was also a potential limitation because they sat completely outside of the Indonesian culture, and therefore, had the potential for bringing Western cultural bias and misunderstanding of the cultural context. We attempted to mitigate this through repeated detailed cross-cultural discussions to unpack our various assumptions and emotional reactions to the data throughout the candidature.

As indicated in Chapters 1, 5, and 6, I am both an insider and an outsider in this study. While the 'insider' role heavily influences the study of information or evidence in the field, the process of extracting evidence from the findings to develop new insights is predisposed by the 'outsider' position. Combining these roles enables researchers to deploy their discoveries for both academic and practical usefulness, notably for knowledge development. Working closely with my supervisors during the analysis stage also ensured that I could evaluate the data as an outsider. Thus, by introducing this trustworthiness, the researcher's personal biases and peculiarities were avoided as much as possible.

The thesis references fragmentation in mental health service delivery but does not sufficiently highlight the influence of the current political system, where each district formulates its own policies within the healthcare sector. This poses a significant obstacle to the execution of national agendas, as the central government lacks direct authority to compel local governments to enact national programs, such as the eradication of Pasung. In cases where the local government does not prioritize Pasung on their healthcare agenda, the district health office may not fully or earnestly implement the Free Pasung Programme. It is imperative to acknowledge this issue because it signifies that the programme's implementation and any future recommendations derived from this thesis are locally specific and may not be universally applicable to other regions.

Furthermore, the research location and the researcher's cultural background are Sundanese, which may differ from the cultural and ethnic backgrounds of other regions in Indonesia. Indonesia boasts extensive cultural diversity, and while there are certain shared values and norms among Indonesians, some of the Sundanese cultural norms and values may not be universally applicable. As such, the problem of Pasung and its solutions could vary from one region to another. While there is no strong evidence to suggest that Pasung is more prevalent in one culture than another, this cultural diversity is undoubtedly present. Therefore, caution should be exercised when attempting to generalize the findings of this research to apply to the entirety of Indonesia.

11.5 Recommendations

The broad aim of this research was to explore the use of seclusion and restraint in community settings (Pasung*)*, the experiences of those involved, the perceived reasons for its use, current interventions, and potential solutions. This research aimed to balance the many perspectives on this problem in order to inform how Indonesia can build a more suitable model of care for PIPs. In what follows, the recommendations are grouped into two categories, for policy and for future research.

1. For policy

Despite the existence of the FPP, the failure to eradicate Pasung has been because of a failure of policy that then impacted on all other levels of the SEM. As discussed in Chapter 4, the poor development of mental health policy in general, and Pasung in particular, was the root cause of the fragmented nature of the services, resulting in limited access to community mental health services. As a result, the first recommendation prioritises policy change. In this regard, mental health policies must recognise and emphasise the importance of other areas of social and health services that have significant implications for mental health. Unemployment, homelessness, and poverty, to name a few, are all important factors in the primary prevention of mental illness. Policies aimed at improving these social factors will inevitably have an impact on the community's mental health.

Historically mental health services in Indonesia are focused on psychiatric hospitals as the main source of such care, and waiting for the community to bring people with mental health conditions to these facilities. As more funds and resources are allocated to psychiatric hospitals (90% of the national health budget), inevitably, mental health services will be inadequate at the primary care level; where it does exist, it is often of low quality. Systems for post-discharge coordination and follow-up clinical support from the hospital setting are also inadequate, creating unnecessary cycles of illness relapse, with some individuals ending up back in Pasung. The research findings indicate that the development of accessible, sustainable, and affordable community-based mental health care is desperately needed in West Java, particularly in the regional areas, and may help to address the issue of restraint in the home.

Social security, which has been mandatory for Indonesians since 2004, could also have a significant impact. With the issuance of numerous policies, the Indonesian Ministry of Health has stated its commitment to developing and implementing laws to protect the rights of PWMI which include social protection and consumer participation in policy advocacy and intervention. Despite the fact that health care provider-patient interaction is fast evolving towards more active collaboration, fuelled by increased access to treatment information and consumerist attitudes in modern society, the shift towards consumer involvement is not visible in the FPP. Furthermore, despite the fact that carers are considered to be ‘perpetrators’ of Pasung, the participants in this research suggested that legislation should focus on the government's responsibilities towards enhancing mental health services and diminishing the fragmentation of services rather than criminalising family members of people with mental illnesses who perceive that they have no viable alternative to Pasung. Alienating carers may leave PWMI without any form of support and then be vulnerable to vagrancy and/or Pasung. Furthermore, family members could be trained to recognise triggers for the behaviours of concern and to de-escalate violence.

Although the development of accessible, sustainable, and affordable community-based mental health care is desperately needed in West Java, particularly in the regional areas, and may help to address the issue of restraint, a full package of policy reform is likely required which includes the establishment of caregiver support, a community development approach to enhance economic independence, reform on mental health treatment services to include more community outreach, rehabilitation, and follow-up, and broader community education to raise awareness of mental health and to decrease stigma. Instead, health promotion to increase understanding of mental illness and Pasung among all stakeholders involved in every layer of the SEM is critical to managing the barriers that exist in programme management.

2. For future research

Several areas of further research need are indicated. First, the research found people of younger ages who had passed away while in Pasung, far earlier than would be expected of their age group, as a consequence of the severe treatment and conditions in which they were confined. Investigations of death records, on the other hand, provide little information on prevalence, which is unknown, and likely to be under-reported. This is an area that requires further investigation to determine the scope of the problem. Further research should be conducted to determine specific mechanical devices associated with particular injuries and possible death. However, given the scarcity of evidence, this association should be investigated further using rigorous research methods.

Second, this research provided some information on the occurrence and nature of psychological problems for PIPs; however, many issues remain unresolved, and there is currently little information on the prevalence of psychological problems for this population. As a result, determining the magnitude of the problem is impossible. Further research could also examine the impact of Pasung on psychological problems or pre-existing mental illness. For example, the man in the urban area in one of the photograph 7.33 (page 173) who showed good communication had a high muscular density and appeared neat, implying that he showered and ate adequate food. Some of these proposed reasons for the variations observed for PIPs need to be confirmed, as there may be many missing connections and variables, especially for why some PIP become disengaged and in social distress while others do not. Further research needs to be conducted in order to shed light on these issues.

Third, the findings identified a significant burden associated with PIPs and their families. However, families are heterogeneous; hence, future research must account for structural, cultural, economic, and social variations within and between families. For instance, do higher income families also use Pasung? If not, what is the reason? In addition, further research should consider the pressures placed on families when caring for the PIP, such as interpersonal stresses, family burden, finances, and other family member needs. Further research could explore these issues in detail. An understanding of these issues must also be built into support and treatment programmes for this population. There is a potential mismatch between consumer and family preferences and the services offered, and also between what families expect/demand and what is offered by existing support programmes. More longitudinal research is needed, ideally connecting multi-disciplinary professionals/stakeholders and those with lived experience at all levels.

Fourth, the findings of this research revealed that family psychoeducation programmes are available, but existing programmes vary widely, with inconsistencies in how they are delivered,

their content, who conducts them, and where they are conducted (in hospitals or in the community). More understanding is needed about the best approaches for delivering psychoeducation to families with lived experiences of Pasung. The diversity of approaches and the limited strength of evidence found here suggest that currently there is no single approach that suits all family situations and that a diversity of approaches is likely to be warranted in order to address Pasung.

Fifth, more work is needed in general to develop interventions that address the use of Pasung; these interventions need to include family and community participation, and to evaluate how they might benefit the consumer themselves. While the need for civic engagement in the development of interventions has been identified, such as the inclusion of lived experience perspectives, an understanding of how to do this effectively and how to involve the family and the person subject to Pasung remains unclear.

Sixth, health care providers, as well as other stakeholders, may have recognised that interdisciplinary teamwork is critical in achieving quality treatment for people and groups in the community through the Free Pasung Programme intervention. However, cooperation measures, including policy, have been limited in breadth and complexity. To improve outcomes and reduce adverse events in the management of the Free Pasung Programme, further research is needed to build a framework for interdisciplinary collaboration.

Seventh, individuals of both genders have various symptoms and causes for being in Pasung. To create gender-specific treatment for people with serious mental illness in Pasung, and address community attitudes about Pasung, more research is essential to understand the causal roles of gender differences in PIPs.

Eighth, although regulation explicitly stipulated penalties for those who practice Pasung, and outlined procedures for sending individuals with mental illnesses to hospitals when their behaviour could not be managed by their families or communities, the law enforcement was absent which creates another barrier in eradication pasung practise. Thus, further research could focus to identify the law enforcement particularly in West Java including the personnel involved in the Free Pasung Programm in West Java. It could explore why law enforcement officers were not prioritising protecting people in mental illness from being in Pasung, what their views are on Pasung, and how the community perceives the role of law enforcement in combating Pasung.

Ninth, while there is no field per se and relatively little research that has focused on the historical perspective of Pasung both before and after Indonesia's independence, in the broad sense we propose here, there is an extensive range of research on seclusion and restraint in psychiatric

settings that provides important insights on how these practises are known, how to promote or ban the use of this SR, or at least understand the intervention to end this practise.

Tenth, the findings underscore a central theme, 'No room for escape,' which poignantly describes that for patients in Pasung, coercive restriction becomes an enduring reality. However, amid their portrayal of this inescapable situation, patients and their families also express a cry for help. Pasung represents an urgent and extreme circumstance that demands swift resolution. Any delay in treatment or intervention would only compound their suffering. Therefore, suggesting further research projects to delve deeper into Pasung appears to be of lesser priority. The body of research, including this study, has provided ample insights to formulate new intervention programs or enhance existing ones. It is imperative to recommend an implementation research approach, involving the testing of community-based intervention models while concurrently evaluating their effectiveness.

Finally, despite Indonesia issuing a number of policies to increase the participation of PWMI in all aspects of economic, political, and social life, the success of the implementation is so far unknown and there is little research among Indonesian researchers on social exclusion among PWMI, particularly those in Pasung. Thus, the findings of this thesis make another significant contribution to research on Pasung, and future research could focus on this issue with photovoice for example to capture the voice of those in Pasung in relation to social exclusion.

11.6 Summary

This research is underpinned by concern for the human rights of PWMI and how they experience stigma and discrimination in care (in the form of Pasung) within their community. This chapter concludes that it is critical to understand and contextualise why Pasung occurs in a specific context such as West Java. Violations of human rights such as Pasung are frequently multifaceted, and simple solutions are unlikely. A sufficient understanding of the causes of Pasung in community settings may result in effective interventions and legislation to address the issue. The overarching theme, ‘No room for escape’ encapsulates that Pasung, although regarded as a last-option treatment, is perceived as the only effective, accessible means participants had to manage persons who were deemed as having aberrant behaviour given the significant barriers to accessing mental health services. Pasung is multidimensional, socially and culturally accepted among communities, and there are dynamic inter-relationships that exist across SEM contexts that reinforce its use.

The findings call for more focus on the intersection of individual level experiences with Pasung, their families, community level dynamics, and policy inadequacies in mental health care infrastructure. Pasung is not solely a result of individual symptoms or the refusal of the family to

accept psychiatric treatment. It can more accurately be attributed to a range of factors across the SEM, including the government's failure to provide basic mental health services for people with severe mental illness, community stigma, and the fragmentation between hospital and community services and the policy. Pasung is a problem that is unlikely to be fully addressed by simply offering mental health treatments in a hospital. Even in Indonesia, where the FPP is being implemented, the emphasis is on providing psychiatric medicine and basic psychoeducation rather than ongoing outreach or rehabilitation. Instead, I provide a call to action that outlines the importance of establishing solutions to address stigma, social exclusion, and service provision, which is critical for both structural and place-based social change. Potential solutions include increased funding and expansion of non-profit services, more strategic utilisation of community mental health services, education and awareness campaigns or programmes, and culturally-informed training for service providers.

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APPENDIX I
CO-AUTHORSHIP DECLARATION FORM

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APPENDIX II
THE USE OF PASUNG FOR PEOPLE WITH MENTAL ILLNESS: A SYSTEMATIC REVIEW AND NARRATIVE SYNTHESIS." *INTERNATIONAL JOURNAL OF MENTAL HEALTH SYSTEMS* 14, NO. 1 (2020): 1-21

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International Journal of Mental Health Systems

REVIEW Open Access

The use of pasung for people with mental illness: a systematic review and narrative synthesis

Muhamad Taufik Hidayat[1,2], Sharon Lawn[1,3*], Eimear Muir-Cochrane[4] and Candice Oster[1]

Abstract

Background: Pasung is the term used in Indonesia and a number of other countries for seclusion and restraint of people with mental illness in the community, usually at home by their family. While pasung has been banned because it is contrary to human rights, its practice continues to exist within the community, particularly where community mental health services are limited, and in the absence of adequate social support, and pervasive negatives beliefs about mental illness. It is essential to understand the reasons for the ongoing use of pasung and to examine potential solutions.

Methods: A systematic review and narrative synthesis of peer-reviewed international literature was conducted to identify the socio-cultural contexts for pasung use, and interventions to address it. The analysis draws on the socio-ecological framework, which focused on relationships between the individual and their environment.

Result: Fifty published articles were included in the review; all studies were conducted in Asia and Africa, with 32 undertaken in Indonesia. Most studies were qualitative (n = 21). Others included one case–control study, one cross-sectional study, and seven surveys; only four studies examined the application of an intervention, and each used a pre and post methodology. Of these, two studies tested psychoeducational interventions which aimed to overcome family burden due to pasung, and each suggested a community mental health approach. The remaining two studies evaluated the intervention of 'unlocking'; one study used a community-based culturally sensitive approach, and the other used a community-based rehabilitation program. Reasons for pasung given by family appear to be as a last resort and in the absence of other supports to help them care for the person with severe mental illness.

Conclusion: The findings highlight that a mixture of individual, interpersonal, community and policy interventions are needed to reduce the use of pasung. While consumer and carer involvement as part of a socio-ecological approach is understood to be effective in reducing pasung, an understanding of how to elaborate this in the management of pasung remains elusive.

Review Registration CRD42020157543: CRD

Keywords: Pasung, Lived experience, Systematic review, Narrative synthesis, Community mental health, Restraint, Human rights

Introduction

Seclusion and restraint are interventions used to control people with mental disorders (PWMD) who exhibit aggression and violence in psychiatric settings [1]. However, little is known about their use in non-psychiatric settings, particularly in a community environment such

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APPENDIX III
INDONESIA FREE FROM PASUNG: A POLICY ANALYSIS. *INTERNATIONAL JOURNAL OF MENTAL HEALTH SYSTEMS*, *17*(1), PP.1-22.

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International Journal of Mental Health Systems

RESEARCH Open Access

Indonesia free from pasung: a policy analysis

Muhamad Taufik Hidayat[1,2], Candice Oster[1], Eimear Muir-Cochrane[3] and Sharon Lawn[1,4*]

Abstract

Background Many people with mental illnesses remain isolated, chained, and inside cages, called Pasung in Indonesia. Despite numerous policies introduced to eradicate Pasung, Indonesia has made slow progress in decreasing this practice. This policy analysis examined existing policies, plans and initiatives in Indonesia targeted at eradicating Pasung. Policy gaps and contextual constraints are identified in order to propose stronger policy solutions.

Methods Eighteen policy documents were examined, including government news releases and organisational archives. A content analysis was undertaken of national-level policies that address Pasung within the context of the health system, social system and human rights since the establishment of Indonesia. This was followed by a case study analysis of policy and program responses particularly in West Java Province.

Findings While policy to address Pasung exists at a national level, implementation at national and local levels is complicated. Pasung policy has generated a sense of awareness but the different directions and ambiguous messaging across all stakeholders, including policy actors, has created a lack of clarity about institutions' roles and responsibilities in the implementation process, as well as accountability for outcomes. This situation is exacerbated by an incomplete decentralisation of healthcare policymaking and service delivery, particularly at the primary level. It is possible that policymakers have overlooked international obligations and lessons learned from successful policymaking in comparable regional countries, resulting in disparities in target-setting, implementation mechanisms, and evaluation.

Conclusion While the public has become more informed of the need to eradicate Pasung, ongoing communication with the various clusters of policy actors on the aforementioned issues will be critical. Addressing the various segments of the policy actors and their challenges in response to policy will be critical as part of building the evidence base to establish a feasible and effective policy to combat Pasung in Indonesia.

Keywords Pasung, Policy analysis, Mental Health, Seclusion, Restraint, Community Care

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APPENDIX IV
PROTOCOL SYSTEMATIC REVIEW

Citation

Muhamad Taufik Hidayat, Sharon Lawn, Eimear Muir Cochrane, Candice Oster. Systematic Review of Pasung use for people with mental health conditions: experiences, reasons for its use,and potential solutions. PROSPERO 2020 CRD42020157543 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020157543

Review question [1 change]

a. Why does pasung continue to be the primary option for the family and community when their family member is severely unwell?

b. What are the social and cultural meanings of pasung practice in a variety of settings and cultures in West Java Province?

c. What is the relevance of community beliefs about mental illness and psychiatric treatment to the practice of pasung?

d. What is the connection, if any, between poverty and pasung?

e. How are personal recovery processes for people with severe mental disorder understood from the professional, consumer and carer perspective?

f. How are consumer and carer views on pasung understood?

g. What programs (formal, informal and innovations) have been implemented to overcome the practice of pasung, and effectiveness of these program?

h. What is the most appropriate model of treatment for those who would otherwise be subjected to pasung, within West Java Province?

Searches

- The search involves the following databases: MEDLINE, PsycINFO, CINAHL, Scopus, ProQuest, Ovid Emcare, Google Scholar.

- Relevant peer-reviewed articles will be searched using only the 'P' from the PICO tool to identify main concepts. This is because we constructed a full PICO (see attached), initially applying it within MEDLINE and then translating it into PsycINFO, Ovid EMcare, Proquest, and Scopus databases. However, it produced a very large number of potential sources (270017), most of which were irrelevant to the review purpose. Following a further trial of revised search criteria and further discussion with the expert librarian and research team, we decided to only search by using the keyword 'pasung', given the uniqueness of the term and our focus on pasung specifically. There will be no timeframe limit placed on the publications for potential inclusion as there are very few articles on this topic and we believe there will, therefore, be significant value in including an extensive search timeframe.

- The keyword 'pasung' was entered into MEDLINE, then into the PsycINFO, Ovid EMcare, Proquest, and Scopus databases.

APPENDIX V
CRITICAL APPRAISAL SYSTEMATIC REVIEW

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APPENDIX VI
SYSTEMATIC REVIEW SEARCHING STRATEGY

Initial PICO that was not used, and outputs from databases that were searched

What is the nature of and evidence regarding the traditional practice of pasung?
What best practice have been invoked to address the issue (particularly with the community-based program/recovery-based program, /consumer carer involvement?
In pasung practice, Is Consumer and carer involvement/community-based treatment/recovery-based treatment effective to reduce the community restraint practice?

P: severe mentally ill with pasung/seclusion and restraint in the community
I: consumer and carer intervention/community-based intervention/recovery-based intervention
C: non-Hospital Based intervention/institutional treatment
O: Quality of life/end pasung/least restrictive

#	Medline	Results
1	(pasung* or traditional restrain* or community restrain* or shackl* or seclu* or chain* or physical restrain* or mechanic* coersi* detension*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1048662
2	(mental* or psycho* or schizophren* or depression*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	2270143
3	1 and 2	16007
4	(consumer* or care* or patien* or family* or recovery* or community or civi* or participat* or involve* or person*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	10868017
5	3 and 4	9590
6	(hospital* or institutional* or unit* or rehab* or social*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	3961666
7	5 and 6	2828
8	(least restrictive* or quality of life* or wellbeing* or free*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1599432
9	7 and 8	311

#	PsychInfo	Results
1	(pasung* or traditional restrain* or community restrain* or shackl* or seclu* or chain* or physical restrain* or mechanic* or coersi* or detension*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	26288
2	(mental* or psycho* or schizophren* or depression*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	1854451
3	1 and 2	6888
4	(consumer* or care* or patien* or family* or recovery* or community or civi* or participat* or involve* or person*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	2400117
5	3 and 4	4526
6	(hospital* or institutional* or unit* or rehab* or social*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	1379348
7	5 and 6	2051
8	(least restrictive* or quality of life* or wellbeing* or free*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	224089
9	7 and 8	180

#	Emcare	Results
1	(pasung* or traditional restrain* or community restrain* or shackl* or seclu* or chain* or physical restrain* or mechanic* or coersi* or detension*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	154749
2	(mental* or psycho* or schizophren* or depression*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	75421
3	1 and 2	4518
4	(consumer* or care* or patien* or family* or recovery* or community or civi* or participat* or involve* or person*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	3394872
5	3 and 4	32372
6	(hospital* or institutional* or unit* or rehab* or social*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1741138
7	5 and 6	1412
8	(least restrictive* or quality of life* or wellbeing* or free*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	442341
9	7 and 8	167

#	Proquest	Results
1	ab((pasung* OR traditional restrain* OR community restrain* OR shackl* OR seclu* OR chain* OR physical restrain* OR mechanic* coersi* detension*)) AND ab((mental* OR psycho* OR schizophren* OR depression*)) AND ab((consumer* OR care* OR patien* OR family* OR recovery* OR community OR civi* OR participat* OR involve* OR person*)) AND ab((hospital* OR institutional* OR unit* OR rehab* OR social*)) AND ab((least restrictive* OR quality of life* OR wellbeing* OR free*))	496

#	Scopus	Results
	(pasung OR seclusion OR restraint OR chain OR shackle OR coercion OR detention OR traditional AND restraint OR traditional AND restraint OR community AND restraint) AND (mental* OR psycho* OR schizophren* OR depression*) AND (consumer* OR care* OR patien* OR family* OR recovery* OR community OR civi* OR participat* OR involve* OR person*) AND (hospital* OR institutional* OR unit* OR rehab* OR social*) AND (least AND restrictive* OR quality AND of AND life* OR wellbeing* OR free*)	819

#	Cinahl	Results
1	(pasung or traditional restraint or restrain or community restraint or shackle or shackling or seclusion or chain or chaining or physical restraint or mechanical coercion or detention)	
2	(mental* or psycho* or schizophren* or depression*)	
3	(consumer* or care* or patien* or family* or recovery* or community or civi* or participat* or involve* or person*)	
4	(hospital* or institutional* or unit* or rehab* or social*)	
5	(least restrictive* or quality of life* or wellbeing* or free*)	
		44

#	Google scholar	Results
1	(pasung OR seclusion OR restraint OR chain OR shackle OR coercion OR detention OR traditional AND restraint OR traditional AND restraint OR community AND restraint) AND (mental* OR psycho* OR schizophren* OR depression*)	268000

#	Databases	Results
1	Medline (Ovid)	311
2	psycINFO	180
3	Emcare	167
4	Proquest	496
5	Scopus	819

6	Cinahl	44
7	Advance google scholar	268000
	Total	270017

PICO that was used, and outputs from database searches, only focused on 'P' – 'pasung' as the search term

Relevant peer-reviewed article will be searched using only the 'P' from the PICO tool to identify main concepts. This is because we constructed a full PICO, initially applying it within MEDLINE and then translating it into PsycINFO, Ovid EMcare, Proquest, and Scopus databases. However, it produced a very large number of potential sources (270017), most of which were irrelevant to the review purpose. Following a further trial of revised search criteria and further discussion with the expert librarian and research team, we decided to only search by using the keyword 'pasung'. There is no limited timeframe on the publication as there are very few articles on this topic and we believe there will, therefore, be significant value in including an extensive search timeframe.
The keyword 'pasung' was entered into MEDLINE, then into the PsycINFO, Ovid EMcare, Proquest, and Scopus databases. The titles and abstracts of all results will be screened based on the agreed inclusion and exclusion criteria. Full-text peer-reviewed papers will be further screened based on these same inclusion and exclusion criteria.

#	Databases	Results
1	Medline (Ovid)	13
2	psycINFO	8
3	Emcare	4
4	Proquest	34
5	Scopus	64
6	Cinahl	0
7	Psycharticle	6
	N from 6 databases	129
8	Google advanced search	9
9	Reference lists	22
10	Alerts	3
	N Identified Article	163

APPENDIX VII FREE PASUNG PROGRAM INFORMED CONSENT

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APPENDIX VIII
FREE PASUNG PROGRAM ASSESSMENT TOOLS

INTERVIEW GUIDANCE FOR THE PERSON IN PASUNG

1. Number of siblings of the patient
2. Who is living with the patient .....
3. The main caregiver .....
4. Occupation of the patient (if any) or previous work
5. Let's talk about everyday life experiences - things you've had, things your extended family and/or friends have had, things you've heard other people in the community have had, and so on
   a. How long has it been known/diagnosed with mental illness?
   b. What did you and the family do, and how and when was this done?
   c. What is the main challenge in seeking treatment for you and your families?
   d. Are there any health officials/health cadres/elders/community management coming to support you and your families?
   e. Who provides the fund? Insurance? Out of pocket? Do you have difficulties in obtaining insurance?

6. You've discussed your life's stresses and challenges as a person with mental illness. As you might expect, we believe that these factors are inextricably linked to your life.
   a. What did you do when you think your stress level is increasing/your symptoms reappear?
   b. Did you or the family seek help to overcome your condition?
   c. Is another family member step up to bear the burden?
   d. What do you do to manage stressors?
   e. How is your relationship with other family members since diagnosed with mental illness?
   f. What are the various ways you or others in your community deal with these stressors?

7. Let's talk about Pasung
   a. What is your understanding of Pasung?
   b. What type of Pasung have you known? How many of them are being implemented to you?
   c. Experience during Pasung
   d. Is there any influence from other family members? Neighbour? Other community members? Informal leader?
   e. What is the main reason?
   f. Is the treatment continued while in Pasung? How far is the access?
   g. What is your opinion about the Free pasung program? Expectation? What satisfied you so far? What problem arise during joining the program? Suggestion if any for future program

8. What have your or others' experiences been with attempting to access mental health services?
9. Do you have any suggestions for the provision of services in psychiatric hospitals/community health services, or services that don't exist but should, or additional social assistance programmes?

INTERVIEW GUIDANCE FOR FAMILIES

1. Number of siblings of the patient
2. Who is living with the patient .....
3. The main caregiver .....
4. Expenditure of the family .... Occupation.....
5. Occupation of the patient (if any) or previous work
6. Condition of the house ……
7. Status and condition of the place of residence ……
8. Condition and description of the patient's rooms (for Pasung) in the house/If located apart from the house, calculate the approximate distance from the house.....

9. Let's talk about everyday life experiences - things you've had, things your extended family and/or friends have had, things you've heard other people in the community have had, and so on
   a. How long has it been known/family know that a family member is suffering from mental illness?
   b. What did the family do, and how and when was this done?
   c. What is the main challenge in seeking treatment for families?
   d. Are there any health officials/health cadres/elders/community management coming to support families?
   e. Insurance or another similar scheme for health service

10. You've discussed your life's stresses and challenges as a carer. As you might expect, we believe that these factors are inextricably linked to mental health. What are your thoughts on the mental health of families in general?
    a. What did the family do, and how and when was this done?
    b. Did the family seek help to overcome their stress?
    c. Is another family member step up to bear the burden?
    d. What is the way family do to manage stressors?
    e. How is the relationship with other family members since diagnosed with mental illness?

11. Let's talk about Pasung
    a. What is your understanding of Pasung?
    b. What type of Pasung have you known? How many of them are being implemented for your ill family member?
    c. When did you decide to do Pasung?
    d. Is there any influence from other family members? Neighbors? Other community members? Informal leader?
    e. What is the main reason?
    f. Is the treatment continued while in Pasung? How far is the access?
    g. What is your opinion about the Free pasung program? Expectation? What satisfied you so far? What problem arise during joining the program? Suggestion if any for future program

INTERVIEW GUIDANCE HEALTH PROFESSIONALS, NON-HEALTH PROFESSIONALS, POLICYMAKERS, AND HEALTH SYSTEM MANAGERS

1. How long have you been involved in Free Pasung Program?
2. In what role have you been involved?
3. Could you describe your role?
4. When was the first time you know Free Pasung Program?
5. What do you think about the Free Pasung Program?
    - First impression of the Free Pasung Program?
    - How the program is implemented
    - What is the Objective of the Free Pasung Program (Specify the outcomes of Free Pasung Program is designed to achieve)
    - What is the structure of the Free Pasung Program
    - How familiar you are with the Regulations and Policies of the Free Pasung Program? What is your opinion?
    - How is the Funding/ budget of the Free Pasung Program allocated?
    - What is the Target setting of the Free Pasung Program?
    - How are the Monitoring and evaluation? How is the outcome so far? Clearly define the problem being addressed by this program.
    - How many cases are detected? How does early detection work in Free Pasung Program? If there is a case, how is it implemented from start to treatment and follow-up?
6. Have you been trained for Free Pasung Program?
7. How's are the team works for Free Pasung Program? Who chose the team? Is any standard of procedure for the team to work on? How is the reporting?
8. How is experience when involved in the Free Pasung Program? Family reaction? Community Reaction? Engagement with community and families and clients? Engaging with multiple sectors?
9. What are the main problems encountered in the Free Pasung Program?
10. How to overcome the barrier?
11. Suggestions for future progress/success indicators?

APPENDIX IX
ETHICS APPROVALS

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APPENDIX X
PERMISSION LETTER

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